INTENSIVE CARE NURSES' THOUGHTS AND FEELINGS RELATED TO THEIR EXPERIENCES OF CARING FOR CADAVER ORGAN DONORS AND THEIR FAMILIES

by

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submitted to the Univeristy of Manitoba
in partial fulfillment of the
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ABSTRACT

A qualitative approach was utilized to examine intensive care nurses' thoughts and feelings related to their experiences of caring for cadaver organ donors and their families. A convenience sample of 11 intensive care nurses was obtained. Participants' age range was from 26 to more than 35 years. Nursing experience ranged from 6 to more than 15 years; ICU experience from 1 to more than 15 years. Data were collected using informal and partially structured interviews. Each participant was interviewed twice. A hermeneutic phenomenological approach guided the analysis of the data. The participants recounted stories of their experiences of caring for donors. These stories had both similarities and differences. The participants' thoughts and feelings related to their experiences were discussed through four themes that emerged from the data. These themes were: (a) "It depends;" (b) "They're dead, but they're not dead;" (c) "Finishing the case;" and (d) "Something good came out of it." The key findings of this study relate to the situational dependency of the thoughts and feelings of the participants, the confusion surrounding the concept of brain death, the importance of the informational letters sent by the transplant coordinators, and the assignment of positive meaning to the death as a result of organ donation. Recommendations for nursing practice, education, and research have been made on the basis of these findings.

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CHAPTER 1: INTRODUCTION

It seems contradictory to suggest that a situation can be "at once life-saving and death-ridden" (Fox & Swazey, 1974, p. 95). Yet human organ transplantation can indeed be that kind of situation. A human being dies in an intensive care unit; the family consents to organ donation and organs are retrieved. Within hours, perhaps in a different city or even a different country, these same organs are transplanted into other human beings, prolonging and/or altering their lives. Of the more than 1200 vital organ transplants performed in Canada in 1989, the vast majority were the result of cadaveric donations (Canadian Organ Replacement Register, 1991). Bart, Macon, Humphries et al. (1981) found that 73 percent of potential donors died in intensive care units and 98 percent of cadaveric kidney donations occurred from patients in intensive care units. Intensive care nurses provide care to cadaver organ donors and their families in this death-ridden aspect of the transplantation situation. This study examined the experiences of intensive care nurses caring for cadaver organ donors and their families.

Sandelowski (1986) has stated that "any study and its findings are at least as much a reflection of the investigator as of the phenomenon studied" (p. 34). It is essential, therefore, that the reader understands the lenses through which the investigator views the topic of study. As an intensive care nurse, I have cared for five to ten cadaver organ donors. Some of these patients I remember quite vividly; others are a blur. Like all patients, they had names, faces, families, and histories. Some images are stamped in my memory -- a face, a bedside scene, a family's reaction, a story. I particularly remember that caring for a cadaver organ donor was an emotionally charged situation. Both the emotions I experienced and the memories I recall are best understood in the context of the situations in which they occurred. It seemed to me that much of the literature I read on this topic failed to capture the context of the cadaver organ donor experience. It was this context that I was interested in exploring with the eleven participants of this study.

It is instructive to explain the language used in this study. One must first understand the concept of brain death. Brain death is the irreversible cessation of the functioning of the entire brain and is both a "necessary and sufficient condition" in declaring the death of an individual (Korein, 1978, p. 20). The Vital Statistics Act, Revised Statutes of Manitoba (R.S.M.), c.V60 (1987) states that "the death of a person takes place at the time at which irreversible cessation of all that person's brain function ceases" (p. 3). Once the brain is dead, the individual is dead. Two terms require explanation based on the definition of brain death: cadaver organ donor and patient. First, the term cadaver organ donor describes a dead body that is artificially maintained for the purposes of retrieving organs for transplantation. In contrast to a dead body that is not being maintained artificially, the cadaver organ donor is warm and respiring.

Thus, the cadaver organ donor represents a different kind of dead body. The term cadaver organ donor readily identifies the specific patient of interest to this study.

The term patient used in reference to a cadaver organ donor also requires explanation. Pallis (1983) has cautioned against resorting to "terminological sleight of hand" when discussing brain death (p. 36). For example, Pallis suggests that using the term life-support systems when referring to the brain-dead is inappropriate. If one extends this argument, it may also be inappropriate to refer to cadaver organ donors as patients, if one believes the word patient implies personhood. Indeed, Lamb (1985) uses the term "ex-patient" when referring to an artificially maintained body. The <u>Oxford English Dictionary</u> (1970a) defines patient as "a person or thing that undergoes some action, or to whom or which something is done" (p. 555). It is thus appropriate to refer to a cadaver organ donor as a patient. My decision to follow suit was also influenced by the fact that all study participants referred to the cadaver organ donors they had cared for as patients.

Background of the Study

Mechanical ventilation, refined pharmacopeia, statute revisions, and developments in transplantation medicine have created a new kind of patient -- the brain dead, cadaver organ donor. Referred to as a neomort, non-living donor, or beating-heart cadaver, this patient has been declared dead because of the irreversible cessation of the functioning of the entire brain (Gaylin, 1974; Martin, 1984; Searle, 1981; Vital Statistics Act, R.S.M., 1987). Death is most commonly caused by a severe head injury but also may result from a subarachnoid hemorrhage, brain tumour, cardiopulmonary arrest, or drug overdose (Darby, Stein, Grenvik, & Stuart, 1989; Maher & Strong, 1989).

Following the declaration of death, the donor's body is not shrouded and discharged to the morgue --rituals associated with a hospital death (Sudnow, 1967; Wolf, 1988; Youngner et al., 1985). Instead, demanding care is provided to a "hemodynamically fragile" cadaver by the health care team to ensure that the organs remain perfused for transplantation into other human beings (Corman, 1987, p. 58). For periods usually not exceeding 24 to 48 hours, the donors are hemodynamically monitored, artificially ventilated, and infused with pharmacological agents until such time as organ recipients can be identified and the organs surgically removed (Black, 1978; Pallis, 1987). It should be noted, however, that cases of organ-support continuing for two months in brain dead, pregnant women have been cited in the literature (Dillon, Lee, Tronolone, Buckwald, & Foote, 1982; Field, Gates, Creasy, Jonsen, & Laros, 1988; Shrader, 1986; Stewart-Amidei, 1988). During this time, intensive care unit (ICU) nurses are required to provide close and extensive care to what is essentially a "corpse on a ventilator" (Davis & Lemke, 1987, p. 37).

Intensive care nurses are also required to provide care to the grieving family of the cadaver organ donor. Donor families cannot help but be struck by the signs of life they see before them, as the chest of their loved one rises and falls and the cardiac monitor signals continued cardiac activity. Indeed, in terms of appearance, there is little to separate the brain dead, cadaver organ donor from most other patients in the ICU (Navarra, 1987; Youngner et al., 1985). The family's grief is often further intensified by the fact that the vast majority of cadaver organ donors are young and die suddenly (Bart, Macon, Humphries et al., 1981; Corman, 1987).

Purpose of the Study

Few studies have explored the experience of ICU nurses caring for cadaver organ donors and their families. Fewer still have considered nurses' thoughts and feelings regarding such experience. The purpose of this study was to explore the experience of caring for cadaver organ donors and families to address this knowledge gap.

Research Questions

Two research questions were posed in this study.

1. What are the experiences of intensive care nurses caring for cadaver organ donors and their families?
2. What thoughts and feelings are intensive care nurses expressing about these experiences?

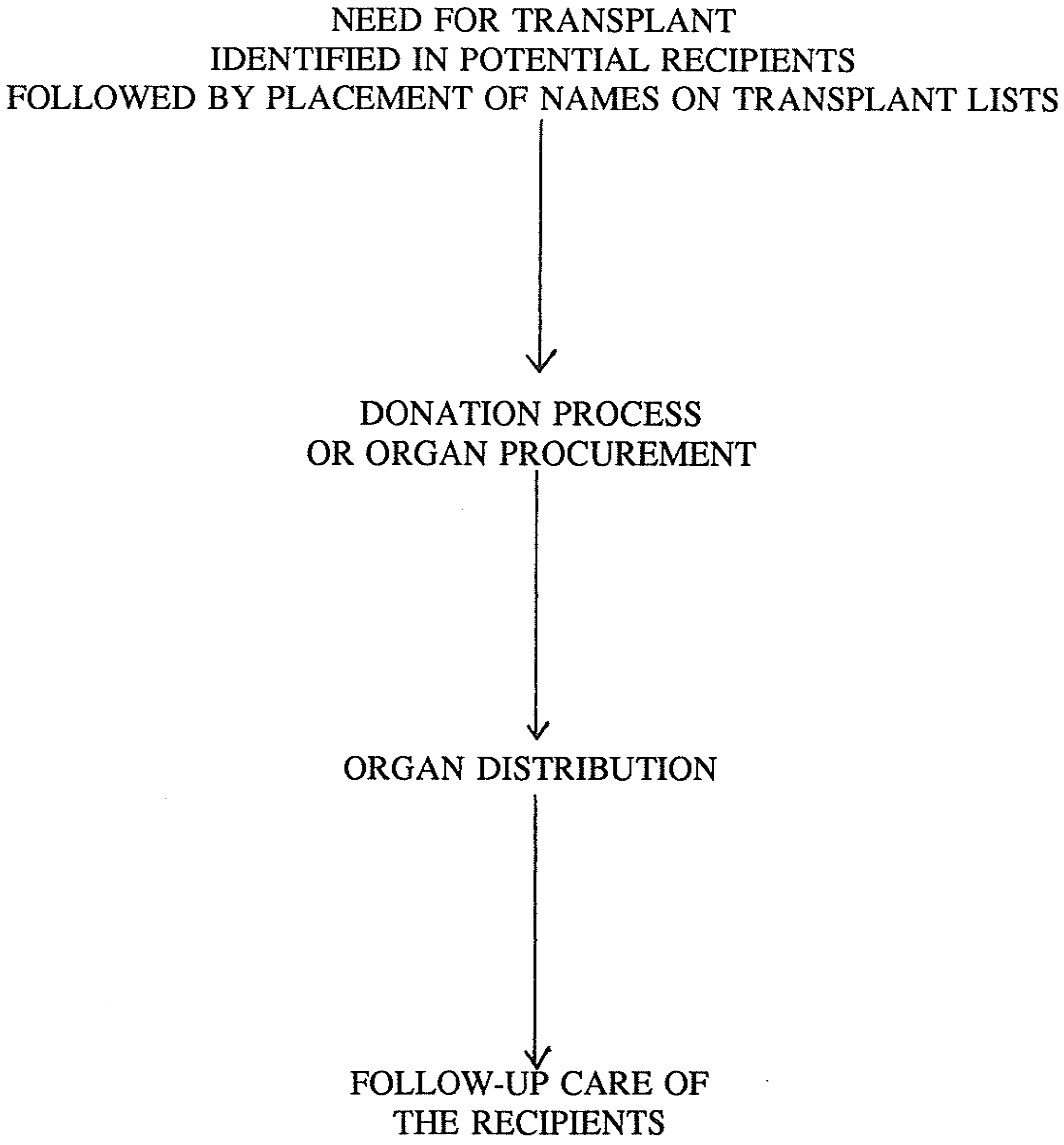
Significance of the Study

The need for education of health care professionals in all aspects of organ procurement, including donor care, has been identified by the Canadian Nurses' Association (1988), the Ontario Task Force on Kidney Donation (Stiller, Robinette, & Reed, 1985), and the United States (U.S.) Surgeon General's Workshop on Organ Transplants (Koop, 1983). In view of increasing public awareness of organ donation and the potential to perform greater numbers of transplants each year, an increasing number of nurses will care for cadaver organ donors and their families in the future. Documentation of nurses' experiences with donors and their families is essential and would prove instructive in giving direction to not only nursing education but also clinical practice and further research.

The Transplantation Process

The process of procuring and distributing human organs is complex and multi-faceted. An understanding of the transplantation process will facilitate the reading of this study. The transplantation process can be divided up into four stages: (a) the identification of the need for a transplant in potential recipients and the subsequent placement of the potential recipients' names on transplant lists, (b) organ procurement or retrieval, (c) organ distribution, and (d) recipient follow-up care. For the individual recipient, the process is linear (see Figure 1). The process is not linear from a more global perspective.

Figure 1. The stages of the transplantation process

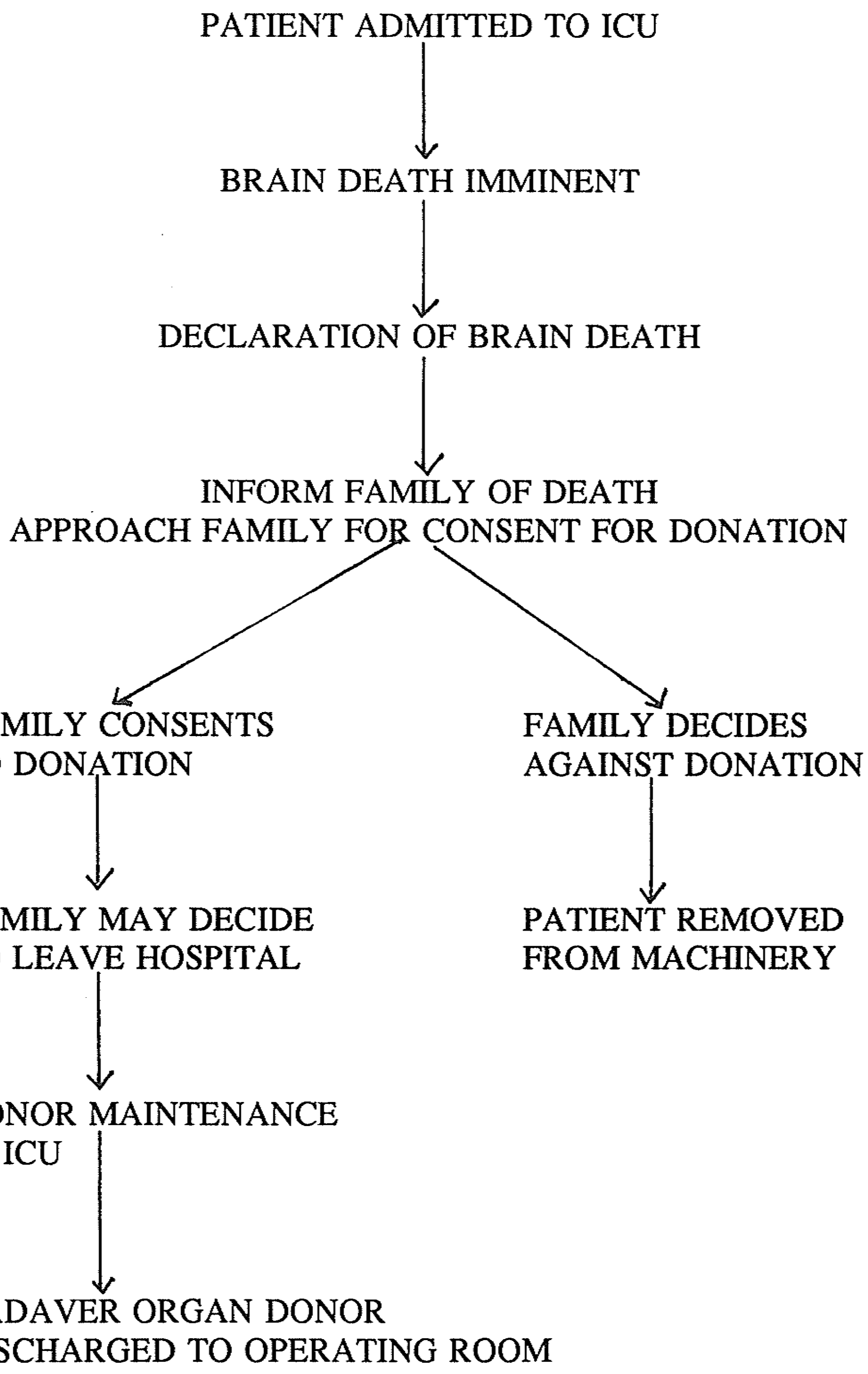


This study deals specifically with the stage of the transplantation process involving organ procurement. For the purposes of this study this stage will be referred to as the donation process (see Figure 2). The steps of the donation process have been outlined by Stiller (1990). The donation process begins with the realization by physicians and/or other health care providers that the irreversible cessation of the function of the entire brain of a patient is either imminent or has already occurred. Two physicians, who have no association with the organ retrieval team, will examine the patient to determine brain death. If death is declared, then the transplant coordinators are contacted and the suitability of the patient for organ donation is determined. It is possible that the coordinators may be contacted prior to death in some cases.

A member or members of the health care team (it may be the physician and a nurse and/or the transplant coordinator) then approach the family. The diagnosis of brain death is explained and discussed and organ donation is presented as an option for the family. If the family consents to donation, a decision is made by the family as to which organs they wish to donate. Once the family consents to donation the patient becomes a cadaver organ donor. If the family opts not to donate, steps are taken to discontinue the machines that are artificially maintaining the dead body. Stiller (1990) suggests that if the family consents to donation they be advised to go home at this time. Some families say their goodbyes then and leave; others stay until the surgical procedures are completed.

The family's consent for donation sets off a series of activities organized by the transplant coordinators. If the patient is not in a facility with the resources to retrieve organs, they will need to be transferred to such a centre. Suitable and compatible recipients need to be located; surgical retrieval teams, often from out of province or out of country, need to be notified to arrange times for retrieval; and operating rooms need to be booked. Until everything is arranged, the cadaver organ donor remains mechanically ventilated in the ICU and is cared for by the staff of the unit. Usually within 24 to 48 hours from time of death the donor is sent to the operating room and the organs are retrieved. The organs are then either transplanted into recipients within the same centre or sent away to centres where a need has been identified and a match obtained. In a few weeks, the transplant coordinator writes the donor family and the staff of the ICU to let them know what has happened to the organs and how the recipients of the organs are faring.

Figure 2. Steps in the donation process



Sensitizing Framework

This study was grounded in the work of Martin Heidegger (1962) as interpreted by Dreyfus (1983, 1991), Benner (1984a, 1984b, 1985), and Benner and Wrubel (1989). Heidegger saw human beings as always situated in a meaningful context (Benner & Wrubel, 1990; Dreyfus, 1991). Meaning is grasped directly by the individual in a nonreflective manner (Benner & Wrubel, 1989). This meaning results from a transaction between the individual and the situation (Allen, Benner, & Diekelman, 1986; Benner, 1985). The interaction is relational because humans can "be-in-the-world" (Allen, Benner, & Diekelmann, 1986, p. 28). Individuals bring background meaning, embodied intelligence, and concern to the individual-situation transaction (Benner & Wrubel, 1989).

According to Heidegger, human beings are self-interpreting (Dreyfus, 1991). This interpretation is not individually generated but rather based on socialization into a culture (Allen, Benner, & Diekelmann, 1986; Dreyfus, 1983). Cultural, social, and family practices provide us with background meaning, which determines our understanding of what it is to be human (Benner, 1984a; Benner & Wrubel, 1989; Dreyfus, 1983). It is impossible for background meaning to be made totally explicit, but it is against this background that human beings interpret their activities (Benner, 1985; Dreyfus, 1991). Thus, we come to situations with this background meaning or history.

Individuals bring two other elements to the individual-situation transaction.

The first is embodied intelligence (Benner, 1985; Benner & Wrubel, 1989). Dreyfus (1979) suggests that "what distinguishes persons from machines, no matter how cleverly constructed, is not a detached, universal, immaterial soul but an involved, situated, material body" (p. 236). Embodied intelligence is our bodily-way-of-knowing. It implies mind-body unity and accounts for such things as skilled action, movement, and the maintenance of culturally defined personal space (Benner, 1985; Benner & Wrubel, 1989). We do not consciously think about such activities. Walking, for example, is a complex activity. If you asked an individual to explain how to walk, it would be reasonably difficult for him/her to break the activity down into its component parts. Walking is not something we think reflectively about each time we do it. We just do it. Benner and Wrubel (1989) use the example of the learning of a skill such as suctioning a patient to explain embodied intelligence. When first learning the skill, we may feel awkward and clumsy. But eventually, "the body takes over" and the skill is performed smoothly and with apparent ease (Benner & Wrubel, 1989).

The other element persons bring to a situation is concern. Concern is one way of being involved in the world as a social being (Benner & Wrubel, 1989; Dreyfus, 1983; Dreyfus, 1991). It is because things "matter" to us that we become involved in our world. Benner and Wrubel (1989) suggest that while embodied intelligence and background meaning explain how we can directly grasp meaning, concern explains why.

In summary, meaning arises from the transaction between the individual and the situation. The individual brings to the situation background meaning or history, embodied intelligence, and concern. The suggestion is not, therefore, that meaning is assigned to a situation, but rather that meaning is embedded in our backgrounds, our skills, and our practices (Benner & Wrubel, 1989). It follows that the meaning of the experience of caring for cadaver organ donors and their families will be embedded in the nurse's background, skills, and practices.

From this framework flow the two assumptions of this study. The first assumption is that an understanding of the experience of caring for cadaver organ donors and families and the thoughts and feelings associated with this experience can best be gained through attention to context. The second assumption is that the meaning of the experience of caring for cadaver organ donors and families will be embedded in the nurse's background, skills, and practices.

CHAPTER 2: REVIEW OF THE LITERATURE

There is a paucity of literature specifically relating to the nursing experience of caring for cadaver organ donors and their families. The literature dealing with organ retrieval and donor care has focused on four interrelated areas: (a) brain death, (b) health care provider attitudes toward organ donation, (c) the identification of barriers to organ procurement, and (d) the feelings of health care providers toward cadaver donor care. This literature will be critically examined. A brief examination of literature related to post-mortem care will be provided at the end of the chapter.

Brain Death

In 1968, the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death (hereafter known as the Harvard Committee) published an historic article on irreversible coma. The Harvard Committee had been established for the purpose of defining a new criterion for death. Two factors created a need for a new criterion. First, resuscitative techniques had improved markedly in the 1950s and 1960s. The result was that individuals with irreversible brain damage and loss of spontaneous breathing could be maintained for periods of time on respirators, their hearts beating, but their brains destroyed. Using the age old standards of respiration and circulation these patients were deemed alive. The Harvard Committee expressed concern for these patients, their families, and for hospitals whose beds were occupied by these patients.

The second factor necessitating a new criterion for death was the potential for controversy in the retrieval of organs for transplantation. The transplanting of organs from one human body to another was a relatively new phenomenon in the 1960s. The first human to human kidney transplant occurred in 1947 at Peter Bent Brigham Hospital in Boston. Drs. Charles Hufnagel, Ernest Landsteiner, and David Hume attached a cadaver kidney to an artery and vein in the arm of a young, pregnant woman in a deep coma (Katz & Capron, 1975). A few days later the woman's condition had improved and the cadaver kidney was removed. The first successful permanently implanted kidney transplant occurred in 1954, again at Peter Bent Brigham Hospital, followed by the first human to human heart transplant, performed in 1967 by Dr. Christiaan Barnard at Capetown (Sanders & Dukeminier, 1968; Starzl, 1985). It was heart transplantation that generated the kind of controversy anticipated by the Harvard Committee. Katz and Capron (1975) stated that in 1968, at congressional hearings on health sciences issues, Senator Carl Curtis questioned "whether transplant surgeons were not deciding that a patient was dead whenever it suited their convenience" (p. 207). This kind of perception, based on the application of what had become outdated criteria of death, concerned the Harvard Committee. A new criterion for death would either eliminate the potential for controversy related to the removal of human organs or make the problem more readily solved (Ad Hoc Committee of the Harvard Medical School [AHCHMS], 1968).

The Harvard Committee advocated that irreversible coma become the new criterion for death. Irreversible coma or brain death (the terms were used interchangeably) could be determined if the following characteristics were noted on examination: (a) unreceptivity and unresponsiveness to stimuli, (b) the absence of movements during a one hour period accompanied by the absence of spontaneous breathing for three minutes off the ventilator, (c) the absence of reflexes, and (d) an isoelectric electroencephalogram. Confirmation of brain death required the repetition of the above tests 24 hours after initial testing and the exclusion of hypothermia or drug-induced central nervous system depression in the patient in question. If the patient exhibited the characteristics outlined, then death was to be declared (AHCHMS, 1968).

In 1968, the Canadian Medical Association (CMA) acknowledged the usefulness of the Harvard Committee's suggestions for determining death (CMA, 1968). More recently, the CMA (1987a) endorsed the guidelines of the Canadian Congress of Neurological Sciences for the diagnosis of brain death. The guidelines state that "although irreversible cessation of circulatory and respiratory functions acceptably defines death, irreversible cessation of brain function is also equivalent to death even though the heart continues to beat while the patient is on a respirator" (CMA, 1987a, p. 200A). A diagnosis of brain death is made when: (a) a cause of brain death has been established and reversible conditions have been excluded, (b) no movements or response to cranial nerve stimulation are present, (c) no brain stem reflexes are present, (d) the patient is apneic for 10 minutes following 10 minutes of preoxygenation with 100% oxygen. As with the Harvard Committee's recommendations, these conditions must be reassessed after a "suitable interval," 24 hours being the recommended interval (CMA, 1987a, p. 200A).

Despite the medical community's acceptance of brain death as death, the common law in Canada continues to define death as the irreversible cessation of circulation and respiration (Sneiderman, 1989). The Law Reform Commission of Canada (1981) has recommended statutory changes that would acknowledge that death occurs when all brain functions irreversibly cease. At present, Manitoba is the only province in Canada with a statute defining death (Sneiderman, 1989). The Vital Statistics Act, R.S.M., c.V60 (1987) states that "the death of a person takes place at the time at which irreversible cessation of all that person's brain function occurs" (p. 3).

Brain death is not a new way of being dead. The cessation of respiration and circulation has always signalled that brain death was imminent (Lamb, 1985). Given present technology, however, it is possible for brain function to cease (i.e., for death to occur) while circulation and respiration continue through artificial means. In effect, the sequence has been reversed. It has been suggested that the persistence of the term brain death "indicates some ambiguity and confusion about its meaning and implications" (Youngner, Landefelt, Coulton, Juknialis, & Leary, 1989, p. 2205). Veatch (1978) has argued that the confusion surrounding brain death stems from the Harvard Committee's use of the term irreversible coma synonymously with the term brain death. The term irreversible coma has been equated with persistent vegetative state, a condition involving the destruction of the cerebral cortex with retention of some brainstem function (Pallis, 1987). Brain death, in contrast, involves the destruction of the whole brain.

Another contributing factor to the confusion surrounding brain death is the persistent attempt to differentiate between brain death and somatic death --death of the person and biological death (Agich, 1976; Dillon et al., 1982; Lamb, 1985; Rix, 1990; Shrader, 1986; Siegler & Wikler, 1982; Walton, 1980). Advocates of the brain death-somatic death differentiation suggest that the death of the brain is a "tragic, ultimately fatal loss, but not death itself" (Siegler & Wikler, 1982, p. 1101). Death becomes a process, a series of deaths. Only when the whole organism has ceased to function is the process complete. Certainly the persistence of signs of life in the brain dead patient, most notably the warm body, the beating heart, and the movement of the chest wall, contribute to this argument (Agich, 1976; Youngner et al., 1985).

Both linguistic and conceptual confusion regarding brain death are evident in the literature (Bernat, Culver, & Gert, 1982; Bouressa & O'Mara, 1987; Byrne, O'Reilly, & Quay, 1979; Dillon et al., 1982; Hannegan, 1987; Oro, 1989; Siegler & Wikler, 1982; Tendler, 1989; Tomlinson, 1989; Wikler & Weisburd, 1989; Wolf, 1990; Youngner et al., 1985). Two examples from the literature demonstrate this confusion. Dillon et al. (1982) when referring to a brain dead, pregnant patient, artificially maintained to allow a fetus to mature, state that "attempts to prolong maternal life in the face of brain death are expensive" (p. 1091). If brain death is equivalent to death, then the woman is dead and her life cannot be prolonged. Obviously, it is difficult to comprehend that a dead body can nurture a living fetus. Wolf (1990) states that "O.R. nurses...are present in the O.R...when the brain dead donor dies at the time of organ procurement" (p. 1020). The donor is declared dead when brain death is diagnosed not when organs are removed.

A number of studies illustrate the confusion over the concept of brain death. Crosby and Waters (1972) sent questionnaires to 100 nurses, selected randomly from two hospitals in Wales, to identify their apprehensions about kidney transplantation. Eighty-seven nurses responded. Respondents with 15 or more years of nursing experience were classified as senior nurses and those with less than 15 years as junior nurses. Forty-seven percent of senior nurses and 50% of junior nurses indicated that they had difficulty with the decision as to when the patient had actually died. Information about the validity and reliability of the questionnaire was not provided. However, these results point to the fact that in 1972 the concepts of brain death and organ transplantation were new and definitions of death imprecise in the minds of practising nurses.

More recently, Borozny (1988a, 1988b, 1988c) circulated a questionnaire to 126 ICU nurses at two hospitals in Vancouver. Seventy-six nurses responded. Borozny found that the nurses were uncertain about the clinical criteria for brain death. When respondents were asked to identify criteria for determining brain death, only 42% and 46% respectively identified apnea and unresponsiveness as criteria. Ninety-five percent of the sample had provided nursing care to a brain dead patient. Borozny does not report the validity or reliability of the questionnaire used.

Youngner et al. (1989) interviewed 195 physicians and nurses "likely to be involved" in the care of patients with catastrophic brain injuries to explore their knowledge of the concept of brain death. The sample included 40 nurses from intensive care units chosen randomly from four university-affiliated hospitals in Cleveland. This study's attention to descriptions of questionnaire development, reliability, validity, sampling technique, data collection, and analysis is impressive. Participants were asked the question "What brain functions must be lost for a patient to be declared brain dead?", and were provided four possible responses. Of the 40 ICU nurses sampled, 55% (22) answered the question correctly. Participants were then presented with two case studies and asked to decide whether the patient in each case was legally dead. Only 23% (9) of ICU nurses knew the whole-brain criterion of death and applied it correctly to the two cases. Youngner et al. (1989) concluded that "many health professionals involved in the care of potential donors and responsible for talking with their families are confused about the clinical and legal applications of a brain-oriented standard for determining death" (p. 2209).

It is not surprising that confusion related to brain death is also demonstrated by donor families. Morton and Leonard (1979), who interviewed 32 relatives of cadaver kidney donors six months or more after donation, found that 38% (12) were stunned by the request to donate organs as they had not realized the gravity of their loved ones' condition. Batten and Prottas (1987) mailed questionnaires to 455 cadaver donor families. Of the 264 respondents, 39% found brain death hard to understand. Savaria, Rovelli, and Schweizer (1990) sent questionnaires to a convenience sample of 196 families six months after donation. Eighty of the 99 respondents felt they understood the concept of brain death, while 14 stated they lacked a clear understanding of the concept. The latter explained their lack of understanding on the grounds that the donor did not "appear dead" or that the concept was not well explained (Savaria et al., 1990, p. 316). The Batten and Prottas (1987) study and the Savaria et al. (1990) study do not provide any information regarding the validity and reliability of the questionnaires utilized, clouding interpretation of the findings.

Tomlinson (1989) has argued that the confusion Youngner et al. (1989) discovered --and perhaps the confusion generally regarding brain death --stems from the fact that "'brain dead' in the vernacular of both the health professions and the lay public refers to a whole spectrum of severe brain damage" (p. 2836). Tomlinson advises that given the vagueness of the term brain death, perhaps health care professionals should not be using it when talking to families. Annas (1988) and Jasper, Harris, Lee, and Miller (1991) have suggested replacing the term brain dead with the term dead.

In summary, the literature related to brain death illustrates linguistic and conceptual confusion surrounding the concept. Studies have suggest that both health care providers and donor families experience this confusion.

Organ Donation

Despite statute changes and public and professional education, there remains an insufficient supply of transplantable human organs (DeChasser, 1986; Houlihan, 1988; Iglehart, 1983; Kolata, 1983; Koop, 1983; McLennan, 1987; Prottas, 1983; Robinette, 1987). Estimates suggest that of the roughly 200,000 deaths that occur annually in Canada, three percent (6000) could provide organs suitable for transplantation (McLennan, 1987). If 50% of all possible donation situations resulted in actual donations, the needs of the greater than 2100 Canadians awaiting donated organs could be met (CMA, 1987b). Yet in 1990, it is estimated (from incomplete data) that there were 856 cadaver donor referrals and 522 actual donations (personal communication, Terry Leeke, Data Coordinator at Canadian Organ Replacement Register, August 9, 1991).

The discrepancy between organ supply and demand has been termed "a paradox of shortage in the face of plenty" (Bart, Macon, Whittier, Baldwin, & Blount, 1981, p. 379). The problem was studied in 1983 by the U.S. Surgeon General's Workshop on Organ Transplants and a U.S. Congressional Inquiry, by the Ontario Task Force on Kidney Donation in 1984, and by the Alberta Human Tissue Procurement Task Force in 1985. A recurring barrier to transplantation, identified by all four studies, was a reluctance on the part of health care providers to participate in the organ donation process (Alberta Human Tissue Procurement Task Force, 1985; Corlett, 1985; Iglehart, 1983; Koop, 1983; Robinette, 1987; Robinette, Stiller, & Marshall, 1986). This reluctance has led to the suggestion that physicians and nurses are the "weak link" between organ procurement programs and the public (Iglehart, 1983, p. 126).

The question that arises is: Why are health care providers reluctant to participate in the donation process? Studies have examined health care providers' attitudes toward organ donation and barriers to the donation process in an attempt to answer this question.

Attitudes toward Donation

Five studies have examined nurses' attitudes toward organ donation. All five used questionnaires to gather data. Varying degrees of information regarding the questionnaires were provided in each study, but not one of the studies discussed the development of the questionnaire utilized by the researchers or its reliability or validity.

Sophie, Solloway, Soreck, Volek, and Merkel (1983) examined the role of ICU nurses in cadaver organ procurement. Questionnaires using both open and closed-ended questions were sent to 560 ICU nurses working in 27 hospitals in the American midwest. Of the 312 nurses who responded, 44% were experienced in the nursing care of a potential organ donor. Eighty-seven percent of respondents approved of cadaver organ donation, though only 28% carried signed organ donor cards. When asked to identify the rationale for approval, 77% of nurses mentioned the benefit of transplantation for the recipient.

Stark, Reiley, Osiecki, and Cook (1984) examined attitudes affecting organ donation in intensive care units. Intensive care nurses from eight hospitals in Boston volunteered to collect information for a seven-item questionnaire each time a potential donor was identified in their respective units. Over the period of one year, 26 patients were identified as potential donors and eight donations took place. Stark et al. (1984) found that the eight nurses involved in the donation cases "favored donation" (p. 403). The authors acknowledge that this finding is not surprising since the nurses surveyed were also involved in the data collection. It would have been instructive to examine the attitudes toward donation of the nurses involved in the care of the 18 patients who did not become donors. A discussion of interrater reliability, given the number of data collectors utilized, would also have been worthwhile.

In a study of health professionals' attitudes and reservations toward organ procurement, Prottas and Batten (1988) mailed a 50-item questionnaire to a random sample of four ICU nurses per hospital from 344 acute care hospitals in the U.S. Of the 878 respondents, 93% strongly approved of organ donation, 94% would consider donating their own organs, and 71% had discussed their views about donation with their families. Multivariate analyses revealed that experience with donation and perceptions of physician support for the process were associated with favourable attitudes to donation.

In a study of attitudes toward organ donation, Gaber, Hall, Phillips, Tolley, and Britt (1990) surveyed non-physician health care professionals "most likely to be involved" in the care of donors from three southern U.S. states (p. 313). The sampling method for this study is not clearly articulated. One thousand questionnaires were sent out and 766 were returned. The respondents included nurses and other health care professionals working in intensive care units, emergency departments, and operating rooms. However, the authors do not specify how many of the respondents were nurses. Ninety percent of respondents had no moral objection to organ donation and 45% indicated a willingness to donate their own organs. Thirty-five percent of respondents had signed an organ donor card. Respondents who had prior experience in caring for cadaver donors had a higher degree of "willingness to donate" organs and "willingness to solicit donation" (Gaber et al., 1990, p. 314).

Bidigare and Oermann (1991) examined the attitudes and knowledge of critical care nurses regarding organ procurement. Sixty nurses working in a U.S. hospital that did not perform transplantations and did not have an organ procurement team filled out questionnaires. Seventy-one percent (43) of respondents had participated in the care of a donor. Ninety-four percent (56) approved of organ procurement, though only 51% (31) had signed a donor card. Seventy percent (42) of respondents indicated that they would actively pursue organ donation with the family. Using a Likert-type scale with 0 representing strongly disapprove and 10 representing strongly approve, nurses were asked to indicate their feelings toward organ procurement. A mean of 9 was obtained. Positive relationships between: (a) previous experience with donor care and comfort in approaching family for consent for donation and (b) previous experience and knowledge scores were noted. Nurses with higher knowledge scores had more positive attitudes toward donating their own organs and toward participating in the care of the donor.

The five studies examined demonstrate approval for organ donation by the nurses (and other health care professionals) sampled. The difference noted between approval of donation and the signing of a donor card in the Sophie et al. (1983), Gaber et al. (1990), and Bidigare and Oermann (1991) studies is interesting. The significance of this finding is unclear, although it appears that one's approval in theory of organ donation will not necessarily lead to the signing of an organ donor card.

Identified Barriers to Organ Donation

A number of studies were examined that identified perceived barriers to organ procurement from the health care professionals' perspective. The barriers identified were: (a) concern for donor families and (b) the emotional demands of involvement in the procurement process.

Several studies have illustrated that health care professionals are concerned for donor families. Crosby and Waters (1972) conducted a study of attitudes toward transplantation using a sample of 100 nurses in Wales. They found that 65% of senior nurses (over 15 years experience) and 80% of junior nurses felt that seeking consent for organ donation would cause extra distress to the deceased patient's family. Oborne and Gruneberg (1979) examined problems associated with kidney donation. They found the major reason physicians in their sample did not refer potential donors to renal units was because of their concern that asking for consent for donation would increase the family's distress. In a survey of 2024 physicians and nurses, the Ontario Task Force on Kidney Donation revealed that 50% of nurses and 45% of physicians surveyed felt inhibited in initiating the donation process because of their concern that obtaining consent for donation would "bother" the already grieving family (Robinette, Stiller, & Marshall, 1986). Prottas and Batten (1988), in their study of attitudes and reservations related to organ procurement, found that 68% of their sample of 246 neurosurgeons believed that their physician colleagues were "somewhat reluctant to approach families about organ donation" (p. 644). Similarly, Gaber et al. (1990), in a survey of attitudes toward organ donation, identified that 35% of the sample of 766 non-physician health care professionals stated that the request for donation "places the bereaved family under an unfair strain" (p. 314). Forty-three percent felt that the request for organs could be offensive to the family.

Malecki and Hoffman (1987) and Norris (1991) found that nurses were uncomfortable approaching families for consent for donation. Sixty-two percent of Norris' (1991) sample of 57 nurses rated themselves as uncomfortable in approaching potential donor families (p. 44). Norris suggested that negative perceptions of donor families' experiences related to issues around death and dying. Further elaboration of the meaning of this statement would facilitate the understanding of these findings.

Personal feelings or the emotional demands of involvement in organ procurement have also been recognized as potential barriers. In the Ontario Task Force study, 50% of nurse and physician respondents identified "personal feelings" as a barrier to organ procurement, although no elaboration of the nature of these "feelings" is provided (Robinette, Stiller, & Marshall, 1986). In a study of housestaff physicians at two hospitals in the U.S., Spital and Kittur (1990) found that 36% of the 91 physicians who responded felt "at least somewhat uncomfortable" with asking a family for consent for donation, and that 26% found caring for a cadaver organ donor "emotionally very stressful" (p. 2415). Prottas and Batten (1989), in a study of 246 U.S. neurosurgeons, identified that 74% of respondents found organ procurement emotionally demanding and 39% did not like to make brain death decisions.

These studies illustrate that concern for donor families and personal feelings may act as a barrier to donation. However, the nature of these particular emotions has yet to be clearly delineated.

Feelings Related to Cadaver Organ Donor Care

Cadaveric donation results almost exclusively from the sudden, unexpected death of a young person. The death of a patient, particularly a young patient, has been identified by ICU nurses as one of the most stressful aspects of their work (Anderson & Basteyns, 1981; Huckabay & Jagla, 1979). The loss of a young patient, who may be identified with friends and family of the caregivers, can lead to anxiety, anger, distress, guilt, grief, or emotional depletion (Bilodeau, 1973; Degner, Beaton, & Glass, 1981; Glaser & Strauss, 1964; Hay & Oken, 1972; Price & Murphy, 1985; Quint, 1966). To cope with the stress associated with the death of a young person nurses may withdraw emotionally from the dying patient or dehumanize him/her in order to distance themselves from their own feelings (Benoliel, 1974; Davis & Lemke, 1987; Degner, Beaton, & Glass, 1981; Glaser & Strauss, 1965; Lippincott, 1979; Price & Murphy, 1985; Quint, 1966).

The family of the cadaver donor must also be cared for by the ICU nurse. Caring for families in need of support has been identified as a source of a stress for ICU nurses (Bilodeau, 1973; Dunkel & Eisendrath, 1983; Gardner & Stewart, 1978; Hickey & Lewandowski, 1988; Huckabay & Jagla, 1979; Solursh, 1990). In one study, 77% of the 226 ICU nurses who responded to a questionnaire indicated that it is emotionally exhausting to provide care to families in need of support (Hickey & Lewandowski, 1988). Intensive care nurses have identified that their perception of lack of time and skills necessary to provide adequate support to families created further stress for the nurse (Bilodeau, 1973; Huckabay & Jagla, 1979; O'Malley et al., 1991).

While aspects of cadaver donor care have been identified as potentially stressful, few studies have explored nurses' feelings related to participating in the care of cadaver donors. Anecdotal and case study reports have suggested that nurses may feel ambivalent, frustrated, depressed, altruistic, hostile, stressed, confused, or challenged when caring for donors (Davis, 1981; Kozlowski, 1988; Schaal & Slemenda, 1984). Three studies have examined the feelings of nurses caring for a cadaver organ donor. Sophie et al. (1983) asked

ICU nurses to describe their reactions in caring for potential donors by completing one open-ended question on a questionnaire. Seventy-eight percent of the total sample of 312 nurses responded. Thirty-two percent stated that providing nursing care to cadaver organ donors did not bother them, 25% found the experience rewarding, 21% found it emotionally draining, 12% felt that it subjected the donor family to added stress, and 5% found it particularly difficult if the donor was young. Excerpts provided by Sophie et al. (1983) illustrate the range of feelings experienced by respondents. One respondent described cadaver organ donors as "objects for salvaging parts - like a junk yard of cars" (p. 264). Respondents described the experience as "depressing," "difficult," or "upsetting." Some respondents felt that donation helped the family "make sense out of a senseless tragedy" (Sophie et al., 1983, p. 265). One nurse stated that the letter from the transplant center regarding the recipients of the organs made the experience "worthwhile."

Using phenomenology, Borozny (1990) examined the experience of ICU nurses providing care to the brain dead patient. The sample consisted of 11 nurses who had from 4 to 20 years of ICU experience and who had cared for between 2 and 10 brain dead patients. Five of the participants were interviewed twice and six were interviewed three times in a semi-structured interview format. Borozny found that nurses experienced two forms of dissonance, personal and interpersonal, associated with caring for brain dead patients.

The participants described feeling personal dissonance when: (a) their personal philosophy of nursing was dissonant with providing care to a brain dead patient; (b) the nursing care provided was dissonant with the participant's knowledge that the patient was dead; (c) the participant's personal belief about the patient was dissonant with the knowledge that the patient was dead; (d) a lack of "internal harmony" regarding issues related to organ retrieval was present; (e) the participant's need to meet her own emotional needs conflicted with her responsibility to the family. Interpersonal dissonance occurred when the participant's beliefs were in opposition to those of the family or health care team.

Borozny (1990) suggested that this dissonance results in personal distress. Participants indicated that they would distance themselves from the patient or designate another, usually the family but also the recipient or the nurse, as the focus of their nursing care in order to decrease the dissonance they experienced. Borozny does not report strategies utilized to ensure rigor, nor does she discuss the attitudes of the nurses she interviewed toward organ procurement.

Bidigare and Oermann (1991), in their study of attitudes and knowledge of nurses regarding organ procurement, asked 60 nurses to indicate on a questionnaire the positive and negative aspects of organ donation. It is unclear if this was an open-ended question or a forced choice question. Positive aspects of organ donation identified included: (a) the improvement of the quality of life of the recipient and (b) helping the donor family to find some meaning from tragedy. Negative aspects included: (a) difficulty of both the family and nurse in understanding brain death, (b) creating false hope in the recipient in case of rejection, and (c) fear expressed by the donor family regarding disfigurement. A discussion of the questionnaire utilized in this study and its validity and reliability would assist the reader in interpreting the findings.

In summary, nurses participating in studies related to the experience of caring for cadaver organ donors have suggested that the experience can be rewarding, emotionally draining, difficult, and stressful. Borozny (1990) found that the experience resulted in both personal and interpersonal dissonance in the participants in her study.

Post-mortem Care

At one time, the care of the body was attended to by the family of the deceased. Jackson (1977) suggests this practice stemmed from the fact that many people "felt that the body deserved more respect than to be handed over to strangers" (p. 230). As more and more people entered hospital when ill, the hospital became the place where death occurred and the staff of the hospital became the caretakers of the body (Aries, 1981; Blauner, 1977).

Sudnow (1967) examined the social organization of "death work" through an ethnographic study. Sudnow was a non-participant observer in two hospitals in the U.S. for approximately 14 months. He describes in detail the practice of "body wrapping" and noted that there was a clear division of labour related to body care. Post-mortem care was termed "dirty work" and was usually handled by aides or orderlies, who generally handled the body "nonreverently." Nurses were found to distance themselves from this activity. Staff used different tactics to avoid the task of body wrapping. For example, a death might be "camouflaged" or wrapping might be delayed so that the next shift was required to fulfill the task. Sudnow also discusses the treatment of comatose patients. He suggests that a patient "dies" in some respects as soon as he/she enters a "terminal coma." A patient in a coma was essentially treated as dead, and staff could be observed talking over the patient or freely discussing the patient's condition in his/her presence.

Wolf (1988) examined the post-mortem care of the body through an ethnography of nursing rituals in an acute care hospital. Participant observation (over a 12 month period), semi-structured interviews, and event analyses were used to explore nursing rituals. Wolf described the rituals associated with the death of a patient -- bathing and shrouding the body. The patients' bodies were washed after death, according to the nurses in this study, so that "all traces of suffering" could be washed away (Wolf, 1988, p. 138). The nurses were noted to be "protective" of the body and to treat it with reverence and respect. Some nurses spoke to their dead patients, and some referred to a "spirit presence" hovering around the body. Wolf (1988) states that "even after patients die, nurses care for them, touching them with gentleness" (p. 139).

Wolf (1990) also explored nurses' experiences of providing post-mortem care to organ donors in operating rooms. This phenomenological study used a convenience sample of eight nurses. Participants were interviewed once and the interviews were audiotaped. Follow-up phone calls allowed the participants to react to the results of the study. Wolf found that the nurses felt that donation was something "positive" and that the death would have been "sadder" if donation had not occurred. These nurses had a need to feel that "something good comes out of a bad situation" (Wolf, 1990, p. 1019). The nurses described making the "patient" more presentable through a bath and stated that the body must be shown respect. Wolf (1990) stated that wrapping the body in a shroud confirmed the death for the nurses.

In summary, the responsibility for post-mortem care has shifted in the last century from the family to the hospital staff. Studies have examined the experience of caring for the dead body. Sudnow's (1967) study suggested that nurses distanced themselves from post-mortem care, which was considered "dirty work." Wolf's (1988, 1990) studies describe how the body is "cared for" and treated with reverence.

Summary

Based on studies to date, there is some indication that ICU nurses generally approve of organ donation, demonstrate some confusion regarding the concept of brain death, express concern for donor families related to the distress of donating organs, and identify personal feelings as a potential barrier to organ procurement. The literature also suggests that cadaver organ donor care can be on the one hand rewarding and on the other emotionally demanding and draining and may create personal and interpersonal dissonance in the nurses required to provide donor care.

CHAPTER 3: METHODOLOGY

Research Approach

A qualitative approach was deemed both useful and appropriate for this study for three reasons. First, qualitative approaches, particularly phenomenology, reject the assumption that there is a private, subjective world that is separate from an outer, objective world (Munhall & Oiler, 1986; Smith, 1989). As Munhall and Oiler (1986) suggest, " subjective experience is not merely a private, inner world; but rather, inextricably bound with objective reality" (p. xiv). Reality, therefore, is "co-constituted" (Smith, 1989, p. 14). One of the goals of a qualitative approach, then, is the discovery of an experience in the context in which it exists (Munhall & Oiler, 1986). Second, little was known about the experience of caring for cadaver organ donors and their families. Field and Morse (1985) and Sandelowski, Davis, and Harris (1989) have suggested that a qualitative approach should be used when little is known about a phenomenon or event. Finally, qualitative approaches allow for rich descriptions of the phenomenon or experience explored (Morse, 1991). I wanted to describe the experience of caring for cadaver organ donors and families using the words of the participants of this study. Thus, a qualitative approach was selected.

This study utilized the hermeneutic phenomenological approach of Heidegger (1962) as interpreted by Dreyfus (1983, 1991), and further described and used by Benner (1984a, 1984b, 1985), Benner and Wrubel (1989), Chesla (1990), and Schilder (1986). Heidegger stated that "hermeneutics, used as an adjunct word to 'phenomenology,' does not have its usual meaning, methodology of interpretation, but means the interpretation itself" (cited in Dreyfus, 1991, p. 34). Hermeneutic phenomenology studies the person in the situation (Benner, 1985; Dreyfus, 1983). The person is recognized as having background meaning. The interpreter may share some aspects of that background meaning. The context of situations is a crucial element in this approach. Benner (1984) states that a description of the context of a situation clearly limits the possible interpretations of a transaction. This results in the maintenance of the "meaning of the situation" (Benner, 1984, p. 40). The participants provide the investigator with a depiction of their lived experience, and the investigator, as interpreter, attempts to establish commonalities in meanings, situations, and practices (Benner, 1985; Benner & Wrubel, 1989). Indeed, hermeneutic phenomenology facilitates the uncovering of "the meanings in everyday practice in such a way that they are not destroyed, distorted, decontextualized, trivialized, or sentimentalized" (Benner, 1985, p. 6).

Study Sample

Eleven female intensive care nurses participated in this study. Five of the participants responded to an advertisement placed in the newsletter of the Winnipeg Chapter of the Critical Care Nurses' Association (Appendix A). The other six participants were obtained through snowball sampling. The participants ranged in age from 26 to more than 35 years, with mean age of 33.9 years (five participants were 35 years of age or older). Years of nursing experience ranged from 6 to more than 15, with a mean of 12.4; ICU experience ranged from 1 to more than 15 years, with a mean of 9.2 (see Table 1). All participants worked in a tertiary care hospital. Seven participants had experience in a medical ICU, four in a surgical ICU, and four in a pediatric ICU. Four had worked in more than one type of ICU. All the participants had diplomas in nursing and four had attained a baccalaureate degree in nursing. Ten of the eleven had taken at least one of the intensive care nursing programs offered in Winnipeg.

The number of cadaver organ donors cared for by the participants ranged from 2 to over 30, with a mean of 11 donors (see Table 2). The length of time the participants had cared for donors ranged from four hours to three shifts. In addition to providing care to cadaver organ donors and their families, eight participants had discussed donation with families, four had asked for consent from families, and five had cared for donor recipients.

Table 1

Summary of Demographic Data

	Range	Mean
Age of Participants (years)	26-35+	33.9
Nursing Experience (years)	6-15+	12.4
ICU Experience (years)	1-15+	9.2
Number of Cadaver Organ Donors Cared for by Participants	2-30+	11.0

Table 2

Breakdown of Cadaver Organ Donor Cases Cared for by Participants

Number of Participants	Number of Cadaver Organ Donors Cared For
3	2-4
3	5-10
2	11-15
2	16-20
1	30+

Data Collection

Sample Recruitment

An advertisement was placed in the newsletter of the Winnipeg Chapter of the Critical Nurses' Association seeking volunteers for the study (Appendix A). This newsletter is published bimonthly and mailed to approximately 135 critical nurses in Manitoba. The advertisement clearly outlined the purpose of the study, sample inclusion criteria, and the mechanism for contacting the investigator for additional information. In order to participate the nurse had to be employed in an ICU at the time of the study or have had ICU experience within five years of the study, have provided care to a minimum of one brain dead organ donor for a minimum of one shift (8 or 12 hour), and live in Winnipeg. When interested individuals contacted me, the study was explained (Appendix B) and questions and concerns addressed. If the person agreed to participate, a time and place for the signing of the consent form (Appendix C) and the initial interview were mutually agreed upon. A written explanation of the study was provided to the potential participant at this time (Appendix D). Every individual who contacted me agreed to participate in the study.

When the advertisement failed to produce the needed sample, snowball sampling was utilized. Participants who responded to the advertisement and participants later obtained through snowball sampling were asked to suggest and to contact possible participants. The names of possible participants were not provided to me. If these individuals contacted me, the same procedure as outlined above was followed.

Interview

Each participant was interviewed twice by me at a mutually agreed upon time and location. All interviews took place in the homes of the participants. Each interview was tape recorded. An informal and partially structured interview as described by Melia (1982, 1987), Weber (1986), and Wilson (1985) was utilized in this study. Melia (1987) suggests that an informal interview takes the form of a conversation. The goal of the interview was to "evoke the participant's lived experience" (Weber, 1986, p. 68). The achievement of this goal was facilitated by an agenda of topics to be covered during the interview (Appendix E). My knowledge as a former ICU nurse, the advice of clinicians and my thesis committee, and the literature were drawn upon to shape this agenda. The agenda acted as a guide to the interview. Deviation from the agenda was anticipated and indeed occurred as the interviews unfolded. As the study proceeded, the interviews became more focused (May, 1991). This was particularly true of the participants' second interview as I discussed the findings with the participants and sought validation for my interpretations of the findings.

An explanation of the study, a discussion of concerns and questions, the signing of the consent form, and the collection of demographic data (Appendix F) occurred at the first interview. The demographic data provided direction to the interview and information related to background meaning. The tape recorded interview followed the completion of these tasks. Participants were asked to recall cadaver organ donor cases. The questions from the agenda of topics were asked when appropriate to the discussion of the cases. Based on the first few participant interviews, I added some topics to later interviews as new areas of interest or concern were identified. While I might have spent one to two hours with the participant, the tape recorded interviews usually lasted from 45 minutes to one hour.

The second interview provided the opportunity to explore further the experiences of the participants, to validate interpretations, and to seek clarification. Often, the participant would begin the interview by saying that she had been thinking about the interview and had remembered other stories of caring for cadaver organ donors. The completed transcript of the previous interview was brought along to the interview and clarification of specific comments was sought. I would also discuss my interpretations of the text and seek validation or suggestions for alternate ways to look at the data. The second interviews ranged from 40 minutes to 2 hours, although the actual taped interviews lasted from 35 minutes to an hour.

Journal

At the end of each interview, I recorded my thoughts, feelings, or observations in a journal. Suggestions for future lines of questioning or participants' comments that required clarification were also recorded in this document. Following review of the completed transcript of the first interview, questions to pursue in the second interview were noted in the journal.

Data Analysis

The transcripts from all the interviews formed the text to be interpreted; I acted as the interpreter. The journal and demographic data were also examined and formed part of the text. Two distinct strategies were utilized in interpreting the text. Both occurred simultaneously with data collection.

The first strategy involved examining the participants' experiences in caring for cadaver organ donors and families. Each participant had been asked to recall experiences that she remembered or that stood out. In response to this question, the participants related stories of caring for donors and their families. According to the Oxford English Dictionary (1970b), a story is a "recital of events that have... happened" (p. 1041). Only stories that involved a cadaver organ donor that the participant had cared for were examined. The participant had to devote a few sentences to the telling of the story for it to qualify as a story. For example, if the participant simply mentioned that she had cared for a young donor five years ago, that would not constitute a story. If she talked about the case for a few sentences and provided some detail regarding involvement in the case, then that did constitute a story. Twenty-nine stories were identified. These stories were examined to establish what was similar about them and what was different. Similarities and differences were quantified where possible. This information, when combined with the demographic data collected, created a picture of the experiences of the 11 participants with cadaver organ donors and families.

The second strategy utilized in text interpretation was thematic analysis as described by Benner (1984a, 1984b, 1985), Chesla (1990), and van Manen (1990). Thematic analysis was used to identify commonalities in meanings and practices within the text. Van Manen (1990) suggests that looking for something "thematic" equates with looking for something telling or meaningful (p. 86). A theme is uncovered by asking questions such as: "What is the focus here?", "What is the point here?", or "What is the meaning here?" Van Manen (1990) views themes as, at best, simplifications of aspects of the lived experience (p. 87).

Although the process was not entirely step-like, I will outline the process of thematic analysis in a step-by-step fashion. It should be noted that the hermeneutic approach to text interpretation involves a to-and-fro movement between the parts and the whole of the text (Benner, 1985; Benner & Wrubel, 1989; Rickman, 1976). An analysis of the whole text is accompanied by an analysis of the parts of the text. A comparison of the two interpretations occurs and is followed by a return to the whole, etc. (Benner, 1985). Dilthey (1976) and Heidegger (1962) describe this as the "hermeneutic circle." Rickman (1976) explains this concept using the example of words and sentences. To grasp the meaning of a phrase like "hand me my clubs," you have to examine the meaning of each word within the phrase; "but we can only select the appropriate meaning of 'club' or discard the use of 'hand' as a noun when we have an idea of what the whole sentence means" (Rickman, 1976, p. 10). The use of the "hermeneutic circle" is apparent in the description of thematic analysis that follows.

To start with, the transcripts were read in their entirety following each interview. This was followed by a line by line analysis of the text. Specific feelings, thoughts, and ideas about cadaver organ donor care that were identified by the participants were underlined in the transcript; and a key word from that feeling, thought, or idea was written in the margin of the transcript. After the completion of the first five participants' interviews, the transcripts were examined for recurring feelings, thoughts, and ideas. My journal and the demographic data were also examined. The whole text and then its parts were again examined. It became evident at this time that I had to ask more questions of the text. Benner (1985) suggests that the interpreter "enters into a dialogue" with the text (p. 9). For example, two participants indicated that they experienced anger when caring for a cadaver organ donor. A review of the transcripts revealed that the cause of the anger was a crucial part of the feeling. So I would ask the text the question: "Why did they feel or think this way?"

It was from the answers to the question "Why?" that themes began to emerge. I continued to examine each transcript, underlining, using key words, and answering the question "Why?", until all transcripts were completed. At this point, verification of these emerging themes was sought from some of the participants, as interviews were still ongoing. This was extremely useful and forced me to go back and re-think my interpretation. Further study revealed that some themes were really part of another theme and could, therefore, be collapsed into a larger theme. I then returned to the transcripts to verify that the themes truly represented the words expressed by the participants.

The final step of thematic analysis involved searching for exemplars from the transcripts to illustrate themes. An exemplar is "a vignette or story of the particular transaction that captures the meaning in the situation so that the reader is able to recognize the same meaningful transaction in another situation" (Benner, 1985, p. 10).

Thematic analysis, therefore, proceeded in the following manner.

1. The transcripts were read in their entirety.
2. The transcripts were analyzed line by line.
3. Key words relating to thoughts and feelings were identified.
4. As each interview was completed the transcripts were read and compared to previous transcripts.
5. The reasons for the thoughts and feelings identified were explored in the

transcripts. Themes began to emerge.

6. Throughout the process the demographic data and journal entries were examined.
7. Verification of emerging themes was sought from some of the participants.
8. Exemplars were located to illustrate the themes.

Bias Control

Strategies to ensure bias control as described by Benner (1984a, 1985) were incorporated into the study. First, multiple interviews took place with each participant. This allowed for clarification of participant comments, participant validation of my interpretations, and the emergence of patterns (Benner, 1984a, 1985). The two meetings also promoted the formation of a trust relationship between myself and the participants.

Secondly, the chair of my thesis committee provided expert consensual validation of the themes. Benner (1984a) suggests that "the assumption underlying this bias control strategy is that meanings discovered and the interpretations offered are shared cultural meanings and therefore recognizable by others who share the same culture" (p. 37). Assistance was provided by my chair in the coding of the transcripts. One full transcript and excerpts of another were coded by her so that I could compare my coding method with hers. There was discussion of the transcripts with both the chair of my committee and my second committee member. These discussions proved invaluable as they encouraged me to continue to ask questions of the text and confirmed that I was on the right track.

The third strategy utilized for bias control was the "hermeneutic circle." The to-and-fro movement results in multiple stages of interpretation and forces the investigator to confront contradictions in interpretation (Benner, 1984a). Finally, interpretations have been presented with as much textual evidence as was feasible to allow the reader an opportunity to participate in the consensual validation process (Benner, 1984a). The exemplars in particular should assist the reader in this process. Both typical and atypical interpretations are included.

Strategies to ensure bias control should facilitate the achievement of the credibility, fittingness, and confirmability of this research. Credibility and fittingness are the criteria used to evaluate the truth value and applicability of a study's findings. Confirmability is the criterion used to evaluate the neutrality of a study, where neutrality refers to the "freedom from bias in the research process" (Sandelowski, 1986, p. 33). Auditability is the final factor that relates to tests of rigor and was attended to as well. Auditability is the criterion used to evaluate the consistency of qualitative findings. My "decision trail" has been outlined in this study in an attempt to make it accessible to the reader (Chesla, 1990) and therefore "auditable" (Sandelowski, 1986, p. 35).

Ethical Considerations

The proposal for this study was submitted to the Ethical Review Committee of the School of Nursing, at the University of Manitoba. Ethical approval was obtained (Appendix G). Every attempt was made to ensure that participants were fully informed and that their rights were protected. Potential participants received a verbal description of the study when they contacted me by phone, and if they were interested in participating they received a written explanation of the study when we met in person. It was stressed to the participants that they could withdraw at any time and that they could refuse to answer any questions. When a participant became distressed, the tape recorder was shut off and a joint decision was made as to the appropriateness of continuing the interview. This situation occurred only once.

A number of strategies were utilized to ensure that the confidentiality and anonymity of all participants were protected. The names of participants appeared only on a master sheet of codes and on consent forms, both of which were kept in a locked file. I was the only person who had access to these documents. Transcripts and audio tapes contained only a code number, which could not be matched to a name. Access of audio tapes was restricted to me and my thesis supervisor, and access to transcripts was restricted to me and my thesis committee. In the findings chapter of this study only code numbers appear with transcript excerpts and caution has been exercised to ensure that identifying facts are not included with the excerpts provided.

CHAPTER 4: FINDINGS

The findings of this study will be presented in this chapter. The experiences of the participants will be examined for similarities and differences. Their thoughts and feelings will be described through four themes that emerged from the analysis of the text. The four themes are: (a) "It depends;" (b) "They're dead, but they're not dead;" (c) "Finishing the case;" and (d) "Something good came out of it."

Experiences

The breakdown of cases cared for by the 11 participants was as follows: three participants had cared for 2 to 4 donors; three had cared for 5 to 10 donors; two had cared for 16 to 20 donors; and one participant had cared for more than 30 donors. Eight of the participants had approached a family regarding the option of organ donation, four had been involved in obtaining consent for donation from a family, and five had cared for an organ recipient. Nine participants viewed organ donation positively; two participants expressed concern about the donation process and had reservations about the donation of their own or their family members' organs.

Participants were asked to talk about the cases that they remembered or that "stood out." Twenty-nine stories about cadaver organ donors and their families were recounted. Participants recalled between 1 and 5 stories each, with a mean of 2.6 stories per participant. The 29 stories were examined to establish similarities and differences.

Similarities in Stories

The 29 stories were similar in four ways. Three areas of similarity related to the participants' discussions of the donor, the cause of donor injury, and the donor family. Each story revolved around a donor, although the donor usually received only brief mention. Only two stories revealed a detailed discussion of who the donor was in terms of characteristics, interests, and personality. In 22 of the 29 stories, participants specifically mentioned the age of the donor or referred to the fact that the donor was young. The participants described the cause of the brain insult in 21 of the 29 stories. This was done with varying degrees of detail. Some participants merely mentioned the cause, while others spent some time explaining how and where the injury occurred. Participants mentioned something about the donor family in 24 of the 29 stories. A few participants briefly described the family situation; others described the reaction of the family to the events that were unfolding. Other comments regarding family related to its presence or absence, the number of family members, the amount of time the family spent at the bedside, the effect its presence had on the participant, and what the participant and family member talked about.

In 24 of 29 stories, there was a "trigger", as one participant described it, which made the story stand out in the memory of the participant. The triggers were participant-identified. Two of the participants, who recounted four stories between them, did not identify a trigger. One other participant identified a trigger in four of her stories, but not in her fifth story. Triggers were usually preceded by a statement like: "This case stands out because...," or followed by statements like "That is why it stands out," "That's what made is so memorable," or "That's what made it so hard." A given story could have one or more triggers. These triggers were classified into three categories: (a) first experiences, (b) overlapping of participant and donor family's lives, and (c) turn of events.

First Experiences

Five of the stories were descriptions of the participant's first experience with organ donation. One participant's first experience with donation was also her first nursing experience with a death. The fact that the experience was a first was mentioned as a trigger in two stories.

Overlapping of Lives

Recollections of six of the stories were triggered by an overlapping of the donor and donor family's life story with the life of the participant. In three of the stories, for example, the participants knew (usually remotely) the donor or the donor family. The participant (or in one case the participant's colleague) and the donor or donor family had something in common in three other stories. In one story, the donor's wife and the participant were the same age. In another, the donor and participant shared a common interest. In a third story, the donor and the participant's colleague, who was on duty when the donor was in the unit, had both been preparing for a major life event.

Turn of Events

In 19 of the stories, the trigger related to the turn of events; something happened in the process of donation that made the story memorable. Three stories were depicted as memorable because of the unusual circumstances surrounding the injury of the donor, while three others stood out because of the intense tragedy suffered by the families. Nine of the stories were described as being memorable because of an unusual occurrence during the time when the participant cared for the donor and donor family. These occurrences included: the nurse going into the operating room with the donor, a physician's interaction with a donor family, a donor family member's reaction or disclosure, the delay of organ retrieval surgery, and the absence of a donor family. Another unusual occurrence identified by one participant was the amount of activity generated by the organ retrieval teams flying in from out of province. Two stories stood out for a participant due to circumstances regarding the recipients of organs obtained from donors she had cared for. Finally, two stories stood out for two participants due to the overall feelings with which they were left.

In sum, the participants' stories were similar in that they revolved around a donor, discussed the cause of the donor injury, and mentioned the donor family. It was also found that most of the stories had a "trigger" which made the story stand out in the memory of the participant.

Differences in Stories

The participants' stories differed in a number of ways. The stories differed in length, recency, richness, depth, and focus. The majority were told in a few sentences and would transcribe from a paragraph to a page of double-spaced typing. In the case of three participants, stories covered two pages of double-spaced typing, with no interruptions from the interviewer. Not all participants identified when their stories had occurred. It is known, however, that the most recent story had occurred only a few day before the interview; the most remote had occurred 12 years earlier. Richness and depth were obviously impossible to quantify, but some stories were vivid and filled with emotion, while others were clinical and concentrated on the facts. One of the most vivid and emotional stories had occurred 12 years prior to the participants' interview. The focus of the stories also differed, and this seemed to be related to the participants' trigger. Variance in the stories were related to differences in: (a) where in the donation process the story took place, (b) the way events unfolded, and (c) the outcome of the story.

Placement in Donation Process

In 15 of the 29 stories the nurse's point of entry or exit into the donation process was not discussed by the participant. In 14 of the 29 stories entry or exit points were discussed. As the participants explained, the placement of their encounter changed what they were required to do. Three stories involved caring for a donor from time of admission to discharge to the operating room (or in one case just prior to discharge). One such story took place over the period of one shift. In the other two stories, the time frame was longer than one shift. Two of the stories dealt with caring for a donor prior to the declaration of brain death; three others involved caring for a donor pre-and post-declaration of brain death. Another three stories dealt with sending the donor to the operating room. One participant described a case in which the donor had been transferred in from another hospital after consent for donation had been obtained. The family had said their goodbyes and did not accompany the body to the second hospital. The participant stated that the case was:

> very straightforward because the family didn't come with the patient and the patient went to the OR maybe four or five hours into my shift. So, I mean that one really doesn't count, I guess, because there really wasn't a lot involved. (014)

Two stories were quite unique in that the participants had cared for the donor and had then become involved in one of the final stages of the donation process by providing care to a recipient of the particular donor's organs. The participant described the situation in one case as follows:

> I looked after her (the donor) one night and I looked after the recipient the next night and it was hard almost to get it straight in my mind that there were two separate people. Like it

> was just weird to know that this person that I was looking after the second night had part of this other person in them. (013)

The stories differed, then, in that some participants identified where in the donation process the story took place and others did not. Those stories that identified placement in the donation process differed in terms of where in the process the story had occurred.

Unfolding of Events

There were any number of variables that affected the way events unfolded in the donation process. Thirteen of the 29 stories contained references to and/or reasons for the way that events unfolded. Of these 13 stories, only 3 had gone "smoothly." One participant explained why she felt the course of events had been so "smooth":

> ...we hadn't even approached them yet, and they approached us about organ donation even before we got to them. Like this was just how much they were into organ donation. It was just everything went so smoothly...It was just almost like textbook. It was just-alright, neuro. came in and did their tests, declared her brain dead, the transplant coordinator came in - like the family approached us about organ donation and everything went along really nicely, really smoothly. (012)

Factors that resulted in the process running less than smoothly, or that complicated the course of events, were the hemodynamic status of the patient in two stories, the actions or inactions of members of the health care team in five stories, the discovery of information that precluded donation in one story, the misunderstanding of the family in one story, and the involvement of the legal system in one story.

The following excerpt illustrates how the inaction of members of the health care team, from the participant's viewpoint, resulted in the course of events running less than smoothly.

> ...it was during the night...it was a young man...I don't even think that they had approached the family yet because somebody wouldn't come in at night to declare him. But everybody was sitting on the fence and we were losing him. He was dying. And I was really - I guess mad. I guess I was really mad because we all knew he was dead, but nobody would say yes, and nobody would say: "Well, okay. He's dead now and if we want to save his organs we have to start doing other things." And nobody was making that decision. And I guess I was getting mad because I thought this is going to be a whole waste of a life and a death. (013)

The stories differed, therefore, in how the events unfolded. Some stories involved situations that had progressed smoothly, while others described how the process had become complicated by any number of factors.

Outcome

The goal of the transplantation process is reached when donor organs are successfully transplanted into recipients. That outcome was described by a participant:

> ...a week later we got a letter in the mail that said: "There is a nine year old boy who received one of those kidneys who actually peed on the operating room table before the case closed, for the first time in three years on dialysis." ... We thought that was the best piece of news we had heard. (021)

Four stories discussed this outcome with specific reference to recipients. Twelve stories either mentioned which organs were retrieved from the donor or mentioned that the intermediate goal of getting the donor to the operating room had been achieved. Three stories described another outcome -- the inability to get the donor to the operating room and the loss of the organs. One participant's experience follows:

> ...he was in our unit for a number of hours and while we were trying to set up teams to fly in to retrieve organs he became increasingly unstable... and basically what happened is the patient ended up arresting and we couldn't get him back to even get kidneys or anything on him. So it was an extremely stressful day of ten hours of basically continuous resuscitation, because he was so unstable because of the nature of his injury, and trying to keep him going to be a donor with that goal in mind of bringing something meaningful out of this entirely meaningless, horrible thing. And then he ended up dying and no organs could be retrieved whatsoever, except bones and corneas. (020)

Ten of the stories did not specifically discuss the outcome of the case.

The 29 stories were different, then, in a number of ways. Differences were noted in length, richness, recency, and focus. Differences in the stories were also evident in terms of where in the donation process the story had taken place, how smoothly the course of events unfolded, and what the outcome had been.

Summary

If it were possible to describe a "typical" cadaver organ donor story, based on the 29 stories told by participants the story would discuss the donor, the donor's age, the cause of the donor's injury, the donor's family, and the trigger or reason the story was memorable. What makes it impossible to describe a "typical" story is that the story triggers were different, although they shared some commonalities, and that the situations the stories were grounded in were quite diverse.

Thoughts and Feelings

The thoughts and feelings of the 11 study participants in caring for cadaver organ donors and their families were at times quite similar and at other times quite distinct. One participant summed it up by stating that: "It's a hodgepodge of emotions that you feel, from sometimes feeling extremely sad and devastated to other times feeling nothing" (015). The four themes that emerged from the text take into account the similar and diverse thoughts and feelings of the participants. The themes are: (a) "It depends;" (b) "They're dead, but they're not dead;" (c) "Finishing the case;" and (d) "Something good came out of it."

"It depends"

All participants noted that their thoughts and feelings were dependent on a number of factors. The circumstances surrounding the cause of the injury, the point at which one enters and exits the process, and the people one works with throughout the process were identified as having an impact on thoughts and feelings regarding cadaver organ donor care. This theme was, therefore, subdivided into three subthemes: (a) It depends on the circumstances, (b) It depends on where you come in, and (c) It depends with whom you are working. Each subtheme will be explained separately.

It Depends on the Circumstances

Each participant suggested that the circumstances surrounding the donor's accident or injury affected the way she felt about the experience. Each felt a sense of sadness related to the death of a young person and many felt empathetic toward the families. The untimely death was described as "unfair" or "a waste." One participant was saddened because the child "barely had a shot at it," another felt that young donors were "robbed" of a full life. A third participant suggested that:

> You feel it is more of a tragedy when someone dies at the beginning or middle of their life as opposed to at what we perceive as the end --or well, "They've lived a good life." We have no idea if they've lived a good life or not, but anything above 70 or 75 is deemed a good life. (020)

Almost all of the situations faced were described as tragic, although some were described as more tragic than others. Participants described cases involving the death of an only child, an abused child, or a young parent, or death by suicide as particularly sad or tragic. Situations that involved families facing multiple tragedies were also viewed as particularly tragic. Five of the participants expressed anger when the cause of the brain injury related to physical abuse or alcohol. One participant said she felt "anger sometimes, especially when it's the drunk that's hit them and they are sort of the innocent bystander" (013).

In summary, the participants described how the circumstances surrounding the injury or accident of the cadaver organ donor affected the way they felt about the case. Different circumstances could elicit different or more intense thoughts and feelings.

It Depends on Where You Come In

An influential factor in determining how participants thought or felt about an experience was the point at which they entered or exited the process of donation. According to one participant:

> It will be a case of locating my place. Is it going to be prior to brain death? Will I be doing that right off the bat? Have we just got to the point where the patient has declared himself? Will that be my next step? It will be locating where I fit in that continuum and then placing myself there and going on. So, I will place myself there. And I mean that in the fact that I don't go through the grieving and the loss process with the family if I'm already at donation.

Because I will approach that differently. (021)

Participants divided up the process in two distinct ways. The first division revolved around the declaration of death. The second division revolved around the departure of the family. Participants suggested that they viewed the process very differently pre- versus post-brain death. One participant stated:

> Dealing with brain dead kids is either very simple or very hard. What makes it simple...is that other shifts or the other days before have done all the work. They've done all the resuscitating, they've done all the worrying, they've done everything. You come on - it's over. I mean, the child is brain dead. It's an established fact and either they are going to take him off or they are waiting for organ donation. And you don't get emotionally involved in that. You've missed it. The family has been up, they've been down, you just walk into the situation and it's that day and they are taking him. (018)

Participants described how the "focus of care" changes after death has been declared. Some participants stated that the cadaver organ donor's bedside often becomes less "busy" or "quiet" once death has been declared. One participant stated that:

> People kind of clear out a little bit, you know. The activity moves say from the bedside to the desk. (011)

The declaration of death also brought changes in the way the patient was viewed. Participants spoke of starting to "separate" from the donor, of "shifting gears," of "shutting off" their emotions, and of recognizing or feeling that something was now different. One participant described the situation as follows:

> There is something that happens that gives you an empty feeling. A really eerie feeling. And you know that you are no longer dealing for a life. Like the sense of life, the sense of being, the sense of presence has gone from the body. And it literally is just a storage place for organs. (021)

One participant suggested that this "shift" from life to death was difficult for her, and that difficulty was partly related to feelings of guilt. She would ask herself: "Did I miss something" (018)?

The nursing care the donor received could change in subtle ways. Almost all the participants stopped speaking to the patient after the declaration of death, although one participant continued to do so because she wondered if a soul could hear. Turns, mouth care, combing or braiding of hair, and efforts to make the donor "look comfortable" were continued almost without exception by the participants. When asked whom they were doing these things for, the responses were: the donor family, the donor, and themselves. When asked why they continued these measures, the responses were: (a) so that the family can see that the donor is still cared for by the nurses; (b) out of respect for the person that has died, but whose body remains in their care; and (c) so that they can demonstrate that they care. One participant stated:

> I think you do it for yourself because you see yourself, or I see myself as a caring person who respects human beings. And so if that were my child or that were me being in intensive care with hair every which way and drooling, needing suctioning, you know, incontinent, you name it. I just - I need to give that care (pause) so I can demonstrate my caring. And that's how I would want to be treated. (015)

One participant stated that she did those things for her mother. She said:

> She's always told me if and when she dies all she wants is somebody to sit there and hold her hand and talk to her. And I guess when I deal with people like that, that's who I think of sometimes too. (013)

The second division of the donation process revolved around the presence or absence of the donor family. One participant summed this division up as follows:

> To me there's two different phases of how the day goes. And it's before the family has had their last visit and after the family has had their last visit. Because until the family has come in for the last time, I really focus my nursing care on the family... And after they go, it is actually a big relief. Even though you want to support them as much as possible, once you know that they have said their goodbyes and they have gone...then you can really focus your energy just on the patient, and making sure their blood pressure is stable and making sure there is optimum setting for those organs. (020)

Caring for the family was described as "difficult" but essential. Many of the participants viewed caring for the family as one of the more "challenging," "satisfying," and "fulfilling" aspects of the process. For many it was the families that made situations memorable:

> But the three children, and the children coming to the bedside; the toddler walking in, the 10 year old walking in to say goodbye to daddy and that sort of thing. That is why they always ring home -- because you can remember that. (021)

It was also the families that enabled the participants to recognize that the donor had been a human being. The family was the link to the person the donor had been. One participant suggested:

> You've never really known the child except through the parent's eyes...You sit and you talk to them and you learn about them. They talk about their little girl...We encourage them to bring pictures and we pin them on their little beds so that we remember that this is a little girl that used to play and ride a bike. (016)

A picture of the patient or information regarding the patient could make caring for the donor more difficult for the participant. But it seemed quite important to the participants that they knew about the donor. One summed it up by saying that knowing about the donor "put the patient in perspective as a person" (021). Three participants reported that they were unable to learn about the patient's personal history because of the absence of the donor family. One stated she felt that something was "missing" when she was unable to meet the family of the donor. She described feeling "empty." Another mentioned that not having a family present and not knowing anything about the donor brought home the reality that she was truly looking after a "corpse."

Families also brought the reality of grief to the situation. One participant stated:

> It's just as soon as these family members start coming in and they start saying goodbyes and start doing their thing that...It's as soon as I see them then I'll start crying behind the curtain and I'll start getting sad. (012)

One participant stated that she experienced a feeling of "helplessness" when dealing with the families because she couldn't "give that parent what they ultimately want. And what they want is for them to have their child back" (015). According to the participants, families had diverse ways of grieving. The family's way of grieving on occasion proved "hard" or "difficult" for the participant to witness. Many found dealing with the family's grief at times "overwhelming" and "exhausting."

Once the family had said their final goodbyes, the participants viewed the situation differently. Then it was "just the nurses left with the body" (021). One participant stated that once the family left:

> You stop looking back at the family and the past and the tragedy and you look ahead to the hope that is in the future for someone. (020)

Others did not necessarily shift the focus to the recipient, but they agreed the departure of the family changed the dynamics of the situation considerably.

In summary, the participants divided the process of donation into different phases. These phases related to two events: the declaration of brain death and the departure of the family. Depending on the phase of the process, thoughts and feelings related to the experience could differ.

It Depends With Whom You Are Working

All participants discussed how the people with whom they were working through the donation process affected the way they thought or felt about the experience. Nurses, physicians, orderlies, chaplains, pastoral care workers, and the transplant coordinators were mentioned as playing a role in making the process easier or more difficult for the participant. All participants agreed that nursing colleagues had been helpful in their experiences. Nurses "chipped in," provided relief for a break, provided "an extra set of hands," and often provided much needed support. Three participants mentioned that nursing colleagues introduced humour into a particularly stressful situation. For some participants, it was helpful to talk to colleagues (usually at work) about the course of events. When asked how she dealt with her thoughts and feelings about the donor, one participant replied:

> You often save them (feelings) at the bedside and take them elsewhere with you. Take them to the coffee room and talk to your colleagues as you literally talk your way through the process of grieving. You do that by talking to your colleagues. They may not realize that is what they are doing. Like it is just coffee chat, supposedly. (021)

Sometimes it was difficult for participants to get assistance or support from their colleagues. One participant found that some nurses "sort of think you are looking after a dead body --you don't need any help" (013). One participant discussed how nursing colleagues had made inappropriate remarks when assisting her or had treated the body in a manner that she viewed as less than respectful. This annoyed her and she wondered out loud if this was their way of dealing with the situation.

Physicians were mentioned by seven of the participants as affecting the donation process, all of whom described physicians as very helpful and supportive. Two participants mentioned, however, that working with a very junior or inexperienced physician could make the process more difficult. Chaplains and pastoral care workers were mentioned by four participants as being "supportive" of both the family and the staff.

Without exception, the participants expressed appreciation for the role of the transplant coordinators. The coordinators were described as "great," "invaluable," and "wonderful." One participant remarked that she was "thrilled when they come" (017). It was felt that the transplant coordinators took a lot of the "burden" away from the bedside nurse by handling the "frustrating things," or the "piddly work," or the "scuz work," like phone calls, desk work, and the general coordination of the donation process. This was particularly welcome because of the unfamiliarity with some of the tasks associated with organ retrieval. The coordinators "openness in dealing with families and staff" (015) was valued, as was the support they provided to the staff. One participant stated:

> The fact that they have nursing background...helps a lot because they understand the intracacies of things and they also have all the things at their fingertips in terms of it's best to give them this or give them this much DDAVP (a drug used with diabetes insipidus) or whatever it happens to be. And they always have the answers...Like they are always able to give you some direction if you encounter some difficulty. So they are knowledgable, they are resourceful, they are positive, they are supportive, they believe you when you say something is going wrong. (020)

The contribution of the transplant coordinators sometimes extended beyond the donation process. A story recounted by one participant described the feelings she experienced witnessing a situation involving a transplant coordinator and a husband who had decided not to donate the organs of his dead wife:

> And I remember him saying: "Well, you know, I don't know what she would have thought. And what if I donate her organs and that's not what she would have wanted." And nobody coerced him. I mean she (the transplant coordinator) was there and she was just amazing. And she stayed through the whole thing, even though they weren't donating. She stayed until the patient was taken off the respirator and until the heart stopped beating and she stayed with them after. So that was a very warm, wonderful feeling to see her do that. (014)

Only one participant had experienced a situation where she felt that the transplant coordinator had been less than helpful, an experience that left her feeling quite distressed. Generally, the arrival of the transplant coordinator was a welcome sight.

Other health care team members were also noted as being helpful or less than helpful. One participant found the operating room staff quite helpful in the process. This was not always the case, however. One participant described how the actions of two orderlies affected the feelings she had regarding a cadaver organ donor experience:

> And she just looked, for all intents and purposes, like a child sleeping. And we combed her hair and we braided it and she was just this beautiful little girl. And her mom and dad had brought in her blanket and her doll, so everytime they came in she had her doll tucked under her arm and --I mean we just kind of cherished this body and watched them grieve. And so that morning we took her to the O.R. And we got there and these --I remember in my mind, you know, it was probably blown out of proportion --but these kind of mogully orderlies came along and literally just picked up this body that we had been like lovingly caring for and dumped her on to their operative stretcher. Like dumped her. And I was just furious and sick about it. (018)

The participants suggested, therefore, that thoughts and feelings related to donor experiences were certainly influenced by the people that they worked with. Some people had a positive effect, others a negative effect.

"They're dead, but they're not dead"

A predominant theme in the discussions of the participants related to thoughts about the life/death status of the cadaver organ donor. One participant, who had stated earlier in the interview that she viewed the cadaver organ donor as dead, stated:

> But they are not dead. I mean they really aren't. They are if you consider thinking. But really, I mean when you still see the heart beating and their skin is still pink. They're dead, but they're not dead. (018)

This comment typified the perplexing nature of the experience of caring for a warm and respiring dead body. All of the participants acknowledged that the body looked life-like. They said things like: "they don't look so dead," "she looked like a child sleeping," or "they don't look any different than your normal ventilated patient." At some point in their two interviews, almost all participants stated that they considered the cadaver organ donor to be dead. Six expressed that view clearly, although they recognized that the reality of being faced with a warm and respiring body confounded the issue. When asked what they would call that which they were caring for following the declaration of death, the six used terms such as: "a dead body" or "a body," "a cadaver," "an empty shell," "a storage place for organs," or "organs." The acceptance of the death of the donor led to different feelings in the six participants. One stated that she felt "more like a technician than a nurse" (017) when looking after a dead body because she felt that it was impossible to have a nurse-patient relationship with a corpse. Another participant described her inability to feel anything when caring for a dead body:

> ...I never met a single family member. And I cared for this girl, who was brain dead who I knew not at all, and I felt like I was a --well I felt like I had no emotions because I felt I was looking after a body, literally a corpse. I looked after her, did all the hourly things every hour on the Friday and the Saturday...I came on duty (on the Sunday) and the night nurse had --she had braided this hair down and she had this beautiful terry cloth, bright yellow blanket on her and she had put a rose beside her head. I couldn't handle it. I just burst out crying. Because what I had been looking after as a corpse wasn't -- like I think that was the first time I sort of put humanity to her. Like, in my mind, rationally, I knew this was a girl, how sad, how awful, but I hadn't felt anything. (015)

While the six participants accepted the death of the donor, they still wanted to know about the donor's history. As one participant put it:

> Just because it is a cadaver now doesn't mean that you can forget the fact that ten minutes ago or two hours ago it was an alive, healthy person. (014)

Three other participants acknowledged that the person was dead but felt there was still some life left in the body. One participant suggested that "maybe there is still a flicker of something still there" (013). All three talked about continuing comfort measures for the donor. One wondered if "maybe the person can feel this, maybe they are still there" (012). Interestingly, two of the three participants, using very similar words, mentioned that they did this because the soul might be "looking down" on them. The third explained her rationale for this as follows:

> ...You sort of want to do as much as you can to do some of the last comfortable things for them. I know -- even though, like I said, the person is dead, it is just this body that you're doing this to. I guess it's something about doing, going through the motion that helps me psychologically with the person part being dead. (012)

When these participants were asked what they were caring for after the declaration of death, they used terms like "a dead body," "a dead person but a live body," or "just the body." One of the participants qualified the statement "just the body" by saying that "I still like to think of them as people" (013).

The remaining two participants talked about the cadaver organ donor as if he/she were still alive, although they recognized the inevitability of the donor's death. One stated that "they are alive in the sense that --you are keeping them alive" (019). Both participants referred to the donor as a person. One suggested that "if you didn't think of them as people it would be very hard to cope with this" (016). When asked what she was caring for after the death declaration, one said that she was caring for the family's loved one.

In summary, the life/death status of the cadaver organ donor was viewed in three different ways by the participants. Six participants clearly considered the donor dead, three acknowledged that the person was dead but felt that "some life" still remained, and two considered the donor still alive.

"Finishing the case"

A third theme that emerged from the text revolved around finishing, disengaging, or bringing closure to the nurse-cadaver organ donor relationship. As one participant noted, with cadaver organ donors "the end is sending somebody to the operating room being ventilated" (015). This ending was acknowledged by all participants as quite different from wrapping a body in a shroud and sending it to the morgue. The ritual of shrouding was described as the "completion of an event" (011). One participant stated:

> For the nurse to go through the rituals of putting on a shroud and taking that child to the morgue -- it's very, very difficult, but it sort of closes the chapter like a funeral does. (015)

Two participants found that the absence of the shrouding ritual made it more difficult to end the nurse-donor relationship. For one participant, the difficulty related to not being able to "clean up and fix up the patient" (017). She stressed the importance of ensuring that the patient is "taken care of" and that "everything is looked after" in terms of bathing the body and removing the tubes that occupied many body orifices. The other participant thought that with a cadaver organ donor there isn't "a complete finish." She stated:

> It's like nobody is really finished. The parents go home and yet the child is still here and yet they are told he's dead and they're still ventilated. It doesn't feel like it is completed. (016)

This participant stated that she didn't like this ending.

In contrast to this view, some participants found a finality in sending the patient to the operating room which was preferable to shrouding the body. Four participants commented on how much they disliked the shrouding ritual. They tended to consider, as one participant stated, that sending the donor to the operating room was "just as final as taking them to the morgue" (020). One participant summed it up as follows:

> It is such a short period of time. The pastoral care deals with the family, you deal with the patient. The patient leaves, the family leaves and it is kind of -- the book is closed. (019)

The time element was mentioned by a few participants. Some felt that in some senses there was not a need to finish anything because it was almost as if it "hadn't really started," given the short time period during which care had been required. One participant suggested that the death of an individual who becomes a donor was "easier" to cope with than other deaths because "within 8 hours, 24 hours, sometimes 48 hours...it's over" (015).

Three participants suggested that because the donor had been declared dead at some point prior to being discharged to the operating room, the finishing process starts with that declaration of death. One participant remarked:

> I don't think you really need that final performing of that little ritual of wrapping and all that stuff because I think you've probably already -- you go through that, you struggle with that

> throughout the whole 12 hour shift, or
> whatever. (012)

It was described by one participant as a "situation that's resolved already. It is almost like past tense in a way" (018).

For two participants, the finish or the end came with the letters the unit received from the transplant coordinator letting the staff know what had happened to the retrieved organs. One participant suggested:

> I have this picture in my mind of a bed being wheeled out of the unit, with an anaesthetist bagging and two other people with them, porters or whatever, driving the bed and they are gone. And like they wheel around the corner and that's the last you ever see of that patient. And then you kind of go -- okay...we got those organs to the O.R. alive. And I guess for me, I guess then I take a quantum leap and I skip the shroud and the trip to the morgue and I see and I wait for the letter in the communication book that says where those organs went. And that's about it. (020)

The other suggested:

> It is the letter, I think, that finishes -- or knowing where the organs went, or what happened to them, that sort of finishes off the case. The little girl story won't be finished until we find out where everything went. (021)

To summarize, most participants had little difficulty finishing the case despite the fact that they had not personally been involved in the shrouding of the body. Two participants reported that they found sending the donor to the operating room much more difficult to deal with than situations which enabled them to provide after-death care.

"Something good came out of it"

The final theme that emerged from the text related to the participants' thoughts and feelings about the outcome of the donation process. Nine of the 11 participants saw the fact that the organs retrieved from the cadaver donors were transplanted into other human beings as the "silver lining" or the "plus side" to this "negative" situation. One participant stated:

> Knowing the end result -- two people will get a kidney, one person might get a heart, one person might get a liver and live ten more years, or however long, that is very positive. (014)

Participants described feeling "better" or "good," or feeling a sense of "satisfaction," "exhilaration," or "relief" as a result of this outcome. The outcome enabled some participants to "make sense" of the death or put it into perspective. As one participant put it:

> In somebody who is brain dead where we do get organs, I feel like actually something good has come out of the situation. And it makes me feel better about the death and about the tragic situation. I feel, well, it hasn't all been for naught. (011)

All participants mentioned the follow-up letters that the transplant coordinators had sent to the units. The letters were described by some participants as "rewards," and it was mentioned that the staff particularly appreciated that the nurses who had been involved in caring for the donor were specifically named and thanked.

The flip side of "something good" was discussed by a number of participants through the concept of "waste." Six participants commented on the anger, frustration, and disappointment they felt when: (a) families were not approached regarding donation or did not consent to donation, (b) they had been unsuccessful in maintaining the patient long enough to retrieve organs, or (c) retrieved organs were not transplanted. This group of participants viewed this as "a real waste" of "good organs." All of these participants expressed concern for the families in these situations because they were "denied an opportunity." One participant described her feelings regarding the use of organs for research:

> It was frustrating -- sort of a waste. That they had harvested his heart and when they finally got it out and saw it they realized it wasn't suitable for transplant. And I'm not sure how I feel. Or I know that I don't feel particularly comfortable with them using it for research...And I guess it is because the families have signed these consents thinking they are doing something wonderful. That they are saving somebody's life, sight, or whatever. And I don't know if they ever get the feedback that: "Sorry, this heart wasn't used and somebody used it for experimentation instead." (013)

For two of the participants, the "good" that resulted from transplantation was too remote for them to really appreciate. One participant remarked:

> I can't say that I get all fired up and go: "Yeah, this is a good thing." Maybe what I need to see are more of the rewards. I need to see the child walking down the street that

> has the kidney, or somebody who can't see who gets the corneas. I don't see enough of that end of the reward and maybe that would make me feel better. (018)

The other participant stated that she felt "a little bit angry" about the donation process because she saw it as extending the time the family had to see their loved one attached to the machinery necessary to maintain the organs. She stated:

> Yes there is good coming out of it, but that is removed. That is distant because I don't know the recipient. My concern is with the patient that I'm looking after and his family because they are there. (017)

In summary, almost all the participants viewed the fact that organs retrieved from the donors had gone to other human beings as "something good." Two participants did not share this view. They found it difficult to look beyond the situation of the family and the donor under their care.

Summary

The 11 study participants recounted stories of caring for cadaver organ donors and their families. These stories were similar in that they revolved around a donor, usually mentioned the donor's age and cause of injury, and usually discussed the donor family. Almost all the stories had a trigger that made the story stand out for the participant. The stories were different in their length, recency, richness, depth, and focus.

The thoughts and feelings generated by the participants' experiences could be understood through four themes that emerged from the text. The first theme, "It depends," illustrated that thoughts and feelings were situation dependent. The circumstances surrounding the brain injury, the participant's point of entry or exit in the donation process, and the people the participant worked with through the process all affected the way a participant viewed an experience. The second theme, "They're dead, but they're not dead," demonstrated that the participants viewed the life/death status of the cadaver organ donor in different ways. Some definitely viewed the donor as dead, others felt that some life remained in the donor, while others viewed the donor as still alive. The third theme, "Finishing the case," discussed the ease or difficulty participants had finishing the cadaver donor case given its ending of sending the body to the operating room. The final theme, "Something good came out of it," described the feeling of most participants that organ donation was a way of making something good come out of a tragic situation.

CHAPTER 5: DISCUSSION

The findings of this study will be discussed in this chapter. A comparison of the findings of this study will be made with the existing literature utilizing the main themes identified in the previous chapter. Possible explanations for similarities and differences between the two will be offered. The implications of the findings will be discussed and recommendations for nursing practice, education, and research will be provided.

Experiences

Intensive care nurses' experiences of caring for cadaver organ donors and their families have not been well documented. Case study examinations of cadaver donor care do exist and provide valuable insight into the experience (Hannegan, 1987; Kozlowski, 1988). These case studies tend to (a) follow the donation process from the patient's admission to hospital through to organ retrieval and (b) provide relatively equal attention to all aspects of the process. In contrast to the case study approach, the experiences described by the participants of this study tended to focus on a particular period within that admission-retrieval time frame. This reflects the reality of caring for a patient for one 8 or 12 hour shift and accounts for some of the differences in the stories recounted. During the time a participant cared for a donor, it is quite possible that only portions of the donation process might have transpired. The result is a more episodic view of the process. Rather than examining all aspects of cadaver donor care, the participants' stories focused on aspects of the experience that were particularly memorable, disturbing, or moving for the participant. The idea of a trigger making the experience stand out in the participant's memory demonstrates the importance of the context of an experience and helps to explain why each situation could produce different responses in the nurses experiencing them.

The stories recounted by the participants were similar in that all revolved around a donor, most discussed the age of the donor and the cause of his/her injury, and most discussed the donor family. The brief attention paid to the person that had become the donor in the stories was not surprising given that the donor, at some point, had been declared dead and, almost without exception, the participants had not been able to interact meaningfully with the person. Most participants' experiences had taken place over one or two shifts. This limited the amount of information that they could obtain about the donor. The more central role of the families of the cadaver donors in the stories was also not surprising. Just as in Borozny's (1990) study, the family often became the main focus of nursing care, particularly if the cadaver organ donor was stable.

The recurring discussion of the donor's age in the stories warrants comment. The death of a young person has been identified as a particularly stressful aspect of nurses' work (Anderson & Basteyns, 1981; Bilodeau, 1973;

Degner, Beaton, & Glass, 1981; Glaser & Strauss, 1964; Hannegan, 1987; Hay & Oken, 1972; Petrin & Koutsogiannopoulos, 1991). According to Glaser and Strauss (1964), the value North American society places on living a "full life" results in differing appraisals of the "social loss" associated with the death of a young versus an old patient (appreciating that the definition of what constitutes old and young may be quite arbitrary). Age becomes "a gauge for a patient's actual and potential social worth" (Glaser & Strauss, 1964, p. 119). Glaser and Strauss' suggestion is that the death of a young patient is assigned a high social loss value by nurses due to the social loss experienced by family and society. The older individual, it is argued, has had an opportunity to make a contribution to family, the work-force, and society. The same might not hold true for the younger individual who dies. Deaths which carry high social loss value may prove upsetting or distressing for the caregivers involved (Glaser & Strauss, 1964; Quint, 1966; Mumma & Benoliel, 1984). Stress associated with the death of a young patient and the concept of social loss may explain the consistent emphasis on the age of the donor in the stories.

The tendency of the participants to discuss the cause of the brain injury served to put the story into context. The cause of an injury is an integral part of any patient's history. Even when the nurse entered into a case long after the injury had occurred, efforts were made to establish what had initially brought the patient into the hospital. This was an important part of the patient's story.

Implications

Further study is needed to: (a) describe the experience of caring for cadaver donors and their families and (b) explore the similarities and differences in the experience. Descriptions of these experiences would prove invaluable in the education of both nursing students and practising nurses.

Thoughts and Feelings

"It Depends"

The participants of this study clearly stated that the way they felt about an experience of caring for a cadaver organ donor and the thoughts that an experience generated were dependent on a number of factors. The cause of the injury, the circumstances surrounding the injury, the nurse's entry or exit point in the process, and the people with whom the nurse had worked all had an impact on the participants' thoughts and feelings. This situational dependency is not a surprising finding, although it has not been well documented in the literature. The reason for this may relate to the design of previous studies. Most studies that have looked at organ donation and cadaver donor care have utilized questionnaires to gather data. This design may have restricted the amount of information respondents could provide in terms of the context of situations. Just as important as understanding what the nurses' feelings are regarding cadaver donor care is understanding what kind of situation produced those feelings.

The finding that the circumstances surrounding the donor's injury affected the way the participant felt about an experience relates to both the suddenness of the injury and its tragic nature. Sheskin and Wallace (1976) have suggested that unanticipated deaths create severe bereavement reactions in family members. The ICU nurses are required to care for families at this time of severe bereavement. In terms of the tragedy associated with the injury, variables like age, whether or not there were dependents, and the exact cause of the injury could change the assessment of the tragedy. Glaser and Strauss' (1964) discussion of the value placed on different aspects of a loss story supports this finding.

The discovery that thoughts and feelings could differ depending on the nurses' point of entry or exit in the donation process was particularly interesting. The use by some participants of the declaration of death and the departure of the family as landmarks in the donation process further validated the importance of context in the participants' experiences. For many of the participants, once the patient had been declared dead, the care that they provided changed. Just as Borozny (1990) and Sophie et al. (1983) described in their studies, some nurses in this study would distance themselves from the dead patient and designate another as the target of nursing care. Rather than viewing this as a strategy to reduce dissonance, as Borozny does, I think it demonstrates the appreciation of the nurses involved that the patient was dead. The participants who stated that their focus shifted once the patient was dead were also the participants who seemed to have the clearest understanding of brain death. Interestingly, they were generally the participants with the most experience in donor care.

Dissonance or personal distress, the "unifying theme" of Borozny's (1990) study, was evident in this study. Two participants discussed their discomfort in having to participate in the donation process. Their discomfort stemmed from the concern that donation prolonged the family's ordeal. Crosby and Waters (1972), Robinette, Stiller, & Marshall (1986), and Sophie et al. (1983) noted the same concern in their studies. Both participants had expressed some reservations regarding the donation of their own or their family member's organs. But personal distress was not a predominant feeling experienced by the nurses in this study. Information regarding the attitudes of the participants in Borozny's study toward donation might shed some light on her findings.

The second landmark, the departure of the family, also changed the way some participants viewed the situation. As has been described in the literature (Bilodeau, 1973; Dunkel & Eisendrath, 1983; Gardner & Stewart, 1978; Hickey & Lewandowski, 1988; Huckabay & Jagla, 1979; Solursh, 1990), caring for a family in need of support could be emotionally exhausting for the participants. The relief expressed by the nurses following the departure of the family was understandable given the probability that the family was experiencing intense grief at the sudden loss of their family member (Sheskin & Wallace, 1976).

The finding that thoughts and feelings were dependent on co-workers has been discussed in previous literature. Petrin and Koutsogiannopoulos (1991) have suggested that physicians and co-workers can make the donation process stressful for nurses. Borozny (1990) found that nurses in her study experienced interpersonal dissonance when their beliefs or opinions opposed those of other members of the health care team. Certainly some participants in this study experienced distress at the actions of members of the health care team. More commonly, however, the participants expressed positive feelings associated with their interactions with co-workers. This is in keeping with suggestions in the literature that intensive care staff tend to work together as a team as a result of both comraderie and the physical set-up of intensive care units (Hay & Oken, 1972; Maloney, 1982; Salloway & Volek, 1987). The obvious appreciation of the work of the transplant coordinators is particularly interesting. The situation in Manitoba, where the coordinators are nurses and participate on site in all donations, may explain their noticeable presence in the remarks of the participants of this study. The absence of the transplant coordinators in previous studies, particularly Borozny's (1990) study, is perplexing.

Implications

The finding that the participants' thoughts and feelings are dependent on the situations that experiences are grounded in highlights the importance of attending to context. It also illustrates that an understanding of the individual -

situation transaction is best achieved through attention to both aspects of the transaction. In this study, the attention to context enabled me to understand the reasons for the thoughts and feelings expressed by the participants. Research studies need to explore nurses' experiences with attention to context in order to better understand those experiences. The finding that the actions of other health care providers affected the way participants' felt about an experience also has implications. Health care providers require a forum to discuss their appreciation of or concern with the actions of their colleagues and co-workers. This could promote the continuance of helpful actions and the prevention of less than helpful actions.

"They're dead, but they're not dead"

The differing ways the participants viewed the life/death status of the cadaver donor illustrates the difficulty some people have in recognizing a warm body attached to machinery, with a chest that moves up and down, as dead. The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1981) suggested that "at the moment of cardiac failure, one can almost see the life pass from a patient, while from the [brain dead patient] it has slipped away so stealthily that its image lingers on" (p. 84). Perhaps it is this lingering image of life, the contradiction between appearance and reality, that makes the life/death status of the cadaver organ donor ambiguous (Law Reform Commission of Canada, 1979). The body of the donor is definitely different from other dead bodies. Understanding that the differences result from artificial maintenance of the body does not change the sensory cues health care providers receive. Some participants stated that viewing the donor as still alive helped them cope with the situation. What impact the nurse's view that the patient is still alive has on the family, if any, needs to be explored.

Certainly confusion regarding the concept of brain death may contribute to the ambiguity surrounding the life/death status of the cadaver donor. Though most participants had a reasonably clear understanding of brain death, some did not. As in Youngner et al.'s (1989) study, it was noted on occasion that some participants confused brain death with persistent vegetative state. Others understood that brain death meant that the brain had been destroyed, but did not equate the death of the brain with death. Perhaps Tomlinson (1989) is correct that the term brain dead in the vernacular of nurses refers to a "whole spectrum of severe brain damage" (p. 2836). If that is the case, education could prove helpful in eliminating this problem. The solution may also lie in the replacement of the term brain dead with the term dead, as suggested by Annas (1988) and Jasper et al. (1991). The problem may prove more complex than merely a misunderstanding of a concept. While the definition of death from a medical and legal perspective may be clear, the definition of death from a social and spiritual perspective may not be (Rix, 1990; Thompson & Cozart, 1981).

Rix (1990) has suggested that "identity relates no less to the body than to the mind" (p. 6). As discussed previously, it may be difficult for people to accept that a warm body with a beating heart and moving chest is dead from a social or spiritual perspective. The definition of death from all perspectives, particularly the social and spiritual perspectives, requires further exploration.

A particularly intriguing aspect of the findings of this study was the fact that five of the participants raised questions regarding the presence of a soul around the bedside of the cadaver donor. They wondered out loud where the soul might be, whether or not it could see what they were doing, and whether or not it could hear. The feeling of a "presence" or "spirit" around a dead body has been discussed by McLennan (1986), Youngner et al. (1985), and Wolf (1990). For some of the participants of this study, this presence was cited as the rationale for ensuring that the body of the donor was treated with respect. For others, it was the reason for continuing comfort measures.

An interesting finding of this study was the lack of consistency evident in the language used by the participants. It was possible, for example, when examining the transcripts, to find that a participant would state that the patient was dead and that the patient was dying within the same paragraph. Some participants would state clearly that the cadaver organ donor was dead at one point in an interview and then make comments like "we got the patient to the O.R. alive" or the patient "ended up dying" before organs could be retrieved.

Evidence of this inconsistency is present in the literature (Dillon et al., 1981; Wolf, 1990). The inconsistent use of language may be a reflection of the ambiguity surrounding the life/death status of the donor. This inconsistency may also reflect the inadequacies of the English language in dealing with this different kind of dead body.

Implications

The implications of the ambiguity and confusion surrounding the life/death status of the cadaver organ donor relate mostly to the transmission of information to the donor family. Studies of donor families have illustrated that confusion regarding the concept of brain death was evident in some families (Batten & Prottas, 1987; Morton & Leonard, 1979; Savaria et al., 1990). The need for clear and consistent explanations of brain death from all health care providers has been identified in the literature (Bisnaire, Burden, & Monik, 1988; Gideon & Taylor, 198; Johnston, 1991; Murphy, 1986; Stuart, 1984; Youngner et al., 1989). Ambiguity and confusion on the part of the nursing staff may interfere with the provision of a clear explanation of brain death. It may also create undue confusion and suspicion in the family of the donor.

The need to explore all aspects of the definition of death, including the social and spiritual aspects, has been discussed. It is important that health care providers explore with family members their view of death and not assume that the medical and legal definitions of death are the only definitions contemplated.

"Finishing the case"

The finding that most of the participants preferred sending the patient to the operating room for organ retrieval to shrouding the body was interesting. As Wolf (1988, 1990) has described, the rituals of post-mortem care have been identified by some nurses as serving the purpose of bringing closure to a case. The participants did not suggest, as Sudnow (1967) has, that shrouding the body was "dirty work." They did, however, express apprehension at having to perform the task of shrouding and relief at having someone else, namely the operating room staff, responsible for it. For most participants in this study, closure could be achieved without this ritual.

For many of the participants, a cadaver organ donor case was finished with greater ease than many other cases. This related to two factors: (a) the short period of time the participants had cared for the donor, (b) the fact that the body went somewhere else to be shrouded, and (c) the availability of letters from the transplant coordinators letting the staff know what had happened to the organs retrieved. Two participants had some difficulty finishing the case because of the absence of the shrouding ritual. It may be significant that these two participants were two of the most experienced nurses in terms of years of experience.

Implications

The ability of most of the participants to bring closure to the organ donor case without shrouding the body demonstrated the importance of the transplant coordinator letters. Continued dialogue with coordinators regarding the importance of these letters could ensure that this practice continues. For those individuals who had difficulty finishing the case, perhaps the institution of a new ritual like a moment of silence following the declaration of death might assist them in bringing some closure to the case (Lynch, 1990; Youngner et al., 1985).

"Something good came out of it"

The feeling that something good came out of donation, namely that other human beings' lives were prolonged or changed, was expressed by 9 of the 11 participants. It was remarkable that the words "something good" were used by almost all of the participants who shared this sentiment. The words "something good" or "something positive" are also evident in other studies dealing with donation (Sophie et al., 1983; Wolf, 1990). Donor families have indicated that donating their relatives' organs helped their grieving and made them feel that something positive had come from death (Bartucci, 1987; Batten & Prottas, 1987; Morton & Leonard, 1979; Savaria, Rovelli, & Schweizer, 1990).

The need to find some "meaning" in death was expressed by some of the study participants. Price and Bergen (1977) and Omery (1991) have discussed the need health care providers have to assign meaning to death. Aries has argued that unlike previous times, death today has no positive meaning (cited in Price & Bergen, 1977). The donation of organs was one way that some study participants could find meaning in the death of the cadaver organ donor.

The letters from transplant coordinators reinforced for most of the participants that something good had come from donation. Kozlowski (1988) and Petrin and Koutsogiannopoulos (1991) have described how the information given to health care providers regarding recipients provided reinforcement for nurses and enabled them to feel that their efforts had not been in vain. Donor families have also expressed a need for and an appreciation of information regarding recipients of organs (Bartucci & Seller, 1986; Soukup, 1991). The importance of feedback and reinforcement for nurses has been discussed by Hay and Oken (1972), Lippincott (1979), and Maslach and Jackson (1982). Since the nurse cannot get any feedback from the cadaver organ donor and may not get positive feedback from the donor family, positive feedback must come from other sources (Lippincott, 1979). It would seem that for some people the letters become a source of positive feedback.

Three participants referred to the letters as a reward. The use of nurses' names in the letter, the often positive outcome for the recipients, and the expression of gratitude by the transplant coordinators made these nurses feel rewarded. Almost all of the participants stated that the letters made them feel good; feeling rewarded may or may not represent a different feeling. Sophie et al. (1983) found that only 25% of their sample found participating in organ procurement rewarding.

Implications

As stated previously, the importance of the letters sent by the transplant coordinators to the staff of the ICU has been clearly illustrated by this study. Transplant coordinators need to be made aware of the importance of the letters to ensure that this practice continues. The suggestion that the letters serve as a reward and the area of rewards generally related to caring for cadaver organ donors requires further exploration.

Considerations

Decisions made related to sample selection and data collection methods require consideration. First, only nurses who read the Critical Care Nurses' Association Newsletter or their colleagues obtained through snowball sampling participated in this study. Nurses who belong to interest groups, in this instance the Canadian Association of Critical Care Nurses, and nurses who volunteer to participate in a research study may be different than other intensive care nurses. The fact that all participants worked in tertiary care centers with transplantation programs should also be noted. Second, utilizing interviews alone may have limited the data collected. Triangulation of data sources could have been obtained if nurses had been observed caring for cadaver organ donors and interviewed regarding these experiences. This study would have been much more difficult to orchestrate, however, given the time constraints of thesis work and the unpredictable nature of organ donation. The use of face-to-face interviewing may have resulted in participants being hesitant to express negative views regarding donation. It is possible that different data might have been obtained through an open-ended questionnaire. Finally, it is possible that closure of data collection and analysis occurred prematurely as a result of time pressures. Certainly precautions were taken to ensure that premature closure was avoided, but a longer period of data collection from a larger number of participants may have produced different findings.

Recommendations

The findings of this study are based on the experiences of 11 intensive care nurses. The final validation of the findings rest with the reader. Based on the experiences of these 11 nurses, however, recommendations for nursing practice, education, and research can be made.

Practice

1. A need for a forum for nurses to talk about issues like caring for cadaver organ donors was identified in this study. A forum for discussion could assist nurses in bringing closure to cases and allow them to share their thoughts and feelings related to experiences. Since other health care professionals were identified as affecting the experiences of nurses, perhaps they too could participate in this forum. Meetings on individual units to discuss issues related to patient care or patient deaths could provide opportunity for this kind of discussion.

2. The ambiguity and confusion surrounding the life/death status of the cadaver organ donor requires some attention. Clarification of the meaning of brain death, of the law, and of the medical criteria for the diagnosis of brain death could be provided through inservice education for practicing nurses and should eliminate some of the confusion.
3. The idea that death is defined from more perspectives than medical and legal indicates that nurses need to explore with families their definitions of death. Information regarding death definitions will assist the nurse to care for the family.
4. The need for a ritual to acknowledge the death of the individual who becomes a cadaver organ donor has been discussed in the literature (Lynch, 1990; Youngner et al., 1985). A ritual that could involve both health care providers and the family might assist all individuals to acknowledge that death has occurred.
5. The importance of the role of the transplant coordinator in the donation process was evident in this study. Dialogue between ICU nurses and the coordinators would assist in the maintenance of this positive relationship.
6. The importance of the letters sent to the intensive care units by the transplant coordinators was evident in this study. Transplant coordinators need to be made aware of the perceived value of these letters so that feedback continues.

Education

1. Most of the participants stated that everything they knew about organ donation and cadaver organ donor care had been learned through clinical exposure to these kinds of experiences. There is a need for some discussion of brain death, organ donation, and more specifically the role of the nurse in organ donation in nursing education programs.

2. The fact that caring for the family of the organ donor could be both challenging and overwhelming points to the need for an understanding of both the needs of families and the means to meet these needs. This kind of information needs to be presented in nursing education programs.

Research

1. The importance of the context of experiences has been emphasized throughout this study. Qualitative studies of the experience of caring for cadaver organ donors with attention to the context of these experiences will provide a description of this experience. The findings of these studies will assist in addressing a gap in nursing knowledge and provide much needed guidance to both basic nursing education and continuing education for practicing nurses.

2. The effect the nurse's perception that the cadaver organ donor is still alive might have on the family needs to be explored. A qualitative study would provide rich and context-based data and provide valuable information for

nursing practice and education.

3. The linguistic inconsistency evident in the literature and in this study warrants further study. A qualitative study examining the words and the language nurses use when discussing brain death with families and other health care providers would prove instructive for both nursing practice and education.

4. The role of the transplant coordinator in the donation process has not received much attention. Two questions were raised by the study. What impact if any, does the fact that the transplant coordinator is a nurse have on the donation process? What impact, if any, does the fact that the transplant coordinator is involved on site in donor management have on the donation process? The answers to these questions could provide some insight into the stresses associated with participating in cadaver organ donor care.

5. The idea that closure may be more difficult to achieve without the shrouding ritual points to the need for a qualitative study to examine how nurses bring closure to cases. This study could provide direction for nursing practice in terms of the need for rituals after the death of a patient.

6. A qualitative study exploring the perceived stressors and rewards associated with participating in organ procurement would provide valuable information for nursing practice.

Study Summary

The life-prolonging yet death-ridden nature of human organ transplantation results in a vast array of emotional responses in the people directly involved in the transplantation process. The death-ridden aspect of this process, caring for the cadaver organ donor, was the focus of this study. Using a qualitative research approach, nurses' experiences of caring for cadaver organ donors and their families and the thoughts and feelings those experiences generated were examined. A convenience sample of eleven intensive care nurses, ranging in age from 26 to more than 35 years, with from 6 to more than 15 years of nursing experience and 1 to more than 15 years ICU experience, participated in this study. Participants had cared for between 2 to over 30 cadaver organ donors. Data were collected using informal and partially structured interviews. Each participant was interviewed twice. The hermeneutic phenomenological approach of Heidegger (1962) as interpreted by Dreyfus (1983,1991), Benner (1984a, 1984b, 1985), and Benner and Wrubel (1989) guided the analysis of the data.

The participants recounted stories of their experiences of caring for donors. These stories were similar in that they all revolved around a donor, most discussed the age and cause of injury of the donor, and most discussed the family of the donor. Most of the stories also contained a trigger that made the story stand out for the participant. The stories differed in their length, recency, richness, and focus. The participants' thoughts and feelings related to their experiences were examined through four themes that emerged from the data. These themes were: (a) "It depends;" (b) "They're dead, but they're not dead;" (c) "Finishing the case;" and (d) "Something good came out of it."

The key findings of this study relate to the situational dependency of the thoughts and feelings of the participants, the confusion evident surrounding the concept of brain death, the importance of the informational letters sent by the transplant coordinators, and the assignment of positive meaning to the death as a result of organ donation. Recommendations for nursing practice, education, and research have been made on the basis of these findings. The importance of attending to the context of a situation in future research studies related to cadaver organ donor care has been emphasized.

The major significance of the findings of this study relates to their contribution to the nursing professions' understanding of the cadaver organ donor experience. This study represents a beginning in the discovery and description of this experience and should stimulate further research.

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Appendix A - Advertisement for Participation in Study

My name is Marie Edwards and I am a registered nurse with experience in I.C.U., and presently a graduate student in the Master of Nursing program at the University of Manitoba. I am interested in exploring I.C.U. nurses' thoughts and feelings related to their experiences of caring for brain dead organ donors and their families as part of my studies. To do this, I would like to interview I.C.U. nurses, a minimum of two and a maximum of three times, each interview lasting one hour.

If you:

1. are presently employed in an I.C.U. in Winnipeg;
2. or have worked in I.C.U. within the last five years;
3. have provided care to a minimum of one brain dead organ donor, for a minimum of one shift (8 or 12 hour);
4. live in Winnipeg;

and are interested in finding out more about this study, please contact me at xxx-xxxx. I welcome any questions you might have.

Appendix B - Telephone Explanation of Study

As the advertisement in the Canadian Association of Critical Care Nurses' (Manitoba Chapter) Newsletter outline, I am a graduate student in the Master of Nursing program, at the University of Manitoba. As part of my program, I am required to complete a thesis. For my thesis, I wish to explore and describe I.C.U. nurses' experiences of caring for brain dead organ donors and their families.

If you agree to participate, you will be interviewed a minimum of two and a maximum of three times in your own home, or another convenient place, at a time convenient to both you and me. These interviews will be tape recorded. I will ask you general questions about your nursing experience, and more specific questions related to your personal experiences caring for brain dead organ donors. If you prefer not to answer certain questions, you do not have to. If you decide to participate, and later, for whatever reason, wish to withdraw from the study, you may do so.

This study has been examined by the Ethical Review Committee of the School of Nursing at the University of Manitoba. Confidentiality and anonymity will be safeguarded throughout the study. Your name will not appear on the tapes, the transcripts of the tapes, or any reports or publications arising from the study. Your tapes and the transcripts from these tapes will bear only a code number. The master list matching names and code numbers will be seen only by me, and will be kept in a locked file. The audio tapes will be listened to by me and my thesis supervisor. The transcripts may be reviewed by my thesis committee, but again no names will appear on them.

If you agree to participate we will arrange a time and a place to meet. I will ask you to sign a consent form, and then the first interview will be taped. There may be no direct benefit to you in participating in this study, but the information gained may help to direct nursing education, clinical practice, and further research. If you have any questions about the study I will be glad to answer them.

Appendix C - Consent Form

I, ________________________________, agree to participate in the study "An Exploratory-Descriptive Study of Nurses' Experiences Caring for Cadaver Organ Donors and their Families," carried out by Marie Edwards, a graduate student in the Master of Nursing Program at the University of Manitoba.

My signature below indicates that:

1. I have read and understand the Explanation of Study form and this Consent form, and have a copy of both in my possession;
2. my questions and concerns regarding the study have been addressed;
3. I agree to be interviewed a minimum of two and a maximum of three times, at a place and time convenient to me and the investigator;
4. I agree to have these interviews taped;
5. I understand that only the investigator and her thesis supervisor will have access to these tapes, and only the investigator and her thesis committee will have access to the tape transcripts, and that my name will not appear on either;
6. I understand that I do not have to answer any questions that I do not wish to answer, and that I may withdraw from this study at any time;
7. I understand that my confidentiality and anonymity will be safeguarded, and that my name will not appear on any reports that arise from this study;
8. I understand that I may not attain any direct benefits from participating in this study;
9. I am willing to participate in this study.

If I have any questions at any time throughout this study, I may reach the investigator, Marie Edwards, at xxx-xxxx, or may contact Marie's thesis supervisor, Dr. Erna Schilder, at xxx-xxxx.
SIGNATURE ____________________ DATE ________

WITNESS ____________________

I wish to receive a written summary of the results of this study.

NAME ________________________________
ADDRESS ________________________________

Appendix D - Explanation of the Study

My name is Marie Edwards, and I am a registered nurse with experience in I.C.U. and presently a graduate student in the Master of Nursing program at the University of Manitoba. I am interested in exploring and describing I.C.U. nurses' thoughts and feelings related to their experiences of caring for brain dead organ donors and their families, as part of my program of study.

To do this, I would like to interview I.C.U. nurses who have taken care of brain dead donors and their families. If you agree to participate, you will be interviewed a minimum of two and a maximum of three times, in your own home, or another convenient place, at a time convenient to you and me. Each interview will last approximately one hour, and will be tape recorded.

During the interviews, I will ask you some questions about your nursing experience generally, and then focus in on your personal experiences of caring for brain dead donors. If you would prefer not to answer any of the questions, you do not have to. If at any time you wish to discontinue the interview, you may do so. If you decide to participate, but later wish to withdraw from the study, you may do so.

All information revealed by you will be kept confidential, and you anonymity will be safeguarded. The audio tapes of your interview will bear a code number, as will the transcriptions of those tapes. Your name will not appear on these items. The only place your name will appear is on a master list matching names with code numbers, which will be seen only be me, and kept in a locked file. The audio tapes will be heard by me and my thesis supervisor. The transcripts will be seen by me, and by my thesis committee at the university. The master list and audio tapes will be destroyed at the completion of this study, but the transcripts will be retained. Any presentations or publications that arise from this study will be written in a way that preserves all participants' anonymity. There will be no way that the information presented could be linked to you.

Your participation in this study may not benefit you directly. There will be some inconvenience to you associated with the time involved for the interviews. It is hoped, however, that documentation of nurses' experiences may give direction to nursing education, clinical practice, and further research. If at any time you have questions or concerns, do not hesitate to discuss them with me. I can be reached at xxx-xxxx. A copy of this explanation and of the consent form will be provided to you for your records.

Thank you.

Appendix E - Agenda of Topics for Interviews

1. DESCRIPTION OF EXPERIENCE/S CARING FOR CADAVER ORGAN DONORS AND FAMILIES

   Possible Questions:
   What prompted you to respond to the study advertisement?
   What do you remember about your experience/s of caring for a cadaver organ donor?
   Describe for me your memories of caring for a cadaver organ donor?

2. RELATIONSHIP WITH PATIENT

   How would you describe the relationship you had with this patient?
   How did you feel caring for this patient?
   What did you do with these feelings?
   How long did they last?

3. RELATIONSHIP WITH FAMILY

   How would you describe the relationship you had with this patient's family?
   How did you feel caring for this family?
   What did you do with these feelings?

4. CONCEPT OF BRAIN DEATH/DEATH

   What does brain death mean to you?
   What kind of understanding of brain death did the family express?
   What does death mean to you?

5. CONTEXT OF EVERYDAY WORK

   How different/similar is caring for a cadaver organ donor from caring for other patients?
   How do you feel about being assigned to care for a cadaver organ donor?

Appendix F - Demographic Data

AGE _____

SEX _____

NURSING EDUCATION ______________________________

I.C.U. COURSE ______________________________

NUMBER OF YEARS NURSING EXPERIENCE ________________

TYPES OF EXPERIENCE ______________________________

NUMBER OF YEARS I.C.U. EXPERIENCE ________________

TYPE OF I.C.U. (ADULT/PEDIATRIC/MEDICAL/SURGICAL/MIXED)

____

INVOLVEMENT IN ORGAN PROCUREMENT

APPROACHED FAMILY OF POTENTIAL DONOR RE: OPTIONS _____

ASKED FOR CONSENT FOR DONATION FROM FAMILY _____

CARED FOR CADAVER ORGAN DONOR _____

LENGTH OF TIME _____

NUMBER _____

CARED FOR ORGAN RECIPIENTS _____

NUMBER _____

CAPACITY OF INVOLVEMENT
(PRIMARY NURSE, CHARGE NURSE, SECONDARY NURSE) _____

Appendix G - Letter of Ethical Approval

The University of Manitoba

SCHOOL OF NURSING

ETHICAL REVIEW COMMITTEE

Proposal Number N#90/14

Proposal Title: "An Exploratory-Descriptive Study of Nurses' Experiences of Caring for Cadaver Organ Donors and Their Families."

Name and Title of Researcher(s): Marie Edwards
Master of Nursing Student
University of Manitoba

Date of Review: June 04, 1990

Decision of Committee: **Approved:** June 4/90 **Not Approved:** ______

Approved upon receipt of the following changes:

No revision required.

Date: June 12, 1990

Theresa George, RN, PhD. Chairperson
Associate Professor
University of Manitoba

Position

NOTE:

Any significant changes in the proposal should be reported to the Chairperson for the Ethical Review Committee's consideration, in advance of implementation of such changes.