

UNIVERSITY OF CALGARY

Knowledge Attitudes and Beliefs of Intensive Care Unit Nurses Regarding Brain
Death and the Donation Process – A Survey

by

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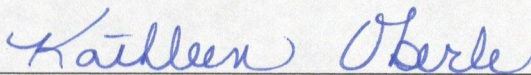
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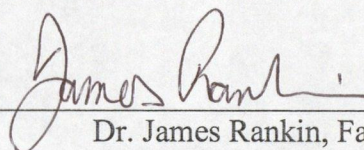
UNIVERSITY OF CALGARY

FACULTY OF GRADUATE STUDIES

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies for acceptance, a thesis entitled "Knowledge, Attitudes and Beliefs of Intensive Care Unit Nurses Regarding Brain Death and the Donation Process – A Survey" submitted by Sandra L. Rogers in partial fulfillment of the requirements for the degree of Master of Nursing.



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ABSTRACT

Canada is currently faced with a transplant crisis that stems from the lack of procurable organs. The recent development of a standardized practice for the management of donor patients when death is inevitable has now enabled health care professionals to offer organ donation as an integral part of end-of-life care in intensive care units (ICU) across Canada. By way of their involvement in the critical care environment, ICU nurses are a valuable and integral part of end of life care as it relates to brain death and organ donation. However, little is actually known about how ICU nurses feel about their role in the donation process. The purpose of this survey study was to explore the knowledge, attitudes and beliefs of ICU nurses in the Calgary Health Region (CHR) as it has been suggested that ICU nurses can impact the success of the donation process by way of their clinical skill and emotional support of the family.

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Lastly, I would like to thank my family for all of their unwavering love and support as they often have a way of believing in me in ways that I do not. At times, this has made all the difference.

Dedication

*This thesis is dedicated to the countless families in intensive care
who are faced with the decision to donate a loved ones organs
in the face of the most unimaginable circumstances.*

It is only from their suffering that another person can be liberated from their own.

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Chapter One

STATEMENT OF THE PROBLEM AND SIGNIFICANCE

Introduction

As an intensive care unit (ICU) nurse, and now as a post-liver transplant clinician, the subject of brain death has always been a topic of interest for me both personally and professionally. Nursing a patient who has met all of the physiological criteria for death but who remains so perceptibly alive has also introduced a new element to my practice that has made me question the link between the biological issue of brain death and the philosophical challenge of questioning when a life really ends. It has been suggested by Capron (2001) that this lack of clarity surrounding the issue only complicates matters further since this new declaration of death based on neurological criteria alone gives rise to a suspicion that death is now a malleable concept that can be adjusted for the purpose of medical convenience.

It is difficult to imagine that with so many individuals waiting, and even dying on transplant lists, the viability of the organ procurement from brain dead donors has been questioned but one must consider the way in which the organs are removed, from individuals who are still physiologically alive, but who no longer have intact brain function. Add the very provocative suggestion that society has invented this “new death” as a way of securing viable organs during a time when procurement in the event of clinical brain death remains an issue of great debate – culturally, socially, ethically and philosophically.

Canada is currently faced with a transplant crisis that stems from the shortage of procurable organs. In the year 2001, 3,800 Canadians were on a transplant list but only 1803 transplants were performed (Canadian Institute of Health Information, 2001). As a result of the lack of available organs 10-30 % of those on a waiting list die before an organ becomes available (Canadian Institute for Health Information, 2001). Organ donation is not only a socially relevant issue but a financial issue as well. For example, Health Care Canada (2002) estimates that the cost of maintaining a renal dialysis patient is \$30,000 per year more than it would be to manage the care of a kidney recipient. Thus, it is essential that the number of organ donations increase in Canada and this may be dependent on a professional body of educated and informed registered nurses.

The recent development of a national agreement and standardized practice for the management of donor patients when death is inevitable has now enabled health care professionals to offer organ donation as an integral part of end-of-life care in ICU (Shemie, Doig & Belitsky, 2003). This standardized approach to organ donation relies not only on the support and knowledge of the attending physician, but also on the commitment and knowledge of those involved in the management of patient care and family dynamics. Professional registered nurses are integral to this equation.

From the point of entry into the health care system, to the provision of neuroprotective therapies in the ICU, severely brain injured patients encounter a variety of health care professionals who ultimately become involved in their care.

The sequences initiated by devastating brain injury and leading up to brain death may include:

- resuscitation in the field
- evaluation and stabilization in the emergency department
- referral and access to ICU services
- prognostication
- ICU based neuroprotective therapies
- withholding or withdrawing life support
- outcomes including survival, death by cardiopulmonary criteria or death by neurological determination
- optimal end-of-life care, including tissue and organ donation

(Shemie, Doig, Belitsky, 2003).

Whether or not ICU nurses feel equipped to deal with the challenges and acuity of caring for a brain dead patient, they are unavoidably and inextricably linked to the process of organ donation by way of their involvement in the critical care environment.

From my experience as an ICU nurse, the physiological maintenance of a brain dead donor and relations with his or her family can be an intense and anxiety provoking experience. The clinical management of a brain dead patient not only requires an enormous amount of clinical knowledge and skill but also knowledge of standard practice and a great sensitivity towards the family. Often, the very arbitrariness of events leading up to brain death makes organ donation untimely and thus emotionally difficult for families to accept. Lock (2002) suggests that

because death occurs in ICU, it becomes an even more out-of-place, technological perversion to witness. Not only must a family quickly confront the reality of the situation but they must dismiss all feelings that their brain dead loved one, "might still be suffering, and further set aside any discomfort about desecration of the body" (p. 196). It has been recognized that brain dead patients do not resemble the usual concepts of the dead as it can be disconcerting for many family members to see their brain dead loved ones who are pink, warm, and continue to breathe with the aid of a ventilator (Kerridge, Saul, Lowe, McPhee & Williams, 2000). Family must also continue to remain in the presence of a dead relative who inexplicably for them, still has a beating heart. For nurses, the confrontation of brain death along with the presence of a patient who is seemingly alive often means having to frame death in an abstract realm (Phillips, Riley & Beatty, 1999; Coolican, 1999; Araujo Salada & Berti-Mendez, 2000).

In the circumstance of brain death, critical care nurses are in a position to best assist family in a sensitive and compassionate way to fully understanding the complexity of the issue of organ donation. More often than not, it is the attending nurse to whom the family puts their urgent questions. Having access to a supportive and well informed nurse is important for family's well being and may also be key in enhancing donor rates. However, in order to provide this support, nurses need to have an understanding of the donation process. Nurses must also possess the knowledge and skill necessary to provide sensitive and competent care for the donor and family.

Critical care nurses are the major caregivers and advocates for potential donors, recipients and families and they are the vital link for patients and families in

relation to the organ donation process (Albert, 1994). However, little is actually known about whether or not nurses in this specialty area feel confident in meeting the clinical and emotional challenges of donor and family support.

Conceptual Framework – Cognitive Dissonance

The theoretical underpinnings of this study are rooted in the notions of cognitive dissonance, which was first introduced by Festinger (1957). Cognitive dissonance is characterized by a sense of emotional uncertainty and psychological inconsistency (Watkinson, 1995) and occurs most often in situations where an individual must choose between two incompatible beliefs or actions. When there is an inconsistency between attitudes and behaviors (dissonance) individuals tend to seek consistency by reducing the importance of one of the conflicting beliefs (Festinger, 1957; Brehm & Cohen, 1962). Because the aim of nursing is holistic care whereby all biopsychosocial needs of the patient are met, the act of providing nurturing and holistic care to a dead patient can be troubling for many nurses and can perpetuate a sense of dissonance. This may occur when nurses are acting in ways that are incongruent with their intuitive feelings or cognitions. For example, as described in one interpretive phenomenological study (Day, 2001), one nurse had to "...talk herself out of providing [the] routine comfort care, such as talking to the patient and giving him a bath even [when she] knew that that he would not benefit from these interventions and that doing them might give the patient's family the wrong message" (p. 310).

Borozny (1990) explored the idea of cognitive dissonance as it relates to ICU nurses caring for brain dead patients (Appendix G), suggesting that ICU

nurses caring for brain dead patients can take two paths. The interpersonal path is one where discussion, sharing and reflection on the current situation can bond the nursing team which can lead to acceptance of the situation, thereby helping to reduce dissonance. This active reflection can also help the primary nurse to become aware of the habitual routines of care (mouth-care, bathing and turning) that may confuse a family attempting to reconcile the death of a loved one.

In contrast, the personal path is one where distancing of care and the blocking of painful stimuli associated with caring for a brain dead patient may lead to detachment from and depersonalization of the patient. As suggested by Borozny this path is especially important for ICU nurses to recognize because this discomfort and detachment from the patient may lead the family to believe that the patient has become objectified for the goal of procurement.

Therefore, it is essential that ICU nurses recognize their own feelings and beliefs about donation prior to caring for a brain dead patient. Because dissonance is only eliminated or reduced by acquiring new beliefs that change the balance between cognition and dissonance (Festinger, 1957), education programs addressing brain death and the clinical and conceptual issues involved in organ donation may help ICU nurses actualize and reconcile any potentially negative feelings about organ donation from brain dead patients.

Purpose of the Study

ICU nurses play a large role in the donation process by caring for and responding to the physiological changes often seen in brain dead donors, and in supporting and interacting with family members. In my experience, caring for a

brain dead donor is a difficult and often emotionally charged situation and yet little is actually known about how ICU nurses feel about their role in the donation process. What level of comfort do ICU nurses have, and what limitations do ICU nurses feel when caring for a brain dead donor? Is it possible that caring for a brain dead patient can actually cause burnout or undue stress if nurses are not properly educated in the ethical and conceptual issues of end-of-life care? As suggested in the literature (Day, 2001; Phillips-Riley & Coolican, 1999; Arujo Sadala & Berti Mendez, 2000; Watkinson, 1995; Pelletier, 1991) caring for a brain dead patient can present attending nurses with a great deal of emotional stress as they attempt to create a space for care while respecting the fact that the patient is dead.

The above questions provided the impetus for this research and provided the foundation for the framework of this study as a whole. Because ICU nurses play such a large role in the donation process, I believe that research about ICU nurses' understanding of brain death and attitudes and beliefs about involvement with brain dead donors and their families is paramount. Thus, the primary goal of this study is to determine the attitudes, knowledge and beliefs that ICU nurses in the Calgary Health Region (CHR) have towards nursing brain dead patients and their families. Ultimately, findings from this study may help in the design of programs to improve nursing care and reduce the stress often associated with caring for brain dead donors and distraught family.

The secondary purpose of this study is to examine the *association* between 1) ICU experience and scores on brain stem death knowledge test 2) Willingness of ICU nurses to donate their own organs and the belief that death of a person occurs when brain stem death has been confirmed in spite of the fact that a

patient's heart is still beating and, 3) The association between having cared for a brain dead donor and knowledge of brain stem criteria.

Research Questions

- How many ICU nurses in the CHR can correctly identify the criteria for brain stem death with a score of 80% or higher?
- What is the *association* between having cared for a brain dead patient and knowledge of brain stem death criteria?
- What is the *association* between ICU experience and actual scores on brain stem death test?
- What beliefs do ICU nurses in the CHR have towards nursing brain dead patients?
- What is the *association* between willingness to donate one's own organs and the belief that the death of a person occurs when brain stem death has been confirmed in spite of the fact that his or her heart is still beating?
- What attitudes do ICU nurses in the CHR have towards nursing brain dead patients?

CHAPTER TWO: BACKGROUND TO THE STUDY

The History of Brain Death

The term “brain death” was introduced in 1968 when transplant surgeons first contemplated the use of organs for transplant from patients believed to be irreversibly unconscious. In response to the consideration that the organs of a human being could be procured based on irreversible unconsciousness, an Ad Hoc Committee of the Harvard Medical School was established (1968) to carefully examine and determine a legal definition of brain death. Identification of the moment of brain death had become increasingly important because it would serve to avert legal complications and would also reassure and pacify an increasingly worried public (Lock, 2002). The current use of ventilator-assisted technology in ICU had raised concerns: first, the fear of being “counted dead before one’s time and over-hastily designated a brain dead donor; second, the fear of being kept alive too long, as a “vegetable” with severe, irreversible brain damage, but not quite technically brain-dead” (Pernick, 1999, p. 16).

While the Ad Hoc committee succeeded in providing a new baseline for determining the diagnostic criteria for brain death, the criteria were not clear as to whether brain death was synonymous with the death of the person. This led to much criticism on both philosophical and ethical fronts, because without this clear distinction locating the exact moment of death, “the irreversible comatose body [becomes] a territory over which sometimes competing, sometimes cooperating technological interests negotiated their claims” (Giacomini 1997 p. 1478).

Current Guidelines for the Diagnosis of Brain Death

In response to the suggestion that a comatose human body may become simply a “territory” over which transplant surgeons may negotiate their claims, a clear and universal definition for brain death was needed. This was needed to define the moment of death and to medically distinguish whether brain death was equivalent to the death of an individual. In 1999, The Canadian Neurocritical Care Group introduced practice guidelines that defined the clinical criteria for brain death that equates brain death to the death of an individual. The guiding framework for the development of the knowledge section of the questionnaire used in the current research study is based on these guidelines. These are the most current practice guidelines regulating the medical determination of brain death, and are the standard in Canadian critical care units.

Brain Death

Brain death is defined as the irreversible loss of the capacity for consciousness combined with the irreversible loss of all brainstem functions including the capacity to breathe. Brain death is equivalent to death of the individual even when the heart continues to beat and spinal cord functions may persist (Brain Death Task Force for the Diagnosis of Brain Death, 1987; Working Group of Conference of Medical Colleges and their Faculties in the United Kingdom, 1995; Medical Consultants on the Diagnosis of Death to the President’s Commission, 1981).

The current practice guidelines from the Canadian Neurocritical Care Group (1999) for the Clinical Diagnosis of Brain Death are as follows:

- An etiology has been established that is capable of causing brain death and potentially reversible causes have been excluded.
- The patient is in a deep coma and shows no response within cranial nerve distribution to stimulation of any part of the body. No movements such as cerebral seizures, dyskenetic movements, decorticate or decerebrate movements arising from the brain should be present.
- Brain stem reflexes are absent. This includes: papillary light, corneal, vestibulo-ocular, oculocephalic, and pharyngeal reflexes must be absent. The pupils should be unreactive to light. Grimacing or other motor responses to corneal stimulation or pharyngeal or tracheal suctioning is incompatible with brain death
- The patient must be apneic when taken off the respirator for an appropriate time. It is recommended that a PaCO₂ of 60mmHg is achieved to ensure that an adequate stimulus is present to the respiratory centre. The test will be positive for brain death if no respirations are observed over the 8-10 minutes of observation and the PaCO₂ rises to > 60mmHg.
- The conditions must persist when the patient is reassessed after a suitable interval. Depending on the etiology, the interval between such examinations may be as short as 2 hours or as long as 24 hours.
- There should be no confounding factors for the application of clinical criteria.

Literature Review

Using the search terms *brain death, intensive care unit, knowledge, beliefs, attitudes, organ procurement, organ donation, understanding brain death, nursing, nursing satisfaction, experience, family, and perception of organ donation*, the databases CINAHL (1980-2002) and Medline (1980-2002) were searched. Findings revealed ample anecdotal and conceptual literature to support the assumption that attitudes and knowledge levels of healthcare professionals have an impact on organ donation (Ehrle, Shafer & Nelson, 1999; Albert, 1994; Sullivan, Seem & Chabelowski, 1999; Phillips Riley & Beaty Coolinca, 1999; Davis & Lushis, 1995) but there is limited research evidence to support these assumptions. Findings from the search also suggest that the act of nursing brain injured patients and their families is emotionally demanding and stressful for nurses (Salloway *et al*, 1983). However, few empirical studies have been done to examine the attitudes, knowledge and beliefs of nurses during their participation in the donation process. Thus, further research is needed in this area to explore the implications of brain death for ICU nurses.

To date, there have been a few studies using survey methods. In relation to knowledge regarding organ donation, Davies (1997) conducted a survey in Bristol, England with a sample of 29 neurological intensive care nurses, in which she explored the relationship between nursing experience and knowledge of brain death criteria. Using a questionnaire designed for the study, Davies explored the relationship between knowledge and attitudes towards brain stem death and organ donation. Results from the study revealed that there was no correlation ($p = 0.1$)

between experience of the nurse and knowledge of brain death. Seven nurses perceived their knowledge on the consideration and confirmation of brain death to be adequate but their test scores revealed further room for improvement, indicating a disparity between perceived knowledge and the actual application of knowledge.

In critiquing Davies' study, it must be noted that the questionnaire was designed for the purpose of the study based on information from current literature about brain stem death and organ donation and Davies did not test the instrument prior to its use because she only had access to 29 nurses and did not want to contaminate the sample. To achieve a degree of content validity, a colleague of unspecified association, and a research supervisor were asked to review the questionnaire but little else is said about development of the instrument. The limited sample size of the study also makes any of the findings difficult to generalize to a larger population. In a Canadian study by Molzhan (1997), a questionnaire was developed by adapting an instrument previously used by Prottas and Batten (1988). Face and content validity of the instrument were established by way of an expert panel of physicians and nurses involved with organ retrieval. Over the course of one year data were collected from a sample of 1098 Canadian nurses. For the purpose of the study, nurses working in ICU, emergency and neurosurgery were combined into one group ($n = 147$) which was compared to four other groups of nurses, specifically those working in medical/surgical areas ($n = 209$), pediatrics/obstetrics ($n = 111$), community/home care ($n = 129$) and other areas ($n = 502$) not clearly defined. Results from the study indicate that the ICU, emergency, and neurosurgical nurses had higher knowledge and a more positive attitude towards organ donation ($p=.03$) than did nurses in other areas. The

difference was statistically significant ($p < .01$). However, it was evident from the results that there was a certain lack of knowledge about organ donation, with only 30.9% of the ICU/emerg/neuro group reporting knowledge about brain death legislation.

An American study (Vritis & Nicely, 1993) reported similar findings. Using a questionnaire designed by the researchers to measure attitudes toward and knowledge about organ donation, a sample of 1416 emergency, ICU and operating nurses in Virginia were surveyed. Instrument validity, reliability and content validity were established in three pilot studies and independent review by three transplant coordinators. Scores on the brain death test were generally high with a mean score of 87.0 % correct. The association between attitudes towards donation and knowledge of brain death was not significant ($p = .17$), suggesting that clinical knowledge about brain death and personal attitude toward organ donation are not related.

In another American study by Youngner *et al*, 1989, 195 nurses and physicians likely to be involved in organ procurement for transplantation were interviewed about knowledge, personal beliefs, and attitudes concerning brain death and donation. For this study, a knowledge questionnaire was used but there was no mention of the psychometric properties of the instrument. In response to factual questions about brain death criteria only 63% of respondents were able to answer correctly that the irreversible loss of all brain function was required for a patient to be declared brain dead. When compared with those who had previously participated in education programs about brain death, the group having no formal

education was less likely to correctly answer factual questions about brain death than were the others in the group having participated in an education program.

Findings from this study suggest that there is confusion about the legal and clinical implications of brain death, and that this may further contribute to the emotional discomfort of those who must care for brain dead patients in the ICU or operating room. Unfortunately, this study was done in 1989, making the findings harder to generalize to the present. The sample also included nurses, medical residents, and anesthesiologists which make the findings difficult to generalize to a nursing population exclusively. However, the study provides valuable insight into the issue of brain death, and the authors suggest that the differences in ability to recognize and explain brain death amongst healthcare professionals may prove detrimental to the “transplantation enterprise” (Younger, *et al* 1989).

Only two studies explored the emotional stressors experienced by nurses while caring for organ donors and their families (Hibbert, 1995; Watkinson, 1995). In Hibbert’s (1995) retrospective, exploratory descriptive Canadian study, 17 neurological intensive care nurses were interviewed about their experience during the donation process. The audio-taped interviews were then subjected to content analysis and the results categorized into main themes. The author did not provide the exact number of these nurses however, other than to state that “most” nurses found family members’ difficulties in understanding the meaning of brain death to be stressful. All nurses in the study ($n = 17$) revealed that they encountered stressors related to caring for the donor patient until organ retrieval. In a second British study, Watkinson (1995), revealed similar findings in her phenomenological study of the perceptions and experiences of critical care nurses in caring for organ

donors and their families. From a population of 146 neurological nurses, a total of (n = 103) nurses returned their questionnaire, representing a 70% response rate. From the qualitative portion of the research, it was found that working with donor patients and their families was considered to be stressful at times. The study highlights the problem of cognitive dissonance in some nursing staff, whereby some nurses may actually block out the painful stimuli of caring for an organ donor, thereby leading to a detachment and depersonalization when caring for these patients.

Summary

From this literature review, it is evident that there is a need for further research concerning nurses' knowledge, attitudes and beliefs about organ donation. Findings from this review also suggest that while ICU nurses have positive attitudes toward organ donation, research has shown that test scores for brain death criteria remain generally low. With the exception of Hibbert's (1995) and Molzhan's (1997) research, all studies have been done in America or British health care systems where the provision of care to donor patients may be different from that which has been established in Canada. Furthermore, many of the studies have limited sample sizes and sample groups that included nursing specialties other than ICU nursing, making any relevant findings difficult to generalize to a larger nursing population.

While many of the researchers in the aforementioned studies explored topics such as knowledge about organ donation, they mention very little about how ICU nurses actually feel about their role in the donation process. It is generally

known that ICU nurses feel positively about organ donation. However, little is actually known about the attitudes ICU nurses have about caring for organ donors and their families. Also, little is known about how ICU nurses perceive their role in the donation process.

The issue of organ donation in the event of brain death is a complex biopsychosocial issue. This is important to understand and relevant to the proposed research because it has been suggested that nurses can impact the success of the donation process by way of their clinical skill and emotional support of the family (Ehrle, Shafer & Nelson, 1999; Albert, 1994; Sullivan, Seem & Chabelowski, 1999; Phillips Riley & Beaty Coolincan, 1999; Davis & Lushis, 1995; Brozny, 1988). Sullivan, Seem and Chabelowski (1999) also suggest that ICU nurses are integral to the success of donation, as they may need to explain brain death to family members who are confused that the pronouncement of death is based solely on neurological criteria. An investigation of the knowledge, attitudes and beliefs of ICU nurses in the CHR about organ donation and effective donor care could provide the foundation for education programs designed to increase nurses' confidence and knowledge. This could increase and strengthen communication with donor families. Recognizing how nurses feel about their role and involvement in the donation process is both a timely and important step in helping to positively impact the donation process.

Chapter 3: Method

Study Design

For the purpose of this study, a questionnaire to measure the attitudes, knowledge and beliefs of ICU nurses was developed from a questionnaire used in studies of similar design (Davies, 1997 & Brozny, 1990). An adapted questionnaire on brain death and organ donation was chosen as it captured data in all three of the categories of interest: knowledge, attitudes and beliefs. The survey method was chosen for both cost and convenience. The survey was sent to the entire ICU nurse population at select hospital sites in the CHR.

Instrument

Based on my experience and the literature review, I felt that the revised questionnaire was appropriate to use in the study because it addressed important aspects of attitudes, knowledge and beliefs toward brain death (Appendix A). Similar content and format had also been used in previous survey studies exploring similar topics (Brozny, 1990 & Davies, 1997). Unfortunately, little mention was made of the reliability and validity of the instrument prior to its use in these studies, thus reliability and content validity of the instrument needed to be established prior to its use in the current study.

In methodological research, it has been found that properly designed and reviewed questionnaires significantly reduce respondent burden by allowing the information to be completed readily and easily (Mateo & Kirchoff, 1999). Therefore, to ensure content validity, the adapted questionnaire was reviewed by

five faculty members at the University of Calgary, two of whom have content and questionnaire design expertise. As content validators, faculty were asked to review and evaluate the questionnaire and determine if the items represented the domains of the constructs: knowledge, attitudes and beliefs of ICU nurses about brain death.

Face validity pertains to whether the test “looks valid” to the examinees who assess it and refers not to what the test actually measures, but what it appears to measure (LoBiondo-Wood & Haber, 1998). Thus, face validity of the instrument was addressed by asking two faculty members to assess the questionnaire and to make suggestions regarding missing items and construction and ordering of the questions. Based on suggestions made by faculty, wording, ordering and layout of several items were modified.

To establish a measure of construct validity, knowledge and Likert-style questions addressing attitudes and beliefs were then randomly mixed (Appendix D) and three faculty members were asked to sort the items according to the three identified domains of the construct: attitude, knowledge and beliefs. For any of the items to be included in the appropriate category, an index score of 0.6 (Polit & Hungler, 1999) was required. Items that failed to sort in the appropriate categories with an index score of < 0.6 were deleted or revised accordingly. For every new suggestion, the questionnaire was to be re-distributed to each faculty member until agreement was reached. An index score of 0.6 was achieved after the initial distribution of the questionnaire and only one iteration was required. Norwood (2002) suggests that any new survey should be pre-tested on 5-15

individuals with characteristics similar to those who will be included in the study.

Thus, before the questionnaire was used in the study, five randomly selected ICU nurses not included in the study were asked to complete the questionnaire and answer a set of questions (Appendix E). Information sought included the following:

- Was the questionnaire easy to read?
- Were the instructions clear?
- Was there anything you did not understand?
- Were any of the questions offensive?
- Was organization of the questionnaire acceptable?
- Were there improvements that could be made?

The final version of the questionnaire was divided into three main sections. Part A included demographic information about age, experience and knowledge of brain stem death criteria. Part B consisted of 7 questions related to beliefs about caring for brain dead patients in the ICU whereby respondents placed themselves on a continuum from “strongly disagree” to “strongly agree.” Part C contained five questions regarding personal attitude toward organ donation and blank lines for optional, open ended response from the respondents regarding their experience of brain death and caring for brain dead patients. Polit and Hungler (1999) highlight the difference of opinion concerning the appropriate number of alternatives on a Likert-type scale. Although a five point system could be interpreted as undesirable by some due to the category of neutral which may encourage proverbial ‘fence-sitting’ or the tendency not to state a position, it has

also been suggested that a five point scale with a neutral option can make the task less objectionable for those who simply cannot make up their minds. For the purpose of this study a five point Likert scale was chosen for the responses to allow a nurse the option of indecision, which the author felt, in itself, would provide interesting data on the topic of caring for brain dead patients and their families. The Likert scale was treated as interval level data which allowed for statistical testing using parametric procedures.

Method

A telephone call to all patient care managers at each site revealed a population of 300 ICU nurses. The survey was distributed to ICU nurses in three tertiary care centers in the CHR: Foothills Hospital (FMC), Rockyview Hospital (RGH), and the Peter Lougheed Hospital (PLC). The entire population of ICU nurses, including casual, part-time and full-time staff was included in the sample. Written permission from all patient care managers was received prior to surveys being sent and an information letter about the questionnaires was posted on the units (Appendix F). This letter contained the date of distribution for the questionnaire and provided contact numbers for both the principal and co-investigator of the study. Upon the request of patient care managers a brief education session was given to the charge nurses being asked to distribute the surveys. During this session, I explained the goal of the research and identified the role of the charge nurse in the distribution of the questionnaire. Each

questionnaire contained a standard information sheet (Appendix B) explaining the aim of the research. Questionnaires were then distributed by the charge nurses and were collected over a period of one month from March 2004 to April, 2004.

Sample and Recruitment

According to the literature the response rate for surveys averages around 30-50% (Norwood, 2002; Lo-Biondo-Wood & Haber, 1998). Based on this information, a 50% response rate was assumed, which would yield a margin of error of 7.9% (Polit and Hungler, 1995) with a sample of $n = 150$. There is extensive information about methods to enhance the response rate for questionnaires (Mateo & Kirchoff, 1999; Norwood, 2000; LoBiondo-Wood & Haber, 1998) and during the data collection phase of the study, several of these strategies were employed in attempt to achieve a response rate of 30-50%.

I gave the questionnaires to the charge nurses at each facility, and they hand delivered them individually to each nurse at the beginning of his or her shift. This method was employed to ensure that each staff member under the direction of the charge nurse received a questionnaire. The charge nurse was asked to place a questionnaire in the mail box of each staff member on his or her team who were sick or on vacation during distribution. Participants were informed via their questionnaire information cover letter that a draw for two free movie passes would be conducted for staff at each site once the questionnaires were collected and the data analysis portion of the research complete. This direct motivational

reward was chosen as it has been identified (Mateo & Kirchoff, 1999) that motivational rewards can positively influence the response rate. Staff members were asked to mail the completed questionnaire in the self addressed stamped envelope provided. Response rates were monitored after the initial distribution of the questionnaire in March 2004. To enhance response rates, I re-visited the units to remind nurses to complete their questionnaires if they had not done so already. I also e-mailed patient care managers asking them to remind their staff to fill out the questionnaires.

Data Collection and Analysis

All data were coded and entered into a data base. Data cleaning was undertaken using frequency counts. Statistical analysis was done with the Statistical Package for the Social Sciences (SPSS). Items 5 to 16 on the questionnaire required Likert-type responses and were analyzed using parametric procedures. For any items that did not satisfy the conditions for parametric testing, equivalent non-parametric tests were computed. Descriptive statistics were computed on all variables using frequency counts, percentages, means, standard deviations and cross-tabulations. For the study, alpha was set at 0.05. Please refer to Appendix C for the method of scoring the brain dead criteria knowledge test as outlined in Part A of questionnaire. This scoring for knowledge of brain death in part A of the questionnaire was based on the most current practice guidelines as outlined by the Canadian Neurocritical Care Group (1999).

Initial research questions were addressed and analyzed as follows:

- *How many ICU nurses in the CHR can correctly identify the criteria for brain stem death with a score of 80% or higher?*
- *What is the association between the experience of having cared for a brain dead donor and scores on brain stem death test?* The experience of having cared for a brain dead patient was nominal level data and brain death scores were ratio level data. Therefore, a point-biserial correlation coefficient (r_{pb}) was calculated. Because the computer program used for the data analysis was unable to perform a point-biserial test, the formula was calculated manually using the following equation:

$$r = \frac{[X_1 - X_0] * \text{sqrt } p(1-p)}{S_x}$$

X_0 = mean of X when Y = 0

X_1 = mean of X when Y = 1

S_x = sd of X

p = proportion of values where Y = 1

sqrt = square root

To further test the association, an independent sample t test was calculated to compare mean scores of knowledge between those nurses who had cared for a brain dead patient and those who had not.

- *What is the association between ICU experience and scores on the knowledge subscale?* ICU experience and brain death scores were conceptualized as interval level data and a Person's $sp.$ moment correlation coefficient (r) was computed. Because there is a possibility that these data could also be categorized as categorical, a Spearman's rho was calculated. ICU experience was grouped into 2 categories – 5 years or less and greater than 5 years. An independent t -test was calculated to compare means of the two groups on brain death scores.
- *What beliefs do ICU nurses in the CHR have about organ donation?* Questions from Part B of the questionnaire (items 5 to 11) were treated as interval-level data and descriptive statistics (means, standard deviations) computed.
- *What is the association between willingness to donate one's own organs and the belief that the death of a person occurs when brain stem death has been confirmed in spite of the fact that his or her heart is still beating?* Likert-type responses were conceptualized as interval level data and Pearson's product moment correlation coefficient (r) was used to examine the association between the variables.

- *What attitudes do ICU nurses in the CHR have about towards nursing brain dead patients?* Questions from Part C of the questionnaire (items 12 to 16) were treated as interval-level data. Mean responses were expressed in the form of a bar graph.

Ethical Considerations and Consent

Ethical approval for the study was obtained from the Conjoint Health Research Ethics Board. Ethical considerations for the research were established using guidelines from the Tri-Council Policy statement (1998, section 3, article 3.2). As per the established guidelines, there were no names, initials or other identifying information on the surveys, rendering the data anonymous. A covering information letter (Appendix B) explaining the purpose of the research informed participants that completing and returning the survey was interpreted as indication of willingness to participate. All returned questionnaires were treated as strictly confidential. All raw data is currently being kept in a locked cabinet in the Southern Alberta Nursing and Health Research and Resource unit at the University of Calgary. The principal investigator and co-investigators are the only ones with access to the data. All information will be stored for five years as per University of Calgary research policy and then destroyed after this time.

Chapter 4

Research Findings**Data Collection and Sample**

Data collection for this study extended over a period of one month, commencing March 1st 2004 and ending on April 1st 2004. From a population of 300 ICU nurses in the CHR a total of 141 questionnaires were collected for analysis, giving a response rate of 47.0%. The questionnaire was designed to elicit responses under three separate domains: knowledge, attitudes and beliefs. Participants were first asked to identify the criteria for brain stem death using true or false responses. The participants were then instructed to answer the remaining questions under beliefs and attitudes sections by providing their response on a five point Likert-type scale, ranging from "strongly disagree" to "strongly agree." Descriptive statistics were computed on all variables.

To establish the magnitude of relationship between variables being measured, Pearson's product moment correlation coefficient (r) was computed based on the assumption that the variables being measured could be treated as interval. Point biserial was calculated when the association involved discrete categorical and ratio level data. Lastly, the non-parametric test Spearman's rho was calculated on associations involving ordinal level data. As may be seen from tables 1 and 2, the modal age interval was 31-40. The modal interval for ICU experience of nurses participating in the study was 0-5 years.

Table 1: Age Groups of Participants

Age	20-30yrs	31-40yrs	41-50yrs	>50yrs
Nurses (n = 141)	41	63	31	6
(%)	(29.1%)	(44.7%)	(22.0%)	(4.3%)

Table 2: Years of ICU Experience

ICU Experience	0-5yrs	6-10yrs	11-15yrs	16-20yrs	>20yrs
Nurses (n = 141)	64	43	17	8	9
(%)	(45.4%)	(30.5 %)	(12.1 %)	(5.7%)	(6.4%)

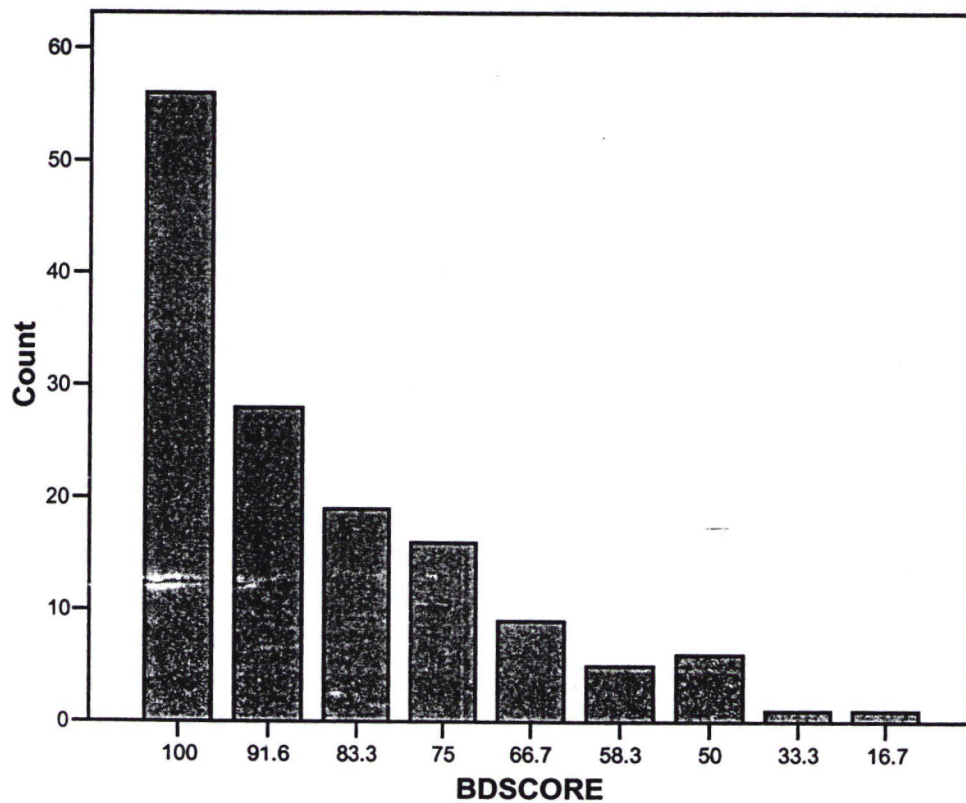
Psychometric Properties of the Instrument

As a measure of reliability, Cronbach's alpha (α) was computed to assess for homogeneity of the items included in the questionnaire. Cronbach's α for the instrument was 0.65. When the separate constructs were analysed individually, Cronbach's α for knowledge, beliefs and attitude sub-scales were 0.82, 0.69, and 0.73 respectively.

Brain Death Scores

Brain death scores were hand marked by the author using the criteria outlined in Appendix C. Results indicated that 73% of the ICU nurses (n = 103) surveyed could correctly identify the criteria for brain stem death with a score of 80% or higher. As can be seen in Figure 1 the modal score on the brain stem death sub-scale was 100.0 %.

Figure 1: Representation of Brain Stem Death Scores



When asked if they had ever cared for a brain dead donor, over 70.0 % of respondents ($n = 107$) answered “yes”. The point-biserial correlation ($r_{pb} = .000$) between experience with a brain dead patient and brain death knowledge scores was found to be non-significant. An independent t - test comparing mean brain death knowledge scores of nurses who had cared for a brain dead donor and those who had not revealed that the means were not significantly different ($t_{139} = -.237, p = .813$). Differences in mean scores between the two groups were minimal (no experience with brain death = 86.24%, experienced with brain death = 87.03%).

Statistical analysis revealed that there was a minimally positive, but statistically non-significant correlation ($r = 0.11, p > 0.10$) between ICU experience and brain death scores. Spearman’s rho was also calculated on ICU experience (grouped by category) and knowledge test scores (treated as ordinal data for the purposes of this analysis). Once again, no statistically significant relationship was found ($\rho = .068, p = .423$). ICU experience was then grouped into 2 categories – 5 years or less and greater than 5 years, and an independent sample t -test calculated. Results were not statistically significant ($t_{139} = .278, p = .781$) as mean scores of the two groups (< 5 years 86.82%, > 5 years 86.06%) were nearly identical.

Beliefs about Organ Donation

Seventy two percent of nurses ($n = 102$) agreed or strongly agreed that they should be asked to participate in discussions about brain death with family members. Only one nurse in the study strongly disagreed with this statement and 26.9 % of nurses ($n = 38$) disagreed or were neutral. All nurses in the study ($n = 141$) agreed or strongly agreed that their role was important in supporting and interacting with family members of brain dead patients. When asked if they found caring for a brain dead patient and his or her family to be an emotionally difficult event, 60.3 % of the nurses ($n = 85$) agreed or strongly agreed that the experience was emotionally difficult. When asked whether or not nurses believed that the death of a person occurs when brain stem death has been confirmed in spite of the fact that his or her heart is still beating, 88 % of nurses ($n = 125$) strongly believed that brain death was synonymous with death of a person. When the belief that the death of a person occurs when brain stem death has been confirmed in spite of the fact that his or her heart is still beating was correlated with whether or not nurses were willing to donate their own organs ($r = 0.36$, $p = < 0.01$) a positive and statistically significant relationship was found.

As can be seen in Tables 3 and 4, most nurses in the study were in favour of organ donation and the nurse's role in the donation process.

Table 3: Mean, SD of Belief Questions

Belief Questions	Min	Max	Mean (s.d.)
(A) Death of a person occurs when brain stem death is confirmed in spite of the fact that his or heart is still beating	1.0	5.0	4.3 (0.92)
(B) I would have adequate professional support from other members of the multi-disciplinary team if I were asked to care for a brain dead patient	2.0	5.0	4.4 (0.59)
(C) Nurses in the ICU should be asked to participate in discussions about brain death with family members	1.0	5.0	3.8 (0.11)
(D) Nurses in ICU have an important role in the physical aspects of caring for a brain dead donor	4.0	5.0	4.7 (0.42)
(E) Nurses in ICU have an important role in supporting and interacting with family members of brain dead patients	4.0	5.0	4.6 (0.48)
(F) I support organ donation as a way of increasing the number of organs available for transplant	1.0	5.0	4.3 (0.77)
(G) I find caring for a brain dead patient and his or her family to be emotionally difficult	1.0	5.0	3.5 (1.18)

* 1= Strongly Disagree and 5 = Strongly Agree

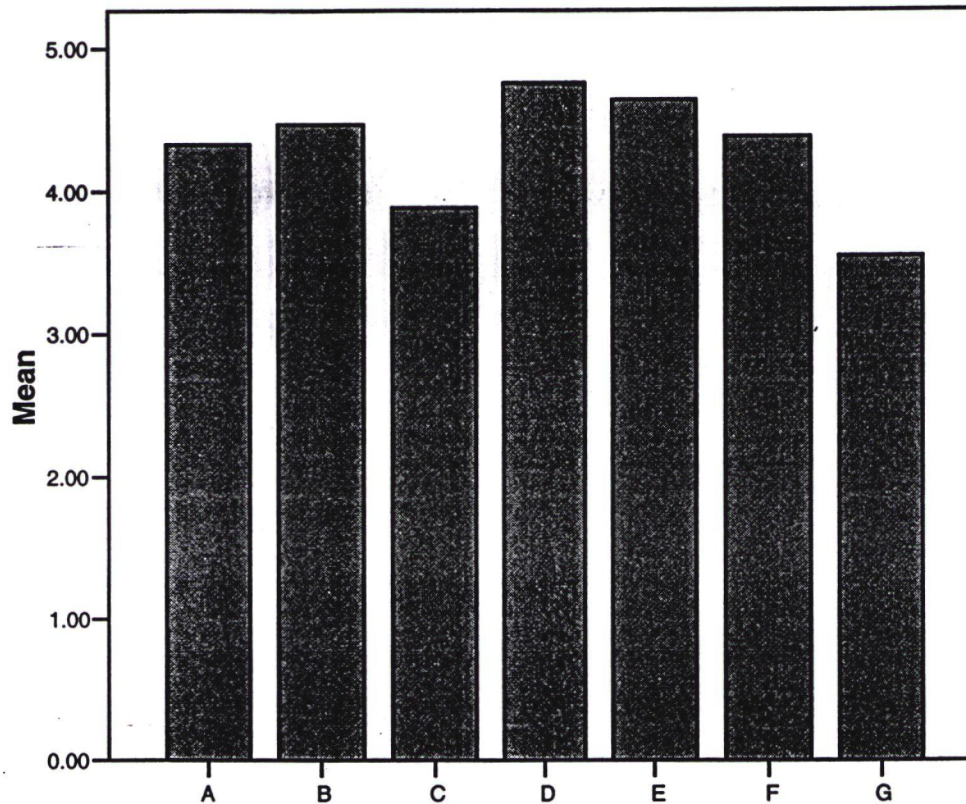
* s.d. (standard deviation)

Table 4: Beliefs about Donation

Belief Questions	Strongly Disagree n (%)	Disagree n (%)	Neutral n (%)	Agree n (%)	Strongly Agree n (%)	Total (n)
(A) Death of a person occurs when brain stem death is confirmed in spite of the fact that his/heart is still beating	4 (2.8%)	4 (2.8%)	8 (5.7%)	51 (36.2%)	74 (52.5%)	141
(B) I would have adequate professional support from other members of the multi-disciplinary team if I were asked to care for a brain dead patient	0 (--)	2 (1.4%)	1 (0.7%)	67 (47.5%)	71 (50.4%)	141
(C) Nurses in the ICU should be asked to participate in discussions about brain death with family members	1 (0.7%)	23 (16.3%)	15 (10.6%)	54 (38.3)	48 (34.0%)	141
(D) Nurses in ICU have an important role in the physical aspects of caring for a brain dead donor	0 (--)	0 (--)	0 (--)	34 (24.1%)	107 (75.9%)	141
(E) Nurses in ICU have an important role in supporting and interacting with family members of brain dead patients	0 (--)	0 (--)	0 (--)	51 (36.2%)	90 (63.8%)	141
(F) I support organ donation as a way of increasing the number of organs available for transplant	1 (0.7%)	5 (3.5%)	4 (2.8%)	60 (42.6%)	71 (50.4%)	141
(G) I find caring for a brain dead patient and his or her family to be emotionally difficult	4 (2.8%)	34 (24.1 %)	18 (12.8%)	51 (36.2%)	34 (24.1%)	141
Total (n)	10	68	46	368	495	987

Figure 2 is a representation of the mean scores for belief questions. As can be seen, responses to belief questions were generally favorable amongst ICU nurses in the CHR.

Figure 2: Representation of Mean Scores for Belief Questions



Attitude toward Organ Donation

Eighty eight percent of the nurses surveyed ($n = 125$) stated that they would also feel comfortable now, or in the future if asked to care for a brain dead patient. However, less than 50% ($n = 60$) of nurses felt that they would be able to explain brain stem death and brain death adequately to family members, and only 53.0 % of the nurses ($n = 76$) felt that their knowledge of brain death testing was adequate for their role as an ICU nurse. Correlation between willingness to donate one's own organs and comfort level in engaging family members in discussions about the topic of brain death revealed a minimally positive and statistically significant relationship ($r = 0.17$, $p = 0.038$). Correlation between perceived knowledge about brain death and actual brain death scores were negative, but statistically significant ($r = -.307$, $p = < 0.01$).

Results from the study indicate that there was a favorable attitude toward donation as demonstrated in Tables 5 and 6, with 85.8 % ($n = 121$) of nurses agreeing or strongly agreeing that they would donate their own organs. Just over seven percent ($n = 11$) of nurses were neutral on the subject, and only 6.4 % ($n = 9$) of nurses strongly disagreed or disagreed with this statement.

Mean scores for attitude questions are represented in the form of a bar graph in Figure 3.

As demonstrated, general attitude toward organ donation was quite favorable.

Table 5: Mean, SD of Attitude Questions

Attitude Questions	Min	Max	Mean (s.d.)
(H) My knowledge of brain death is adequate for my role as an intensive care unit nurse	1.0	5.0	3.3 (1.11)
(I) I feel I am able to explain brain stem death and brain death adequately to families	1.0	5.0	3.0 (1.08)
(J) I am willing to donate my own organs	1.0	5.0	4.2 (0.89)
(K) I feel comfortable engaging in discussions about brain death with family members	1.0	5.0	3.4 (1.00)
(L) I am comfortable now or would be comfortable in the future if I were asked to care for a brain dead patient	1.0	5.0	4.2 (0.75)

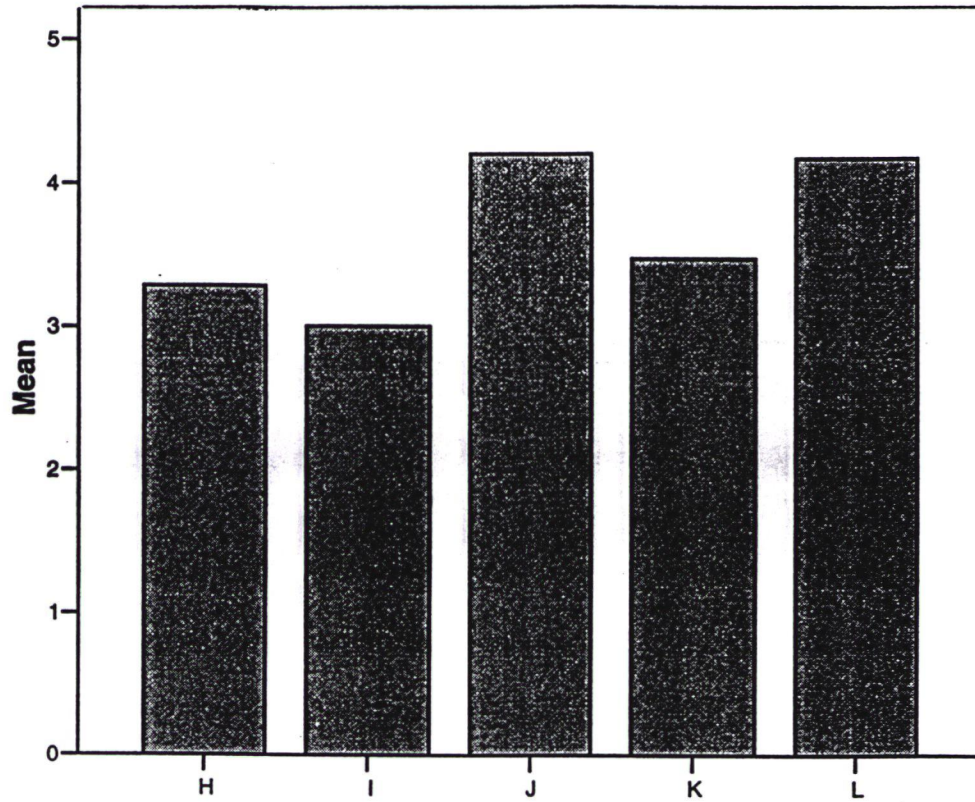
* 1= Strongly Disagree and 5 = Strongly Agree

* s.d. (standard deviation)

Table 6: Attitude toward Donation

Attitude Questions	Strongly Disagree n (%)	Disagree n (%)	Neutral n (%)	Agree n (%)	Strongly Agree n (%)	Total (n)
(H) My knowledge of brain death is adequate for my role as an intensive care unit nurse	3 (2.1%)	45 (31.9%)	17 (12.1%)	60 (42.6 %)	16 (11.3 %)	141
(I) I feel I am able to explain brain stem death and brain death adequately to families	7 (5.0%)	53 (37.6 %)	21 (14.9 %)	52 (36.9 %)	8 (5.7 %)	141
(J) I am willing to donate my own organs	2 (1.4 %)	7 (5.0 %)	11 (7.8 %)	59 (41.8 %)	62 (44.0 %)	141
(K) I feel comfortable engaging in discussions about brain death with family members	2 (1.4 %)	28 (19.9 %)	30 (21.3 %)	62 (44.0 %)	19 (13.5 %)	141
(L) I am comfortable now or would be comfortable in the future if I were asked to care for a brain dead patient	1 (0.7 %)	4 (2.8 %)	11 (7.8 %)	77 (54.6 %)	48 (34.0 %)	141
Total (n)	15	137	90	310	153	705

Figure 3: Representation of Mean Scores for Attitude Questions



Chapter Five

Discussion of Findings and Implications for Practice

Data Collection and Sample

Currently, there are 9,420 registered nurses working in the Calgary Health Region (Alberta Association of Registered Nurses, Statistics, 2003). For the purpose of this research, a convenience sample was obtained from ICU nurses working in the CHR. This method was chosen as it was felt to be the most expedient method given the limited time line for data collection. It has been criticized, however that use of a convenience sample introduces the risk of bias (LoBiondo–Wood & Haber, 1998), and is generally considered one of the weakest forms of sampling with regard to generalizability (Polit, 1996). For this reason, care must be taken in generalizing findings of this study to those nurses in the CHR who did not respond, and to a larger population of ICU nurses in other tertiary care centers.

Validity and Reliability

Prior to using the instrument in the study, content and construct validity were established, and Cronbach's α was computed to assess for internal consistency of the items. Content validity of the instrument was first obtained from a panel of five faculty members at the University of Calgary, two of whom had content and questionnaire design experience. Construct validity was established by asking three faculty members to sort randomly mixed items into their appropriate domain

(or construct). The conditions of selection for an appropriate category were contingent upon an index score of 0.6. The instrument was pilot tested with a group of 5 ICU nurses not included in the study. The initial pilot was only used to obtain information regarding readability, design and suggestions for improvement.

To ensure a measure of reliability, Cronbach's α was computed to assess for homogeneity of the items included in the questionnaire. For a tool to be considered reliable, an α coefficient of 0.70 or higher is considered to be an acceptable level (Lobiondo-Wood & Haber, 1998). For this instrument, the reliability coefficient was 0.65. The reliability coefficient for the knowledge, beliefs and attitudes sub scales were 0.82, 0.69 and 0.73 respectively. Homogeneity of the items was considered to be at a reasonable level for this study, as the sub-scale coefficient was either above or at 0.70.

For this research project, the total number of items included on the questionnaire was enough to capture meaningful data on the identified domains of the constructs. However, the smaller number of items included on individual sub-scales may be a contributing factor when one considers the lower reliability coefficient findings. For this reason, I employed the Spearman-Brown formula. This formula (also known as the Spearman-Brown prophecy formula) is a formula relating psychometric reliability to test length (Burns & Grove, 2001) and is based on the assumption that the reliability of the instrument can be predicted after changing the test length. Thus if the exam length were doubled, an α coefficient of 0.78 can be anticipated for this instrument. Reliability coefficient for knowledge, beliefs and attitudes sub scales can be anticipated at 0.90, 0.81 and 0.84

respectively. It must be acknowledged however, that if the hypothesized items in a longer questionnaire were added, the items would also need to undergo the appropriate psychometric testing prior to their inclusion in the questionnaire.

Brain Death Knowledge

Research Question #1: How many nurses in the CHR can correctly identify the criteria for brain stem death with a score of 80 % or higher?

Analysis of brain death knowledge scores revealed that a high percentage of nurses ($n = 103$) could identify the criteria for brain stem death with a score of 80.0 % or higher. These brain death criteria scores are consistent with brain death scores reported in the literature (Molzhan, 1997; Vritis & Nicely, 1993). It is hypothesized that these high scores are reflective of the fact that organ donation from brain dead patients is becoming an integral part of end of life care in Canadian critical care environments (Shemie, Doig & Belitsky, 2003), and nurses are exposed to brain death testing more often.

Findings revealed that, while a majority of nurses in the study sample were able to identify the criteria for brain stem death, there was little correlation between nurses' ability to identify brain death criteria and their feeling that they were adequately prepared to care for these patients. This is evidenced by the finding that over half (53.9 %) of the nurses' in the study ($n = 76$) felt that their knowledge of the criteria was adequate despite the favorable brain death scores.

This finding has not been previously reported in the literature but it is relevant to clinical practice as it suggests that the ability to recognize brain stem death criteria does not mean that ICU nurses necessarily feel that their knowledge about caring for donor families is adequate. This may have implications for the family of donor patients because findings suggest that although nurses may be able to identify the tests, they may be unable to explain the rationale or need for them in a way that is meaningful. This may actually perpetuate the emotional difficulty family often feels when attempting to reconcile the fact that their loved one is really dead.

Over 70.0 % (n = 107) of the ICU nurses surveyed stated that they had cared for a brain dead donor. However, the mean score on the knowledge test for those who had cared for a brain dead donor (86.24%) was similar to the score of those who had not (87.03%), and the difference was not statistically significant. These findings suggest the possibility that the act of caring for a brain dead donor does not affect knowledge scores. Furthermore it appears that formal education about brain death rather than bedside experience with brain dead patients may be key to improving nurses' understanding of brain death.

Research Question #2: What is the association between ICU experience and brain death scores?

In my experience, the acuity and intensity involved in caring for sick patients, such as donor patients, often requires a senior, and more experienced

nurse. However, findings from the study reveal that there is only a minimally positive, but statistically non-significant correlation ($r = 0.11$, $p = > 0.1$) between ICU experience and brain death scores. This has not been previously reported in the literature but it is relevant to clinical practice because it suggests that experience in the ICU environment does not necessarily guarantee knowledge of brain death criteria or organ donor care. This argument is strengthened by the finding that those ICU nurses with 5 years or less experience in ICU achieved almost the same mean score (86.23%) on the knowledge test as did those with more than 5 years experience (86.06%). This finding draws attention to the need for educational efforts that are directed at the collective professional body of ICU nurses already working in the CHR, not just the new nursing staff entering into ICU positions.

Beliefs about Organ Donation

Research Question #3: What beliefs do ICU nurses in the CHR have towards nursing brain dead patients?

In the results about beliefs regarding donation, it was found that 92.9 % of nurses ($n = 131$) in the study were in favor of organ donation. Eighty five percent of nurses ($n=121$) were willing to donate their own organs. Nurses were also quite favorable toward their role in the donation process, with 72.0 % of nurses' ($n= 102$) agreeing or strongly agreeing that they should be asked to participate in

discussion with family. All nurses in the study also agreed or strongly agreed that they perceived their role as important in supporting and interacting with family members of brain dead patients. This suggests that ICU nurses feel positively toward donation and are willing to engage and support family members during the donation process. However, while nurses feel quite positively toward donation, just over half of the nurses ($n = 85$) identified that the act of caring for a donor patient and his or her family was emotionally difficult.

Because nursing a brain dead patient is, "perhaps the ultimate example of total dependence on the primary nurse to deal with the physical needs of patient as they arise" (Davies, 1997, pg. 65), it is not difficult to imagine why the demanding needs of patients who are in essence, already dead, can be an emotionally draining endeavor for nursing staff. (Day, 2001; Phillips-Riley & Coolican, 1999; Arujo Sadala & Berti Mendez, 2000; Watkinson, 1995 & Peltier, 1991). In retrospect, it would have been interesting to have further investigated which aspects of caring for donor patients and families was most difficult, and thus, further research into this area is recommended. Perhaps these areas could be investigated with focus groups in formal education sessions.

Research Question #4: What is the association between willingness to donate one's own organs and the belief that the death of a person occurs when brain stem death has been confirmed in spite of the fact that his or her heart is still beating?

When the nurses in the study were asked whether or not they believed that the death of a person occurs when brain stem death has been confirmed in spite of the fact that his or her heart is still beating, over 88.0 % of nurses (n = 125) believed that brain death was synonymous with death of a person. When this finding was compared to whether or not nurses were willing to donate their own organs ($r = .363$, $p = <0.01$) a positive and statistically significant correlation was found. This indicates the possibility that ICU nurses' willingness to donate their own organs is related to their own feelings about whether the person they are caring for is really dead. This finding is relevant to practice and important to recognize, because it further reinforces findings by Borozny (1990), who suggests that the emotional stress of caring for a donor patient can be lessened by introspection about personal feelings about donation, discussion, and reflection on the situation which lead to acceptance of the situation (Appendix G).

An interesting finding from this study is that a majority of nurses (n = 138) in the study agreed or strongly agreed that they would have adequate professional support from other member of the multi-disciplinary team if asked to care for a brain dead donor. This is encouraging because it suggests that ICU

nurses who recognize a strong interpersonal connection to the larger health care team when caring for a brain dead donor may also feel less emotional stress (Borozny, 1990). This identification of a supportive network may also have a positive impact on nursing morale (Pallis, 1993).

Attitude toward Donation

Research Question #5: What attitudes do ICU nurses in the CHR have towards nursing brain dead patients?

Findings from the study suggest that there was a favorable attitude toward donation with 85.8 % of nurses' (n= 121) agreeing or strongly agreeing that they would be willing to donate their own organs. Findings also indicate that 88.0 % of nurses surveyed (n= 125) would feel comfortable now or in the future if asked to care for a brain dead donor patient. However, while most nurses in the study stated that they felt comfortable caring for donor patients, findings revealed that less than half (n= 60) felt that they would be able to explain brain death adequately to family members. This is an interesting finding because it suggests the possibility that ICU nurses are comfortable with the physiological aspects of donor care, but that there is an admitted knowledge deficit about brain death which may hinder discussions with family members.

In the author's experience, hesitation and lack of confidence in explaining brain death to families can often stem from the fear of saying the wrong thing, perhaps jeopardizing the chance of procurement. This has been evidenced in

qualitative research whereby nurses have identified that they were often unsure as to “how much information they were at liberty to share with family members” (Hibbert, 1995, p. 401). Because the process of organ donation takes time, which the primary nurse in a busy ICU environment may not always have, reliance on organ procurement teams to engage family members about the possibility of donation is common practice. However, the primary nurses’ reliance on clinicians and organ procurement teams may continue to absolve them from participating in meaningful discussions with family members. This suggests that ICU nurses should receive training in techniques for understanding the approach to donor families often undertaken by organ procurement teams and physicians, whereby nurses are informed about the proper timing and supportive discussions with donor families so important to donation success rates. Understanding the appropriate timing of donation request, also known as “de-coupling” (Ehrle, Shafer & Nelson, 1999) and the nature of discussions family will have with procurement teams and bedside physicians will place bedside nurses in a better position to understand the needs of families during this difficult time. This may also increase the knowledge and confidence of ICU nurses, potentially decreasing the emotional stress identified in engaging donor families.

Correlations between perceived knowledge about brain death and actual brain death scores were negative, but statistically significant ($r = -.307$, $p = < 0.01$). A negative correlation occurs when the high values on one variable, in this case actual brain death scores on the knowledge subscale, are associated with relatively low values on another, in this case perceived knowledge about

brain death (Lo-Biondo-Wood & Haber, 1998). This finding is consistent with Davies 1997 study in which ICU nurses perceived knowledge about brain death was incongruent with actual brain death scores.

Limitations of Study

There are limitations to this study. Because this study was undertaken with a convenience sample, one must be careful in generalizing the results to a larger population. Consideration must also be given to the fact that a selection effect may be present when one considers that participants in this study were given a choice about whether or not to participate. Thus, the author cannot generalize the findings to all the nurses in the CHR as those who chose to participate may have an interest in the topic of brain death not shared by the entire ICU population. The response rate of only 47.0 %, while considered to be quite good for a survey, will also affect generalizability to the whole population of nurses in the CHR. A critical incident causing the death of two ICU patients at the time of questionnaire distribution may have also affected the response rate.

Psychometric properties of the instrument revealed a low reliability coefficient for the instrument in its entirety, but α for the sub-scale sections were higher. However, in giving consideration to doubling the exam length by adding items with similar properties (Spearman-Brown formula) the α coefficient was deemed to be much higher. Repeating the questionnaire with a larger number of items would likely make the instrument more reliable.

Lastly, it is also important to recognize that because the questionnaire used in this research was restricted to forced-choice response format, it is difficult to ascertain which aspects donor care were most stressful for participants. For this reason, subsequent qualitative research studies are recommended. This could shed more insight into the individual aspects of donor care that ICU nurses find the most stressful, and focus groups and education sessions could be directed at these aspects of care.

Conclusion and Implications for Future research

Findings from this study suggest that a large majority of ICU nurses in the sample from the CHR were able to recognize the diagnostic criteria for brain stem death. The study results indicate that while nurses are able to identify these criteria, they rate their own personal knowledge of brain death as generally low. Most participants were in favor of organ donation and a majority also felt that they should be asked to participate in discussions with family. The finding that all of the nurses in this study agreed or strongly agreed that they had an important role in the physical aspects of caring for a brain dead patient suggests that participants were very comfortable with the demanding physiological care of donor patients. However, the finding that less than half of the nurses in the study felt they would be able to explain brain death adequately suggests that nurses believe strongly in their role in the donation process, but that this belief about their involved role is incongruent with admitted knowledge base. This suggests a rather serious gap in knowledge.

The fact that nurses are comfortable and confident in providing donor care is encouraging, because it suggests that participants feel comfortable with the physical aspects of nursing care. However, while nurses may feel comfortable with the physical aspects of donor care, many nurses believed that the act of caring for a donor patient and his or her family was emotionally stressful. The recognition of this finding is relevant to practice because this identified emotional stress may determine the path individual nurses will take (Appendix G) when attempting to reconcile these feelings. This has implications for donor family support and individual coping strategies for the primary nurse.

Intensive care nurses are a valuable and integral part of end of life care as it relates to brain death and organ donation. Findings from this study indicate that there is a definite need to develop educational programs that will identify the ethical, clinical and conceptual issues involved in end of life care. Educational efforts directed at the collective body of ICU nurses in the CHR will ensure that nurses in this specialty area are equipped with the skills to fully understand the complexity of the donation issue as this may improve family communication and may improve donation rates.

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APPENDIX A

Knowledge Attitudes and Beliefs Questionnaire

KNOWLEDGE, ATTITUDES AND BELIEFS OF INTENSIVE CARE NURSES REGARDING BRAIN DEATH AND THE DONATION PROCESS

Please take the time to complete this questionnaire independently. Do not consult any nursing or medical literature while completing your survey. Thank you.

Part A: Demographics/Knowledge: Please indicate your answer by filling in the appropriate circle beside each question
--

1. What is your age? 20-30 ☐
 31-40 ☐
 41-50 ☐
 >50 ☐

2. Numbers of years experience in the ICU? 0-5 years ☐
 6-10 years ☐
 11-15 years ☐
 16-20 years ☐
 > 20 years ☐

3. Have you ever cared for a brain dead patient? Yes ☐ No ☐

4. Please indicate the criteria for brain stem death that MUST be present when declaring an individual brain stem dead by filling in the circle beside each question as "T" for true or "F" for false.

	TRUE	FALSE
Pupils do not react to light.	<input type="radio"/>	<input type="radio"/>
Corneal and jaw reflexes are absent	<input type="radio"/>	<input type="radio"/>
Patient is apneic when removed from ventilator	<input type="radio"/>	<input type="radio"/>
Oculocephalic (doll's eyes) reflex is absent	<input type="radio"/>	<input type="radio"/>
Vestibulo-ocular (caloric test) reflex is absent	<input type="radio"/>	<input type="radio"/>
Motor responses to painful stimuli may be present	<input type="radio"/>	<input type="radio"/>
Motor responses to painful stimuli are absent	<input type="radio"/>	<input type="radio"/>
Apnea Arterial post-test reveals a PaCo2 of ≤ 40 mmHg	<input type="radio"/>	<input type="radio"/>
Facial sensory responses (grimacing, etc.) are absent	<input type="radio"/>	<input type="radio"/>
Absent pharyngeal and tracheal reflexes	<input type="radio"/>	<input type="radio"/>
Vestibulo-ocular (caloric test) is present	<input type="radio"/>	<input type="radio"/>
Sensory capacity remains intact	<input type="radio"/>	<input type="radio"/>

PART B: BELIEFS. For the following statements, please answer if you “Strongly Disagree”, “Disagree”, “Agree”, or “Strongly Agree.” If you have no opinion or are unsure of your answer, please mark “Neutral”

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
5. Death of a person occurs when brain stem death has been confirmed in spite of the fact that his or her heart is still beating.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. I would have adequate professional support from other members of the multi-disciplinary team if I were asked to care for a brain dead patient.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Nurses in the ICU should be asked to participate in discussions about brain death with family members	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. Nurses in ICU have an important role in the physical aspects of caring for a brain dead patient.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. Nurses in ICU have an important role in supporting and interacting with family members of brain dead patients.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. I support organ donation as a way of increasing the number of organs available for transplant.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. I find caring for a brain dead patient and his or her family to be emotionally difficult.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

PART C: ATTITUDES

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
12. My knowledge of brain death testing is adequate for my role as an intensive care unit nurse.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. I feel I am able to explain brain stem death testing and brain death adequately to families.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. I am willing to donate my own organs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. I feel comfortable engaging in discussions about brain death with family members.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. I am comfortable now or would be comfortable in the future if I were asked to care for a brain dead patient.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Any additional comments about your experience of caring for a brain dead patient or your understanding of brain death would be greatly appreciated.

THANK YOU FOR COMPLETING THIS SURVEY

APPENDIX B

Questionnaire Information Sheet



QUESTIONNAIRE INFORMATION SHEET

TITLE: Knowledge, Attitudes and Beliefs of Intensive Care Nurses
Regarding Brain Death and the Donation Process: A
Survey

INVESTIGATORS: Principal Investigator: Dr. Kathy Oberle PhD.
Co-Investigator: Sandra Rogers, R.N., BScN.

This information sheet is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please contact the principal investigator listed on page 2 of this information sheet. Take the time to read this carefully and to understand any accompanying information.

BACKGROUND:

Brain death and organ donation are complex issues, and the care of a brain dead donor often requires the care from a broad spectrum of multi-disciplinary healthcare professionals, including registered nurses. ICU nurses are often the major care givers and advocates for potential donors, recipients and family members in relation to the donation process. However, little is actually known about whether or not nurses in this specialty area feel confident in meeting the challenges of donor and family support.

WHAT IS THE PURPOSE OF THIS STUDY?

Your participation in this research is a vital link in understanding the knowledge, attitudes and beliefs ICU nurses in the CHR have toward brain death and organ donation as this may increase the provision of care to donor patients and their families.

WHAT WOULD I HAVE TO DO?

Please take a few moments to fill out the questionnaire provided. It should take no more than ten minutes of your time. Participants are asked not to consult any nursing or medical literature whilst completing the questionnaire. Please take the time to complete this questionnaire individually and not with other colleagues.

WHAT ARE THE RISKS?

There are no risks to you in completing this study.

WILL I BENEFIT IF I TAKE PART?

Your involvement in this research project is the first step in identifying the attitudes and beliefs ICU nurses have towards organ donation and brain death. The information we get from this study may help us to provide education programs that may improve upon the provision of care and communication with donor families.

DO I HAVE TO PARTICIPATE?

While your participation is fully appreciated, your participation is voluntary and you have the right not to fill out a questionnaire.

WILL I BE PAID TO PARTICIPATE?

As a token of appreciation for your participation, a draw for free movie passes will be completed once the research is complete. However, you will not be paid to participate.

WILL MY RECORDS BE KEPT PRIVATE?

This questionnaire data is collected anonymously to ensure confidentiality. Please do not write your name on the questionnaire. Only the PI and co-investigator will have access to the data. All data will be stored in a locked cabinet in the Southern Alberta Research Unit at the University of Calgary, and will be destroyed by shredding once the data have been analyzed and the research project is complete. A copy of the research findings will be posted on your unit when the project is complete.

AGREEMENT TO PARTICIPATE:

Your decision to complete and return the survey will be interpreted as an indication of your willingness to participate. All information is anonymous, and all completed and returned questionnaires will be treated as strictly confidential.

If you have further questions concerning matters related to this research, please contact:

Dr. K. Oberle @ (403) 220-6268

If you have any questions concerning your rights as a participant in this research, please contact Pat Evans, Associate Director, Internal Awards, Research Services, University of Calgary, at 220-3782.

The University of Calgary Conjoint Health Research Ethics Board has approved this research study.

APPENDIX C

Criteria for Marking Brain Death Subscale

Criteria for Marking Brain Death Subscale

“T” True

“F” False

 T Pupils do not react to light

 T Corneal and jaw reflexes are absent

 T Patient is apneic when removed from ventilator

 T Oculocephalic (doll’s eye) reflex is absent

 T Vestibulo-ocular (caloric test) is absent

 F Motor responses to painful stimuli may be present

 T Motor responses to painful stimuli are absent

 F Apnea Arterial post-test reveals a PaCO₂ of < 40mm Hg

 T Facial sensory responses (grimacing, etc.) are absent

 T Absent pharyngeal and tracheal reflexes

 F Vestibulo-ocular (caloric test) is present

 F Sensory capacity remains intact

(Wijdicks, 1995; Canadian Neurocritical Care Group Guidelines, 1999).

APPENDIX D

Randomly Mixed Questionnaires for Faculty

Please indicate the domain to which you believe the corresponding question should belong by placing a check mark under "K" for Knowledge, "A" for Attitude, or "B" for Beliefs.

	<u>Knowledge</u>	<u>Attitudes</u>	<u>Beliefs</u>
Pupils do not react to light	-----	-----	-----
Corneal and jaw reflexes are absent			
Patient is apneic when removed from ventilator			
Oculocephalic (doll's eyes) reflex is absent			
Vestibulo-ocular (caloric test) reflex is absent			
Motor responses to painful stimuli may be present			
Motor responses to painful stimuli are absent			
Apnea Arterial post-test reveals a PaCo ₂ of < 40mmHg			
Facial sensory responses (grimacing, etc) are absent			
Pharyngeal and tracheal reflexes are absent			
Vestibulo-ocular (caloric test) reflex is present			
Sensory capacity remains intact			
Death of a person occurs when brain stem death has been confirmed in spite of the fact that his or her heart is still beating.	-----	-----	-----
ICU nurses should be asked to participate in discussions about brain death with family members.	-----	-----	-----
My knowledge of brain death testing is adequate for my role as an intensive care unit nurse.	-----	-----	-----

Knowledge Attitudes and Beliefs 66

	Knowledge	Attitudes	Beliefs
I support organ donation as a way of increasing the number of organs available for transplant.	-----	-----	-----
I feel I am able to explain brain stem death testing and brain death adequately to families.	-----	-----	-----
I am willing to donate my own organs.	-----	-----	-----
ICU nurses have an important role in the physical aspects of caring for a brain dead patient.	-----	-----	-----
I would have adequate professional support from other members of the multi-disciplinary team if I were asked to care for a brain dead patient.	-----	-----	-----
I feel comfortable caring for a brain dead patient in the intensive care unit.	-----	-----	-----
I find caring for a brain dead patient and his or her family to be emotionally difficult.	-----	-----	-----
ICU nurses have an important role in supporting and interacting with family members of brain dead patients.	-----	-----	-----
I personally feel comfortable engaging in discussions about brain death with family members.	-----	-----	-----

APPENDIX E

Pre-Test for Five Randomly Selected ICU Nurses

Knowledge, Attitudes and Beliefs of Intensive Care Nurses Regarding Brain Death and the Donation Process: A Survey

Please take the time to review the enclosed questionnaire. Your feedback will enhance my ability to deliver a questionnaire that is clear and easy to complete. If you could please take a moment to fill out this page with your feedback, it would be greatly appreciated.

1. WAS THE QUESTIONNAIRE EASY TO READ?

2. WERE THE INSTRUCTIONS CLEAR?

3. WAS THERE ANYTHING ABOUT THE QUESTIONS THAT YOU DID NOT UNDERSTAND?

4. DID YOU FIND ANY OF THE QUESTIONS OFFENSIVE?

5. WAS ORGANIZATION OF THE QUESTIONNAIRE ACCEPTABLE?

6. WERE THERE ANY IMPROVEMENTS THAT COULD BE MADE?

Thank you very much for your
feedback. Forms can be returned to
me directly, or placed in my mail
box.

APPENDIX F

Information Letter for Intensive Care Units

**KNOWLEDGE ATTITUDES AND BELIEFS OF INTENSIVE CARE NURSES
REGARDING BRAIN DEATH AND THE DONATION PROCESS – A SURVEY**



WHO: Intensive care nurses in the Calgary Health Region

WHAT: A questionnaire will be given to you by your nurse clinician. Your questionnaire will be completed anonymously and returned to the investigators via a self addressed stamped envelope

WHERE: Intensive care nurses at three sites will be included in the study. Foothills Medical (FMC), Peter Lougheed Centre (PLC) and the Rockyview General Hospital (RGH).

WHEN: A questionnaire will be given to you in March 2004.

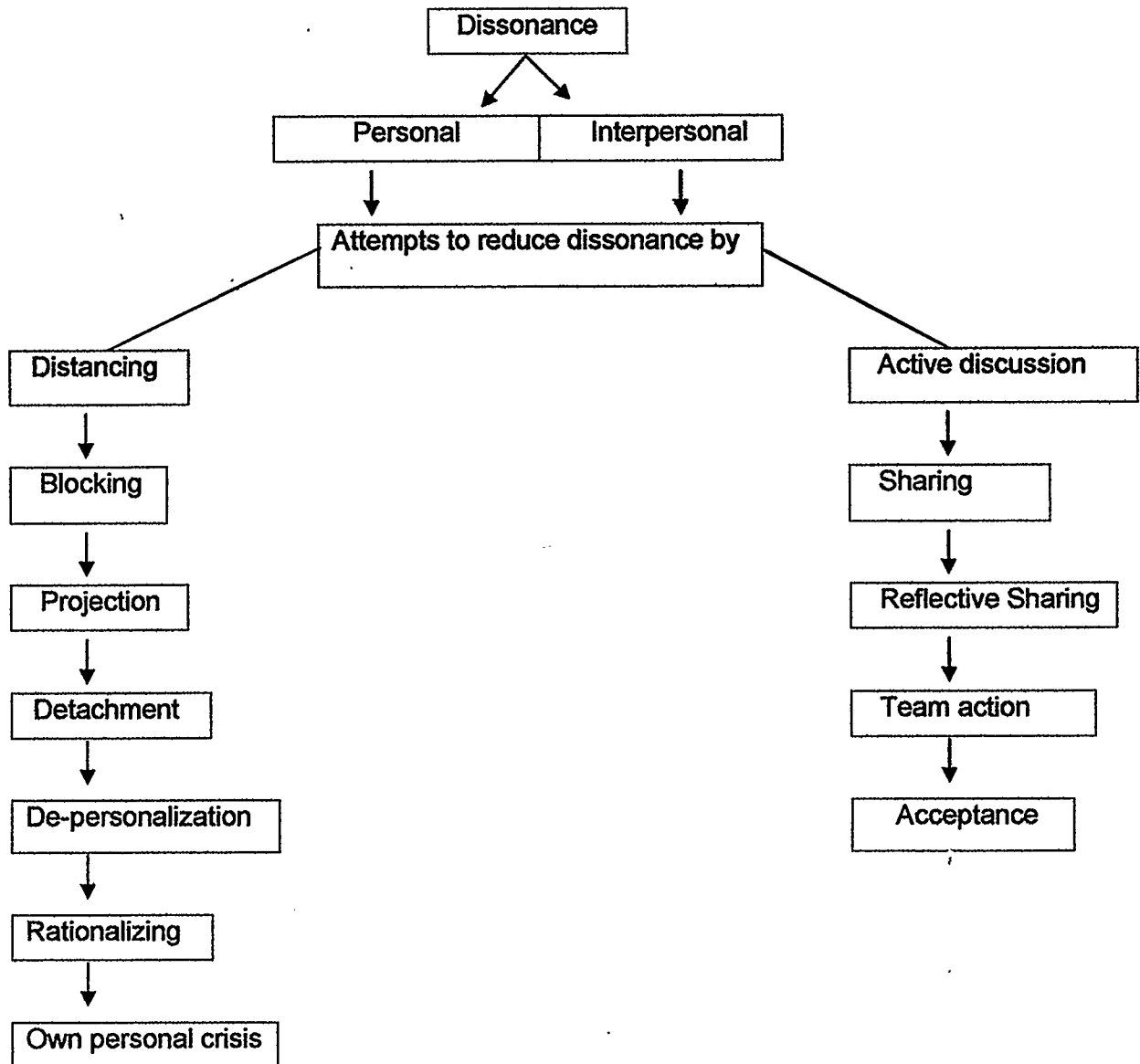
WHY: Critical care nurses are the major caregivers and advocates for potential donors, recipients and families, and they are the vital link for patient and family in relation to the organ donation process. However, little is actually known about whether or not nurses in this specialty area feel confident in meeting the clinical and emotional challenges of donor support. Your participation in this research is one important step in understanding the knowledge, attitudes and beliefs of ICU nurses in the Calgary Health Region have toward the donation process, as this may increase the provision of donor care to patients and their families.

**If you have further questions concerning matters related to this research, please contact:
Dr. K. Oberle @ (403) 220-6268 or Sandra Rogers RN BScN MN (Thesis student)
@ (403) 804-0668**

APPENDIX G

Cognitive Dissonance

Cognitive Dissonance
The Experience of Providing Nursing Care to the Brain Stem Dead Patient



Adapted from Bronzy (1990) The Experience of Intensive Care Unit Nurses Providing Care to the Brain Stem Dead Patient. Codman Award Paper. Axon 12(1), 22.

APPENDIX H

University of Calgary Ethics Board Approval Letter



2004-02-20

Dr. K. Oberle
Faculty of Nursing
PF 2222, University of Calgary
Calgary, Alberta

Dear Dr. Oberle:

**RE: Determining the Knowledge, Attitudes and Beliefs of Intensive Care Nurses Regarding Brain Death and Donation Process.
A Survey**

Grant-ID: 17632

The above-noted thesis proposal, Questionnaire Information Sheet, questionnaire (Appendix A), surveys (Appendix D, Appendix E) and the poster have been submitted for Committee review and found to be ethically acceptable.

Please note that this approval is subject to the following conditions:

- (1) access to personal identifiable health information was not requested in this submission;
- (2) a copy of the informed consent form must have been given to each research subject, if required for this study;
- (3) a Progress Report must be submitted by 2005-02-20 containing the following information:
 - i) the number of subjects recruited;
 - ii) a description of any protocol modification;
 - iii) any unusual and/or severe complications, adverse events or unanticipated problems involving risks to subjects or others, withdrawal of subjects from the research, or complaints about the research;
 - iv) a summary of any recent literature, finding, or other relevant information, especially information about risks associated with the research;
 - v) a copy of the current informed consent form;
 - vi) the expected date of termination of this project.
- (4) a Final Report must be submitted at the termination of the project.

Please note that you have been named as a principal collaborator on this study because students are not permitted to serve as principal investigators. Please accept the Board's best wishes for success in your research.

Yours sincerely,

Christopher J. Doig, MD, MSc, FRCPC

Chair, Conjoint Health Research Ethics Board

CJD/am

c.c. Adult Research Committee Dr. T. Inkson (information)
Office of Information & Privacy Commissioner

Research Services

Ms. S. Rogers (Research Coordinator)