

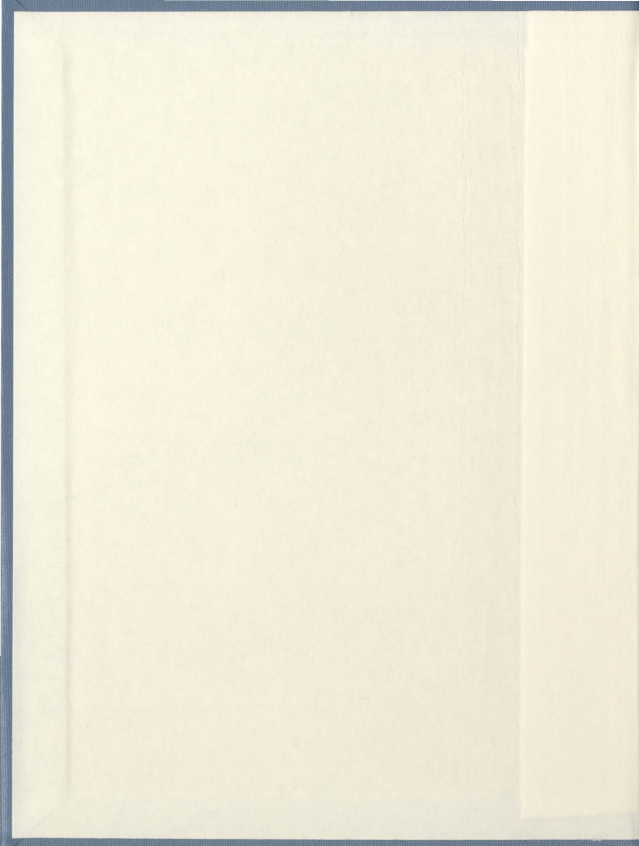
"CREATING A SENSE OF PEACE":  
A PHENOMENOLOGICAL STUDY OF THE  
EXPERIENCE OF A FAMILY MEMBER CONSENTING  
TO DONATE A DECEASED RELATIVE'S ORGANS

CENTRE FOR NEWFOUNDLAND STUDIES

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APRIL MANUEL





**"Creating a Sense of Peace": A Phenomenological Study of the  
Experience of a Family Member Consenting to Donate a Deceased Relative's Organs**

by

© April Manuel

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School of Graduate Studies  
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### Abstract

This study used a phenomenological approach drawing on van Manen's (1997) methods of inquiry in order to describe and interpret the meaning of what life is like for five women who have consented to donate a deceased relative's organs for transplantation. This study captures the meaning of this phenomenon in such a way that nurses and others who read this text, could develop new insights into the lives of these individuals, enabling them to implement strategies to better assist and support the family, and perhaps decrease barriers to organ donation.

A thematic analysis of the participants' narrative descriptions identified five essential themes: the struggle to acknowledge the death, the positive outcome of the death, creating a living memory, buying time, and the significance of support networks in the organ donation decision. The integration of these themes revealed the essence of the experience as *creating a sense of peace*. These five themes and the essence of the experience are discussed in relation to the literature, followed by recommendations for future nursing practice, education, and research.

## Dedication

This thesis is dedicated to my family.

To my parents Melvin and Kathleen Pike who were always there to support me in any way they could, without them I would have never undertook such a challenge.

To the three most important men in my life: My husband Robert who is not only my partner in life but my mentor and friend. Thank you for being there to support me in my times of frustration and to share the joy of my accomplishment without you this piece of work would not exist. Kai, my son whose constant smiles gave me the courage to continue despite 0300 hours feedings and diaper changes. Jonathan, my stepson who reminded me of the importance of enjoying the simple things in life and whose laughter filled my thoughts with joy

## Chapter 1: Introduction

This phenomenological study explores the experiences of individual family members who have made the decision to donate a relative's organs. Nurses working with these individuals and their families have a role in the assisting with decision-making of these families regarding organ donation. The widening gap between organ supply and demand has become a growing concern within the Canadian health care system as the number of individuals waiting for a transplant in Canada is increasing each year. However, the number of transplantable organs remains constant (Health Canada, 2002). If nurses are to contribute to narrowing this gap and to helping families faced with this decision, it is important to conduct research into the family's experience with organ donation and the decision to donate.

The decision to donate a loved one's organs places multiple demands upon the family, and the individuals within those families, at a time when they are struggling to deal with the death. These demands interfere with the ability to absorb and comprehend information to solve problems, to make decisions, and to use effective coping skills at a time when these aspects of critical thinking are most important (Cleiren & Van Zoelen, 2002; Pelletier, 1992, Pelletier, 1993a; Pelletier, 1993b; Riley & Coolican, 1999; Steed & Wagner, 1998). Although every year many families consent to organ donation, we do not know their immediate needs or the needs that continue to emerge, even after their loved one's organs have been retrieved. There is a dearth of literature on the "lived" experience of donating a loved one's organs and the implications of such a decision.

In order for nurses and other health care professionals to plan and deliver care to organ donors and their families, they need a greater understanding of the experience of family members' decisions to donate their loved one's organs. This understanding is critical in assisting health care professionals to develop and implement strategies to explore and prevent barriers to organ donations, implement methods of support for the family and perhaps increase organ donation consent rates.

### *Background and Rationale*

The widening gap between organ donor and supply is well documented in the literature. This disparity exists because the number of organ donors has remained steady over the last five years while the number of individuals awaiting a transplant has grown. The Canadian Organ Replacement Register (2003) reports in 2002 there were 3,956 Canadians waiting for an organ transplant, representing an 84% increase since 1992. From 1996 to 2002, the numbers of Canadians on the transplant list increased by 40%, while the number of cadaveric donors available for transplant remained constant. There is an average of 45 to 50 individuals on the waiting list from Newfoundland alone at any one time (M. Bishop, personal communication, June 3, 2003). Despite public awareness and education, the supply of organs has not increased proportionately to meet the demand. This has caused concern among health care professionals, individuals, and families awaiting a transplant. It is anticipated that an understanding of family members' experiences with organ donation will provide valuable information to challenge this growing gap and help identify the priority needs of the donor family.

The process of dealing with the death of a close family member can be difficult under any circumstances, however the decision to donate the deceased relative's organs may further complicate this process. For some relatives organ donation may bring closure, while others may wonder or even question if they made the right decision. Examining family members' decisions and how they felt about those decisions will help to understand some of the dilemmas that these families face. This will aid nurses in planning for the care of individuals and families who have donated their relative's organs.

Early research between the 1900s and 1950s focused on the medical management of the organ procurement process. The first tissue transplant was in 1905, followed in 1954 by the first successful organ transplant (Smith-Brew & Yani, 1996). These two events lead to discussions on organ donor legislation, brain death criteria, and ethical considerations. It was not until 1968 when the Harvard Medical School proposed the formal definition of brain death and the Uniform Anatomical Gift Act (UAGA) surfaced in the United States that other areas of North America turned their attention to organ donor legislation (Scott, 1981). Canada followed the guidelines of the UAGA with the implementation of The Humans Tissue Act in 1971 (revised 1990).

The majority of research in the last three decades has been conducted on factors that influence the family's organ donation decision (Bartucci & Bishop, 1987; Burroughs, Hong, Kappel, & Freedman, 1998; Cleiren & Van Zoelen, 2002; Culter et al., 1993; Cunningham, 1998; DeJong et al., 1998; Exley, White, & Martin, 2002; Frates & Boher, 2002; Frezza, Krefski, & Valenziano, 1999; Frutos, Ruiz, Requena, & Daga, 2002; Gortmaker et al., 1998; Guadagnoli et al., 1999; Kay & Barone, 1998; Klieger et al.,



1994; Marisma & Escalante, 2002; Martinez et al., 2001; Nakahara, 1998; Pearson, Bazeley, Spencer-Plane, Chapman, & Roberston, 1995; Savaria, Rovelli, & Schweizer, 1990; Schaeffer, Johnson, Suddaby, Steven, & Brighman, 1998; Shih et al., 2001a; Siminoff, Gordon, Hewlett, & Arnold, 2001; Siminoff, Lawrence, & Zhang, 2002; Verble et al., 2002; Von Pohle & Linda, 1996; Yong, Cheng & Ho, 2000). The works of these authors suggested that there was a positive relationship between identified factors (e.g., how families are approached, knowledge of the deceased's wishes, and the quality of family relationships) and organ donor consent rates. However, these authors did not discuss how these factors influenced the family's organ donation experience. In the literature, these factors are often discussed in isolation, thus fragmenting our understanding of the organ donation experience, and therefore requiring further qualitative research if we are to gain a better understanding of the needs of families who have donated their loved one's organs.

Research has shown that the attitudes and knowledge of nurses have an impact on the family's organ donation experience (Al-Mousawi, Abdul-Razzak, & Samham, 2001; Beasley et al., 1997; Bidigare & Oerman, 1991; Bilgin & Akgun, 2002; Boey, 2002; Evanisko et al., 1998; Ingram, Buckner, & Rayburn, 2002; Kent, 2002; Kiberd & Kiberd, 1992; Molzahn, 1996, Molzahn, 1997; Ozdag & Bal, 2001; Prottas & Batten, 1988; Pugliese, Scuderi, Mattucci, Chistolini, & Quintieri, 2001; Roels & Wright, 2001; Sophie, Salloway, Sorock, Volek, & Merkel, 1983). Much of this research is quantitative in nature and reports a statistical correlation between nurse's knowledge, attitudes, and organ donor consent. However, this research does not provide an indepth insight into the

nature of the nurse-client-family relationship during the organ donation experience. Knowledge of this relationship is essential if one is to understand the significance of the role of the nurse in the family's organ donation experience.

Several investigators have used qualitative methodologies to investigate the nurse's organ donation experience (Day, 2001; Hibbert, 1995; Pearson, Robertson-Malt, Walsh, & Fitzgerald, 2001; Pelletier-Hibbert, 1998; Sadala & Mendes, 2000; Watkinson, 1995; Wells & Sque, 2002). These studies focused on nurse-reported stressors related to maintaining the donor for organ retrieval and supporting the family. Few studies had specific strategies that nurses could implement to assist donor families. This indicates the need for further research into understanding the role of the nurse in the family's organ donation experience and identification of strategies to support the family.

Few qualitative studies have focussed on family's experience with organ donation. However, research has explored how families process information (Cleiren & Van Zoelen, 2002; Doering, 1996; Douglass & Daly, 1995; Franz et al., 1997; Pearson et al., 1995; Riley & Coolican, 1999; Shih et al., 2001b; Steed & Wagner, 1998), the impact of donation on the family's grief process (Bartucci & Seller, 1986; Cleiren & Van Zoelen, 2002; Fulton, Fulton & Simmons, 1977; Pearson et al., 1995; Pelletier, 1992; Shanteau, Harris, VandenBros, 1992), and the stress and coping mechanisms used by the family (Pelletier, 1992; Pelletier, 1993b; Shih et al. 2001b). There were only two phenomenological studies that addressed exclusively family's experiences with organ donation (Frid, Berghom, & Haljamae, 2001; Warren, 2002). All of the studies offer valuable information on the phenomenon of organ donation and provide a foundation for

the knowledge required to develop strategies and implement a plan of care to assist organ donor families during their decision-making process. However, a more thorough understanding of the family's organ donation experience is needed. This can be best attained through narrative descriptions of family members who have lived through this experience.

### *Purpose of the Study*

This phenomenological study explored the experiences of individual family members who have made the decision to donate their deceased relative's organs. The objectives of the study were to: (a) describe and interpret the meaning of what life is like for those families who have donated their loved one's organs, and (b) to capture the meaning of this phenomenon in such a way that nurses and others who read this text would develop new insights into the lives of these families, enabling them to implement strategies to better assist and support the entire family, and perhaps decrease barriers to organ donation.

### *Research Question*

The proposed research study attempts to answer the following question: What is it like for family members who have made the decision to donate a deceased relative's organs?

## Chapter 2: Literature Review

Understanding family members' experiences with donating a relative's organs requires a discussion of the relevant literature surrounding organ donation. This literature review is divided into three sections. The first section summarizes research relating to family's experiences with donating their relative's organs. The second section provides an overview of factors influencing the family's organ donation decision. The final section presents nurses' experiences with organ donation and the impact on the family's organ donation experience.

### *Family's Experiences with Organ Donation*

In order for nurses to adequately support donor families, provide them with necessary information, and correctly answer any questions that families may have regarding organ donation, it is necessary to have an understanding of a family's perception of the organ donation experience and the needs relating to this experience. The following section of this literature review will present research on the family's organ donation experience. Previous research on the family's experiences with organ donation can be categorized into three main concepts: information processing, grief resolution, and stress and coping.

### *Information Processing*

Researchers investigating the organ donation experience reported that many organ donor families have difficulty in processing information, asking questions, and making the decision whether or not to donate (Cleiren & Van Zoelen, 2002; Doering, 1996; Douglass & Daly, 1995; Steed & Wagner, 1998, Tymstra, Heyink, Pruim, & Sloof, 1992). Families required information in a clear and concise manner when being approached for donation (DeJong et al., 1998; Franz et al., 1997; Pearson et al., 1995, Riley & Coolican, 1999; Shih et al., 2001b).

Families experienced difficulty and some were unable to process information at the time of the death. They frequently stated that they had forgotten much of the initial factual information, but afterwards expressed a strong urge to get more information about what had happened. Negative emotional feelings were frequent. In particular feelings of numbness and despair during the experience were common and families described "living in a fog" during that time (Cleiren & Van Zoelen, 2002). Other families stated that they were shocked and stunned due to the sudden death of their family member and reported that their ability to take in information and to ask pertinent questions was limited (Douglass & Daly, 1995), referring to a "dream-like state" and a loss of touch with reality (Tymstra et al., 1992). Doering (1996) reported that the family's experiences with consenting to an eye donation of a recently deceased relative included feelings of shock and difficulty recalling the sequence of events.

Some authors report a disparity between intellectual and emotional acceptance of brain death (Franz et al., 1997; Pearson et al., 1995). This disparity generated confusion regarding whether the relative was really dead or whether there might have been a remote possibility of recovery. In Franz et al.'s study of the perceptions of families who had consented to organ donation, feelings of being shocked were common when the family was first approached for organ donation. Families had extreme difficulty accepting brain death, and the reality that their relative was dead. Doubts emerged as to whether their loved one was really dead and if the organs would be sold illegally. Motivating factors for the donation included hope that their loved one would live on and that the donation would benefit some one.

Steed and Wagner (1998) interviewed 20 organ donor families to explore issues in the bereavement process that may be unique to the organ donation process. They reported that some of the families were distressed by the limited time available to make the decision to donate their loved one's organs. This, coupled with misinformation and feelings of being treated poorly, exacerbated their grief. Participants also described turmoil because from not all of the family members were consulted about the decision to donate. However, others described the decision to donate as giving meaning to a tragedy and creating a sense that their loved one was living on. The majority of participants stated that they would have liked some information on the status of the recipient's health.

Families required clear, concise information presented in a sensitive manner (Riley & Coolican, 1999; Shih et al., 2001a). Poor communication may result in a lack of understanding of the organ procurement process, specifically the meaning of brain death. This warrants further research into what information is given to families and their interpretation of what is offered. DeJong et al. (1998) reported that donor families felt comfortable talking with medical staff who were sensitive to their needs and supported their decision, conducted the discussion about organ donation in a language that was easily understood, and were able to answer their questions, including those about brain death. Conflicting findings were reported in Cleiren and Van Zoelen's (2002) research when participants voiced dissatisfaction with the way that organ donation was requested and with the common use of unfamiliar medical terms.

The research on the information processing abilities of potential organ donor families indicated that in order to meet the needs of these families, health care professionals must adequately assess the ability of families not only to process and understand the information provided, but also to ask appropriate questions surrounding brain death, its implications, and available options such as organ donation. In turn, nurses must ensure that the information is being communicated in a clear and concise manner.

### *Grief Resolution*

Several researchers have investigated how organ donation either hinders or facilitates the grieving process and have reported varying findings (Bartucci & Seller, 1986; Cleiren & Van Zoelen, 2002; Fulton et al., 1977; Pearson et al., 1995; Pelletier,

1992; Shanteau et al., 1992). Fulton et al. explored stress, ethical dilemmas, and issues facing organ donor families. The majority of donor families in their study stated that the decision to donate brought them solace and comfort. Apart from the immediate difficulties of the decision-making process and its long-term ramifications, there were other experiences that were unique to organ donor families, for example, changing relationships with extended families who were not directly involved with the organ donation decision. Other studies using self-reported accounts have also found that organ donation facilitated the grief process (Bartucci & Seller 1986; Pelletier 1992; Shanteau et al., 1992). Cleiren and Van Zoelen documented conflicting findings from the above in their study, reporting that consenting to donation neither hindered nor facilitated the grief process post donation, nor did it influence detachment and depression in the months after the loss. Pearson et al. also reported no significant differences between donors and nondonors in grief resolution. Whether consenting to organ donation hinders or helps the grieving process remains open to debate and necessitates further research into this phenomenon.

### *Stress and Coping*

The stress that families experienced during the organ donation experience and the coping strategies used to deal with this stress have been documented in the literature (Pelletier, 1992; Pelletier, 1993a; Pelletier, 1993b; Shih et al., 2001b). Shih et al. investigated the impact of cadaveric organ donation in Taiwanese donor families. Eighty-six percent were concerned with the effect that donation had on the afterlife, while 77%



felt stress due to controversy over the decision to donate, and 45% reported stress due to devaluation of donation. Participants reported being unable to concentrate or maintain activities of daily life and job requirements. Coping strategies included support from families and health care professionals, positive thinking, and shifting attention towards other activities. Positive impacts of donation were reported as having a sense of reward for helping another, increased appreciation of life, and closer family relationships.

Pelletier's (1992) Canadian study investigating family members' organ donation experiences outlined their perception of stressful situations during the experience. The most frequently reported stressors were the threat of losing a loved one, lack of understanding of the concept of brain death, interactions with health care professionals, and adjusting to the many changes associated with the loss. Families perceived their interaction with health care professionals as both stressful and comforting. Information communicated in an insensitive manner or in terms they did not understand, together with a lack of emotional support and a failure of their relative to be identified as a donor by health care professionals, were factors contributing to the stress of family members. Positive interaction was rooted in descriptions of care delivered to the patient, the emotional support received, and the information provided to the families.

The impact that the loss of their loved one had on the family's personal lives was another area of stress. Not only was there a loss of a significant relationship, but also the remaining family members developed new roles and responsibilities. Despite these stressors participants viewed organ donation as a positive experience that gave meaning to their loss and provided a sense of comfort and peace (Pelletier, 1992). Three earlier

studies also reported that many relatives gained comfort from donating their loved one's organs and considered it a positive outcome of their loved one's death (Christopherson & Lunde, 1971; Fulton et al., 1977; Morton & Leonard, 1979).

The coping strategies used by organ donor families included seeking information to reduce stress and to come to terms with the reality of the death, drawing on emotional support of family and friends, exercising control over their emotions, and employing escape-avoidance techniques (Pelletier 1993a; Pelletier 1993b). Making the decision to donate despite feelings of shock, disbelief, numbness and anger was reported to give families a sense of closure and the belief that something good came out of a tragedy. These families needed to receive information and support from health care professionals, be able to visit their relative frequently, and be given the opportunity to consent to organ and tissue donation.

There were only two recent phenomenological studies of the family's experience with organ donation (Frid et al., 2001; Warren, 2002). Frid et al.'s study focused on organ donor families and the meaning of being a relative of a patient declared brain dead. Four themes emerged from the data: the disquieting event, the uncertain vigil, the arduous struggle, and the difficult road ahead. The disquieting event described the anxiety associated with being told that a loved one is ill, the realization of the seriousness of the illness, and the chaos surrounding ambiguity towards these events. The uncertain vigil referred to feelings of hope, despair, and uncertainty as the illness was confirmed. The arduous struggle was characterized by feelings of being unprepared, lack of

understanding of brain death, and the lost opportunity of say good-bye. The difficult road ahead described the state of grieving and how life had changed since the donation.

The only other phenomenological study found included 23 families who experienced the death of a loved one within a year and who were involved in organ donation (Warren, 2002). Family and friends were deemed essential to the healing process. Some participants exhibited concerns regarding financial and legal responsibilities and dealing with other bereaved family members. Families stressed the importance of being able to spend time with their loved one. However, they expressed dissatisfaction with access to physicians, lack of information sharing, and miscommunication of information from health care professionals, specifically regarding the exact cause of death, and information about the donor recipient. Positive feedback on health care professionals referred to their honest, open, and caring attitudes.

### *Summary*

It is apparent from the literature that the family's response to organ donation is one of tremendous grief and is stressful. Despite this, some families perceive the experience as positive, giving them a sense of comfort and peace. There were only two recent phenomenological studies that provided insight into the meaning of the organ donation experience, and described the experience as it was "lived" by donor families. A lack of clarity remains in the literature on the aspects of this phenomenon that facilitates grief reactions, causes stress, and aids the family in coming to terms with their loss, thus enabling them to define the donor experience as a positive one.

### *Factors Influencing the Organ Donation Decision*

There are a variety of factors that influence a family's decision to donate their relative's organs including approach methodologies, understanding of brain death, knowledge of the deceased's wishes, and the impact of culture and socioeconomic factors.

#### *Approach Methodologies*

Approach methodologies are defined in the literature as the methods used by health care professionals to introduce the concept of organ donation to the families and to give families the opportunity to donate a loved one's organs (Siminoff et al., 2002).

Approach methodologies discussed in the literature as having an impact on consent are where the request occurs, which health care professional approaches the family for the donation, and the timing of the request or decoupling. Collaboration between health care staff and organ procurement coordinator(s), and asking for the donation in a private setting have been associated with higher consent rates among donor families (Culter et al., 1993; Gortmaker et al., 1998; Kay & Barone, 1998; Klieger et al., 1994; Marisma & Escalante 2002; Von Pohle & Linda, 1996). However, there is debate in the literature on the benefit of decoupling.

The term decoupling refers to the time frame between when the family is notified of brain death and when they are approached for organ donation (Beaulieu, 1999). A request for organ donation is said to be "decoupled" if it takes place after, rather than

before or simultaneously, with notification of death (Siminoff et al., 2002). Howard (1989) noted that decoupling for at least 30-90 minutes allowed family members time to process the death and was the most critical factor in positive family response to organ donation. Other researchers supported the benefits of decoupling. (Culter et al., 1993,; DeJong et al., 1998; Gortmaker et al., 1998; Helander, Beasley, Gortmaker, Drachman, 1995; Kay & Barone, 1998; Klieger et al., 1994).

Helander et al. (1995) studied the organ donation request process for potential organ donor cases ( $n = 528$ ). Findings revealed that only 50% of organ donor requests were decoupled. Donation requests that were decoupled reported a consent rate of 61%, opposed to 41% for requests that were not decoupled. Gortmaker et al.'s (1998) retrospective study investigated approach methodologies used when requesting consent from potential donor families ( $n = 707$ ). Multivariate linear regressions demonstrated that decoupling occurred in half of the cases with a consent rate of 71.5% whereas the consent rate was 53.1% in cases not decoupled ( $p < .0001$ ). Other research studies also reported an increase in organ donor rates when decoupling had occurred (Cutler et al., 1993; Kay & Barone, 1998; Klieger et al., 1994).

Dejong et al. (1998) conducted structured telephone interviews of donor ( $n = 102$ ) and nondonor ( $n = 107$ ) families in order to identify barriers to organ donation. The timing of the organ donation request resulted in a significant difference ( $p = <0.01$ ) between donor and nondonor families. Eighty-three percent of donor families and only 46% of nondonor families said the subject of organ donation was brought up at the right time. However, no time frame was defined, nor was the use of decoupling indicated in the

study. Another retrospective study by Niles and Mattice (1996) on families approached for organ donation challenged the benefit of decoupling and reported no difference when organ donation was requested before or after death was pronounced. Data indicated however, that when the family was told of the death and asked for donation simultaneously, the consent rate decreased from 37% to 32%.

Other recent studies included the impact of decoupling on consent (Exley et al., 2002; Martinez et al., 2001; Siminoff et al., 2002). Siminoff et al. used data from retrospective chart reviews of potential organ donors, interviews with health care professionals, and organ donor family members, and found that the timing of the request was not significantly related to consent rates when adjusting for other variable such as attitudes, characteristics, and having information regarding the donor's wishes. Exley et al. completed a survey of donor and nondonor families and explored why families say no to organ donation. The authors reported that donation rates were lower when families were approached after being informed of brain death. Martinez et al.'s study on organ donation and family decision-making confirmed there was not a significant correlation between decoupling and consent rates. From this overview of the research on decoupling one might conclude that recent research does not support its significance in obtaining organ donor consent. However, due to large consensus of earlier research on the benefits of decoupling further, qualitative research is needed to further explore this concept.

### *Brain Death*

The successful implementation of decoupling requires that family members have a good understanding of the concept of brain death. Death has been traditionally viewed as the cessation of a heart beat. Thus, the notification of brain death is potentially problematic for donor families (Steed & Wagner, 1998). Studies that have focused on the family's understanding of the concept of brain death and its effect on the decision to donate have reported conflicting findings.

Telephone interviews conducted with nondonor ( $n = 62$ ) and donor families ( $n = 102$ ) 4 to 6 months after death found that a poor understanding of brain death was associated with significant lower rates of consent (Franz et al., 1997). Savaria et al. (1990) and Cleiren and Van Zoelen (2002), however, stated that even if families reported a poor understanding of brain death they still donated. Savaria et al. investigated factors influencing family's consent ( $n = 99$ ) and found that although the majority of family members reported that they understood the concept of brain death, some participants felt they did not have a clear understanding of what it meant to be brain dead. The main reasons contributing to this lack of understanding were first, the donor did not appear dead and second, the concept of brain death was not well explained. Despite this, they still consented to donate their relative's organs and tissues. However, families who refused donation were less likely to have received an explanation of brain death and to be given adequate time to understand brain death, before the physician approached them for organ donation.

A section of Cleiren and Van Zoelen's (2002) cross-sectional quasi-experimental study on post-mortem organ donation and grief in both donor and nondonor families looked at the participants' understanding of brain death in intensive care units in the Netherlands. Seventy-five percent of the donor group stated that they received adequate information on the concept of brain death, but when asked about the details, deficits were noted on the understanding of the diagnosis of brain death. A disturbing result was that 18% of the consent group did not realize that their loved one was deceased at the time of request. Segments of other research studies supported findings of the above studies and reported no association between the degree of comprehension of brain death and consent (Frutos et al., 2002; Pearson et al., 1995; Siminoff et al., 2002). Family member's difficulty with brain death is understandable; nurses working in intensive care have had difficulty with this concept as well (Borozny, 1990). From this review of the literature, it is evident that the understanding by the family of brain death does have an impact on their organ donation experience, but the significance of this understanding on whether or not they decide to donate is open to debate.

#### *Deceased's Wishes and Additional Factors*

The majority of researchers agree that knowledge of the wishes of the deceased is the main factor influencing the family's decision to donate their loved one's organs (Bartucci & Bishop, 1987; Burroughs et al., 1998; Cunningham, 1998; DeJong et al., 1998; Exley et al., 2002; Frutos et al., 2002; Martinez et al., 2001; Pearson et al., 1995; Painter & Langlands, & Walker 1995; Siminoff, et al., 2001). Some researchers concurred that when the wishes of the deceased are known the family's decision is



congruent with it. However, even when the wishes of the deceased are known, up to three-quarters of family members may refuse to consent (May, Auliso, & DeVita, 2000). However, it is essential for nurses to ask families if they have any knowledge of the wishes of the deceased when their loved one has been identified as a potential organ donor.

In addition to following the wishes of the deceased, researchers have noted several other reasons why families consent to organ donation. Painter et al. (1995) mailed questionnaires to donor families ( $n = 49$ ) in order to gain an understanding of why families participated in organ donation. Reasons for donating included meeting the needs of recipients, because they or a member of the family may need a transplant some day, or the donor was a young caring person in good health. The majority of families also reported that they did not consider being asked for donation stressful and felt that consenting to organ donation was the right decision. Approximately half of the participants stated that they would like some information about the recipients. Those who had received information on the recipient's progress found it extremely helpful to the healing process.

Burroughs et al. (1998) used a standardized telephone survey of both donor families ( $n = 159$ ) and nondonor families ( $n = 66$ ) to investigate family decisions to consent or refuse organ donation. Factors influencing the decision to donate were past behaviors of the donor, characteristics of the hospital, previous knowledge of or experience with donation, request methodology, religious beliefs, and response of the donor family, i.e. comfort with decision, time taken for decision, and characteristics of

the potential recipient and deceased. Bartucci and Bishop (1987) studied 37 donor families, and found that families were prompted to donate because they thought their loved ones would have wanted to help somebody. Also, the family's loss was lessened when they knew that other people were leading new lives because of their donation.

Siminoff et al. (2001) carried out the largest comprehensive study to understand organ donor families' decision-making process. Retrospective chart reviews were completed on all potential organ donors ( $n = 420$ ) followed by interviews with health care professionals, organ procurement coordinators, and organ donor families. Multivariate analysis revealed four factors directly related to the organ donation decision – pre-request characteristics, the individual who introduced the issue of donation to the family, organ procurement coordinator request-related factors, and topics discussed with the family.

Pre-request characteristics refer to the characteristics donor families bring with them to the organ donation decision process, i.e., sociodemographics, attitudes, prior knowledge of deceased's wishes, and organ donation process. An optimal request pattern was described as a health care provider, other than a physician, making the initial request followed by discussion with an organ procurement coordinator. This resulted in families being three times more likely to donate. An important factor related to organ procurement included the family's contact with organ procurement coordinator. The amount of time spent by the organ procurement coordinator discussing issues surrounding organ donation was related to higher consent rates. While health care professional attitudes on organ donation did not correlate with consent rates, their comfort level with answering questions on organ donation was significantly related to donor consent. Families who

believed that health care professionals who were involved with their relative were not caring, were more likely to refuse donation.

Martinez et al. (2001) explored factors associated with the decisions made by families of potential organ donors to give or deny consent for organ donation. Findings suggested that factors influencing the family's decision to donate, in addition to knowledge of the wishes of the deceased, included family relations climate, satisfaction with medical attention received, and the number of relatives present at the organ donation interview. Refusal to donate was associated with dissatisfaction with health care professionals, religious and cultural beliefs, and fear of social resentment. DeJong et al. (1998) identified similar factors associated with donor consent, including characteristics of the deceased, family beliefs and attitudes about donation, organ donation approach methodology used, and the family's understanding of brain death. In Exley et al.'s (2002) survey, donor families stated the main reasons for donating were "giving the gift of life," parts of their loved one were living on, better quality of life for the recipient, belief in the value of organ donation, and following the wishes of the deceased.

### *Cultural Factors*

Several studies of various ethnic groups cite the main reason for refusal to donate was because of traditional beliefs related to keeping the body whole (Frates & Bohrer, 2002; Yong et al., 2000). Agreement among family members, religious beliefs, concerns regarding the effect of donation on the afterlife, wishes of the deceased, caring attitudes and explanations by health care professionals, encouragement from friends and family,

and the conscience of family members were also reported as factors influencing the decision to donate (Shih et al., 2001b).

Nakahara (1998) reported that 45.1% of organ donor families they surveyed in Japan felt they were helping others and saw organ donation as a positive and gratifying experience. Although participants agreed that organ donation is a humane contribution to save lives, donor families continued to voice ambiguity with respect to potential social repercussions and feelings of "damaging" the deceased's body.

Studies that focused on ethnicity as a factor in organ donation reported whites as being more likely to donate than other ethnic groups, specifically blacks and Hispanics (Frates & Bohrer, 2002; Frezza, Krefski & Valenziano, 1999; Guadagnoli et al., 1999; Schaeffer et al., 1998). The authors identified factors attributed to the lack of consent among ethnic groups, such as a lack of information regarding organ donation process and brain death, distrust in medical community, negative attitudes towards organ donation, fears of death being rushed, and language barriers.

A multiethnic survey designed to investigate the relationship between families' expressions of fear and their organ donation decision also found that whites had higher consent rates than Hispanics and blacks (Verble et al., 2002). The authors reported that regardless of ethnic origin, if the deceased had expressed wishes not to donate then the family refused consent. Concerns of the families who had decided to donate included a concern that the body would look strange post donation due to mutilation or disfigurement, delay in the funeral, additional cost to donor family, body parts would be wasted, and the donor was not really dead. Concerns voiced by donor families were very

similar to concerns of those who refused to donate with the addition of three other factors; other people might disapprove, hard to make the decision for somebody else, and they might regret the donation later.

The Partnership for Organ Donation (1993) carried out one of the largest national telephone surveys on public attitudes towards organ donation; they reported black respondents less likely than whites or Hispanics to consent to organ donation. Reasons reported for this disparity among ethnic groups were organ donation is against their religion, confusion regarding the meaning of brain death, belief that there would be an additional medical cost to donor family, disfigurement of body, uncertainty about the benefits of donation to the donor family, belief that transplants are experimental, and the fear of an illegal organ trade market. Many authors suggested that the low consent rate among blacks is related to lack of awareness and knowledge about organ donation, religious fears, myths, and misconceptions, distrust in the medical community, fear of premature death, lack of communication with health care professionals, and the perception of an unfair market (Franz, Drachman, DeJong, Beasley, & Gortmaker, 1995; Radecki & Jaccard, 1997).

Research addressing the relationship between culture and organ donor consent has identified a variety of cultural factors that affect the organ donation decision. It is obvious from a review of this research that culture impacts how organ donor family members perceive this phenomenon and whether or not families consent to donate their loved one's organs.

### *Socioeconomic Factors*

Studies have shown that higher rates of organ donor consent are found in white, educated individuals who have a higher socioeconomic status (Burroughs et al., 1998; DeJong et al., 1998; Schaeffer et al., 1998; Siminoff et al., 2002). Schaeffer et al. completed a retrospective analysis of all potential organ donors over three years and reported that the average donor had an income of \$30,000 per year, was white and had at least a high school diploma. Siminoff et al. reported 65.2% of organ donors were female, 83.8% white, 66.9% married with 13.2 years of education, and 34.5 % had an annual income of \$25,000 to \$50,000. Health Canada (2002) reported a positive correlation between household income and willingness to donate needed organs. An income of over \$30,000 had a projected 67% consent rate. Middle-aged Canadian women with at least a high school diploma are reported to have a higher incidence of donation.

### *Summary*

Research studies included in this section of the literature review have identified several factors influencing the family's organ donation experience, such as approach methodology, understanding of brain death, and cultural and socioeconomic factors. Researchers suggest a positive correlation between these factors and organ donation consent rates but failed to adequately address the significance of these factors to the family's organ donation experience. One constant factor that emerged as significant in the donation decision is knowledge of the deceased's wishes. It is also acknowledged that the relationship with health care professionals, specifically the nurse, may influence the

donation experience. However, this aspect will be addressed in a following section of this literature review.

There are several limitations of these research studies. The majority of studies cited were retrospective in nature with data collected by health care professionals who were involved with the donor families under study. Therefore, reported findings may have recall and data collection biases. A vast number of the data collection instruments used to collect data were either new or modifications of several existing instruments that had little or no reported reliability or validity.

#### *The Impact of Nurses on Family's Organ Donation Experience*

Nurses have been identified in the literature as a critical link in the organ donation process, often being the first health care professional to identify the potential donor (Boey, 2002; Martin, 1993; Randhawa, 1997; Siminoff, 1997; Smith-Brew & Yani, 1996; Sophie et al., 1983; Stark, Reiley, Osiecki & Cook, 1984). Nurses have the necessary therapeutic skills to approach families for donor consent (Bartucci & Bishop 1997; Pelletier, 1993a) and to play the dual role of caregiver to the patient and supporter of the donor family (McCoy & Argue, 1999). The family's interaction with the nurse not only affects the family's grief response, and their perception of the organ donation experience, but also has an impact on their decision to donate (Riley & Coolican, 1999).

A large amount of research has been done to investigate the knowledge and attitudes of nurses towards organ donation and has suggested that both these factors have a significant impact on the family's decision to donate their loved one's organs (Al-

Mousawi et al., 2001; Beasley et al., 1997; Bidigare & Oermann, 1991; Bilgin & Akgun, 2002; Boey, 2002; Davies et al., 2000; Evanisko et al., 1998; Ingram et al., 2002; Kent, 2002; Kent & Owens, 1995; Kiberd & Kiberd, 1992; Martin, 1993; Molzahn, 1996, Molzahn, 1997; Ozdag & Bal, 2001; Prottas & Batten, 1988; Pugliese et al., 2001; Roels & Wright, 2001; Siminoff et al., 2001; Sophie et al., 1983; Stoeckle, 1990; Younger, Landefeld, Coulton, Juknalis, & Leary, 1989). Also nurses have described the organ donation experience as both physically and emotionally draining and as affecting their willingness to participate in the organ donation experience (Day 2001; Hibbert, 1995; Hickey & Lewandowski 1988; Pearson et al., 2001; Pelletier-Hibbert, 1998; Sadala & Mendes, 2000; Watkinson, 1995; Wells & Sque, 2002; Willis & Skelley, 1992).

### *Attitudes and Knowledge*

The attitudes and knowledge of nurses are two main factors that have been found to impact the family's organ donation experience. There is a discrepancy between the attitudes and actual willingness of nurses to commit to and participate in the organ donation process. This lack of commitment and knowledge may inhibit nurses in approaching families for donation and in providing adequate support for families when making the organ donation decision, thus affecting the family's organ donation experience. Additionally, some nurses who have cared for the patient in the clinical setting found it difficult to approach that patient's relative to request organ donation (Martin, 1993).



There are at least two positive aspects of participation in organ donation noted. The first is recipient-focused; it is an opportunity to improve the quality of life of the recipient. The second is donor-focused because organ donation is a means to help these donor families deal with their grief. Sophie et al. (1983) looked at intensive care nurses' perceptions of organ donation. They found that an inadequate knowledge of organ donation criteria and a lack of awareness of hospital policies and attitudes towards organ donation influenced the nurse's participation in organ donation. Nurses described their organ donation experiences as having few rewards and many sources of physical and emotional stress. Often potential donors required aggressive nursing management to preserve the organs for retrieval at a time when the nurse's attention was focused on supporting the grieving family. A discrepancy between nurses' attitudes towards organ donation and their actual willingness to donate has been reported. While 86.8% of nurses supported organ donation only one-third carried organ donor cards. Other researchers have found similar results (Ingram et al., 2002; Bidigare & Oerman, 1991, Kibert & Kiberd, 1992).

Ingram et al. (2002) replicated Stoeckle's (1990) study of knowledge and attitudes of critical care nurses related to organ donation and reported similar results. The majority of nurses had a positive attitude towards organ donation, but failed to act on their beliefs. Ingram et al. also found that as a nurse's knowledge of organ donation increased, attitudes were more consistently positive. However, having a positive attitude was not found to result in an increased willingness to donate one's own organs or those of a family member. Bidigare and Oerman (1991) examined attitudes and knowledge of

nurses around organ donation and found that although nurses had a positive attitude towards organ donation, only 70% would pursue donation for clients under their care. Nurses who had previously participated in organ donation were found to be more knowledgeable and to have a more positive attitude towards donation. These nurses were found to be better able to provide support to the donor families in the decision-making process.

Researchers have also studied nurses' attitudes towards organ donation, procurement, and transplantation in Canada (Kiberd & Kiberd, 2002; Molzahn 1996, 1997). Findings are that the majority of nurses supported organ donation, but there was a lack of written protocols, and not enough time to read existing policies. Various perceptions of organ donation were reported among nurses from different units. Operating room nurses felt that they had no support, received no feedback on transplant outcomes, and lacked education in this field. Nurses in the intensive care unit noted the event as both rewarding and depressing. However, they stated that their main concerns were a lack of personnel, education, and psychological support. They felt that too much time was focused on maintaining the donor, thus preventing them from adequately caring for the family. Nurses from general units voiced concerns on the lack of involvement in donor identification and education (Kiberd & Kiberd).

Molzahn (1996, 1997) investigated knowledge and attitudes of Canadian nurses (n = 1239). Findings revealed that the majority of nurses approved of organ donation with 68.8% believing that organ donation helped the family. Even though 77.5% were willing to donate their own organs, only 60.9% had organ donor cards. Approximately half of the

nurses reported that they did not like to be involved in organ donation and 69.0%-82.1% found organ donation emotionally demanding. Nurses reported that brain death was difficult to explain to families and thus verbalized a reluctance to approach families for organ donation. Lack of knowledge about religious beliefs prohibiting organ donation, brain death legislation, and the referral process was identified.

Other researchers who identified a discrepancy between nurses' attitudes towards organ donation and their willingness to participate in organ donation reported that nurses feel uncomfortable performing the tasks related to organ donation, such as explaining brain death, (Pugliese et al., 2001) and that they expressed fears of mutilation and medical neglect (Boey, 2002). Lack of knowledge of organ donation was reported for nurses in a Turkish study (Ozdag & Bal, 2001). They reported only 15% of the participants said they would approach the family for donation despite reported positive attitudes. A similar Turkish study reported that in spite of having a good knowledge about organ donation and enforcing laws, only 37% of nurses reported a willingness to donate (Bilgin & Akgun, 2002). Another study examining the attitudes of intensive care staff towards organ donation reported that despite positive attitudes about donation, only 53% would donate their own organs, 33% would donate a family member's organs, and only 14% stated that they would encourage families to donate (Al-Mousawi et al., 2001).

Evanisko et al.'s (1998) study used the same questionnaire as Bilgin and Akgun (2002) to assess readiness of critical care physicians and nurses to handle requests for organ donation. Findings suggested that critical care staff lacked education about issues, policies, and procedures involved with organ donation. Participants reported discomfort

with their roles in the donation process and in approaching families for consent. When education was provided, staff reported higher levels of knowledge about, support for, and comfort with organ donation. Educated staff were more likely to endorse the idea of decoupling and to obtain consent from a family. In hospitals with lower education on organ donation, consent rates were lower, nurses found organ donation protocols uncomfortable, and they had a decreased knowledge of organ donation and brain death criteria. Another study examined readiness of hospital staff ( $n = 787$ ) in four Canadian hospitals to handle organ donation (Beasley et al., 1997). Seventy-five percent of critical care staff was not ready to handle organ donation requests.

Kent (2002) reported findings from a three-part investigation that examined nurses' willingness to participate in donor identification and discussion of the organ procurement process. Once again knowledge and experience appeared to be vital factors in determining perceptions of ability to discuss donation with families. Participants who worked in areas such as intensive care, where a higher incidence of organ donation took place, felt more able to discuss donation than nurses working in other areas. Identified areas of poor knowledge were criteria for brain death and exclusion criteria of donors. Multivariate analysis identified four variables that may predict the likelihood of participation in organ donation; (1) weak negative attitude towards organ donation; (2) understanding of the donation request; (3) knowledge of brain death criteria; and (4) discussion of the patient's wishes to donate or not. Nurses described the discussion of donation issues as difficult and stated their willingness to raise the issue as being

influenced by traditional practices, personal attributes, and societal factors as well as their knowledge of the donation process.

Roels and Wight (2001) investigated the impact of a Donor Action Methodology Program on organ donation rates in eight North American and European countries. Knowledge and attitudes of critical care professionals towards organ donation and their confidence and self-reported skills in donation related tasks were significantly different among countries. Overall results were that the majority of participants supported organ donation (91.7%) and were willing to donate their own organs (80.4%). Gibson (1996) suggested that professionals are more likely to favour organ donation in the abstract, i.e., a good idea, than on the personal level. She reviewed the attitudes of the public and professionals toward organ donation.

In a cross-sectional survey of knowledge and concepts among health care professionals on brain death and organ retrieval Younger et al. (1989) sampled physicians and nurses about knowledge, personal concepts, and attitudes towards brain death and organ donation. Only 35% of participants correctly identified the legal and medical criteria for determining death. Prottas and Batten (1988) reported similar findings. Despite support for organ donation among health care professionals, significant uncertainty existed regarding donor inclusion criteria. They also found that neurosurgeons and nurses were uncomfortable with making the actual brain death decision and dealing with donor families.

Research on nurses' attitudes and knowledge of organ donation suggests that these two factors have a significant impact on the discomfort that nurses experienced in

approaching families for donor consent, and inadvertently, may contribute to the decrease in organ donation consent rates.

### *The Nurse's Organ Donation Experience*

Nurses are thought to be the logical choice to approach the families for organ donation being that they are the health care professionals spending most of their time with the patient and family (Hibbert, 1995; Pelletier-Hibbert, 1998; Watkinson, 1995; Willis & Skelley, 1992). Nurses frequently described their role in organ donation as emotionally and physically demanding (Hickey & Lewandowski, 1988). They felt that they were expected to perform their professional duties while being emotionally challenged to support the donor family in a time of crisis and desperate need. This emotional challenge had an affect on their perception of the organ donation experience and their willingness to participate in the process.

Watkinson (1995) integrated quantitative and qualitative methodologies to investigate perceptions and experiences of critical care nurses in caring for organ donors. Findings confirmed that the majority of nurses have a positive attitude towards organ donation (91% - 95%) correlated with their knowledge of brain death ( $p < 0.024$ ). Nurses also reported caring for the family more stressful than caring for the donor. Qualitative data analysis identified seven themes related to nursing management of the organ donor including; (1) the working environment; (2) understanding of brain death; (3) the role of the nurse within the organ donation process; (4) nursing factors that may restrict donation; (5) stress reduction; (6) educational preparation; and (7) myths.

Nurses felt that they had a good knowledge of brain death and believed in order to care for the family and the organ donor, their working environment required one to one nursing patient ratio. The role of the nurse within the organ donation process was seen as maintaining a balance between the patient's dignity, respecting the family's wishes, providing family support, and preserving the organs for transplant. Factors that restricted the participation of nurses in organ donation were lack of knowledge of brain death, attitudes towards organ donation, counseling skills, and logistics of organ procurement process. The theme, stress reduction, referred to the emotional strain nurses felt in being part of the donation process and the need for stress reduction. Lack of educational preparation was another concern voiced by the nurses. The final theme emerging was myths surrounding the organ procurement process.

Researchers have identified stressors and coping mechanisms experienced by nurses in eastern Canada while caring for organ donors and their families (Hibbert, 1998; Pelletier-Hibbert, 1995). The three main stressors identified by Hibbert included managing the threat to life, fulfilling the informational and supportive needs of family members, while maintaining a professional orientation to the patient, and the physician's hesitancy to intervene to preserve organs of potential organ donors. Pelletier-Hibbert documented six coping strategies used by nurses to deal with the stressors identified in the 1995 study, including: (1) exercising control; (2) distancing; (3) maintaining normality; (4) seeking emotional support; (5) taking time-out; and (6) positive reappraisal.

Nurses had conflicting views on the definition of properly exercising control. Some nurses believed that it was important to be stoic and not show any emotions while others stated that they showed emotions, but in a way that did not interfere with their ability to support the families. Nurses reported distancing themselves from the donor in order to perform professional duties, mainly by dehumanizing the donor. Others maintained consistency of nursing care in order to cope with the situation. Nurses often sought the support of their colleagues and took time out to reflect on the events and to bring closure to the nurse-cadaver-patient relationship. Several nurses used positive reappraisal when they referred to the good that had come out of the death and their nursing efforts. Nurses reported feeling good and having a sense of satisfaction and relief related to their role in the organ donation process, the benefits of the donation to the recipient, and the donor families.

Phenomenological researchers have identified several themes that provided a greater understanding of nurses' organ donation experiences (Day, 2001; Pearson et al., 2001; Sadala & Mendes, 2000). These three research studies not only captured the stress that nurses associated with the organ donation experience but indicated areas of focus that are in need of support and education if society hopes to decrease the disparity between organ supply and demand. Pearson et al. investigated the experiences caring for brain dead organ patients. Two main themes emerged from the data "the family" and "the nurse." "The family" consisted of six sub themes including; (1) empathizing with the family's tragedy; (2) prioritizing the family's needs; (3) supporting the family's decision; (4) realizing that care for the deceased reflected care of the family; (5) encouraging



privacy; and finally (6) intruding on the family's grief. Participants found that they had a dual function, initially focusing on the management of the donor and then shifting to supporting the donor family. Nurses maintained respect for the deceased by remaining consistent in their nursing care. This was seen as one way in which nurses were able to help the family through the experience and prioritize their emotional needs. Arranging private space for families to grieve was seen as an important aspect of nursing care. Nurses reported feelings of guilt and frustration that their continuous presence at the donor's bedside, although unavoidable, was an intrusion on the family's grief.

The theme "the nurse" included emotional demands, respect for deceased, explaining ambiguities, and focusing on outcomes. Nurses described their experience with families who donated their loved one's organs as challenging on all levels, emotionally, physically, psychologically, and spiritually. One way in which many nurses learned to cope with the experience was to encourage themselves and donor families to focus on the outcomes of the donation decision.

Day (2001) used a phenomenological approach to gain a better understanding of the experiences of nurses making the shift from care of a brain injured patient to maintenance of a brain-dead organ donor. Three themes emerged from the data including; (1) the skill of balancing ambiguity of the prognosis with preserving the organs for donation; (2) the difficulty in making the shift to prognostic certainty without making a complete commitment to organ donation; and (3) the change in patient's status once brain death is declared. Nurses emphasized the importance of not predicting the outcome of the patient's treatment, preferring to wait until the clinical manifestations confirmed brain

death or a physician declared the patient legally brain dead and, thus, strived to assist the patient to regain function. Nurses talked about a grey area where the patient's condition became so unstable that death was inevitable, and the shift was quickly made from care of a patient with a brain injury to preserving organs for retrieval. The change in the patient's status once brain death was declared supported the belief by the nurse that the body no longer needed psychological support but merely physical support once the person was declared brain dead. Others considered the body as an object with significance, having no emotional attachment but they showed respect by handling the body gently and keeping it clean. Some nurses reported uncertainty about the nurse-patient relationship given that the body was no longer a person.

Sadala and Mendes (2000) also used a phenomenological approach to look at the relationship between organ donor families and nurses' perceptions of themselves in professional situations. Although nurses had the knowledge base to participate in the organ donation process, they felt insecure in caring for what they referred to as "the different patient." Nurses referred to the donor as having no traces of humanity and stated that they thus focused attention on the organs and not the donor. Feelings of detachment with the organ donor similar to that reported by Day (2001) were also documented. These feelings extended to the donor family and affected their organ donation experience. Some nurses believed that supporting the donor family was within their scope of practice, but that it was difficult to do so. Other nurses thought that someone else should take the responsibility of caring for the family. Some nurses viewed detachment from the family as a method of distancing themselves from the family's pain and concentrating on the

physical tasks required to maintain the organs. It was only when the nurse started to develop a relationship with the family members that they started to identify the donor as an individual. Nurses expressed difficulty in coping with their dual role of caregiver to the organ donor and family.

### *Summary*

Research on nurses and organ donation indicated that nurses' attitudes and knowledge have a significant impact on the family's organ donation experience. However, the research failed to clarify the significance of this relationship and instead focused on the disparity between nurses' attitudes towards organ donation and their willingness to participate in organ donation process.

Qualitative studies that have examined nurses and organ donation experiences have increased our understanding of the stressors experienced by nurses caring for families who donate their loved one's organs. These stressors included lack of knowledge of the organ donation process, the definition of brain death and donor inclusion criteria, lack of policies guiding organ donor practice, poor administrative support, and a low level of confidence in their abilities to care for potential donors and their families both individually and simultaneously. These stressors influenced the willingness of nurses to take an active role in the organ donation process or to approach families for consent.

### Chapter 3: Methodology And Methods

The following chapter consists of two main sections. The first section provides a brief overview of the methodology used for the study. The second section outlines the specific methods utilized to guide the research process.

#### *Methodology*

Phenomenology as outlined by van Manen (1997) is the research method being used in this study to assist me, as the researcher, in obtaining data to identify essential meaning of the lived experience of family members who have donated a loved one's organs. van Manen describes phenomenology as the study of lived experience aimed at gaining a deeper understanding of the nature or essence of the experience. According to van Manen, phenomenology is a "validating circle of inquiry" that is, data collection is actual lived experiences that are reflected upon by both the participant and the researcher in order to validate the essence of the experience and attain insightful descriptions of the phenomenon under investigation. In this phenomenological study, I ask the question "What is the experience to donate a loved one's organs like?"

The essence of the phenomenon refers to common units of meaning that are reflected in individuals' lived experiences (Streubert & Carpenter, 1999). van Manen (1997) identifies the internal meaning structures of the lived experience as the essence. It is the core of the phenomenon and without it, the experience would not be what it is. The

essence of an experience is presented adequately if the description reveals a deeper meaning and significance of the experience.

In order to reveal the essence of a "lived" experience, van Manen (1997) outlines the interplay of six research activities as the foundation of phenomenological research: investigating a phenomenon that interests and commits the researcher, exploring the phenomenon as it is "lived" by the participants, not as it is conceptualized, reflecting on essential themes that characterize the phenomenon, describing the phenomenon through writing and rewriting, maintaining a strong and oriented relation to the phenomenon, and considering both the parts and the whole in order to balance the research.

According to van Manen (1997), the initial step of phenomenological inquiry is determined by the questioning of the essential nature of a lived experience of interest to the researcher, such as consenting to the organ donation of a family member. The researcher then enmeshes him/herself into the life experience in order to transform it into a written expression of its essence, constructed in such a manner as to reveal the true nature and significance of the experience as verified by the participants. When using the phenomenological method the researcher attempts to bracket his or her perspective to try to ensure that the experience is described as lived rather than conceptualized. That is, the researcher tries to suspend any beliefs, assumptions, and biases about the phenomenon under investigation to become neutral in order to explore the phenomenon as it was lived by the participants and to prevent the information from interfering with the recovery of a pure description of the phenomenon. The degree to which it is possible to use bracketing is the subject of some debate.

Once data are gathered from either literary sources or, as in this research study, from individual interviews, the insight into the essence of a phenomenon starts with the reflection of essential themes that characterize the phenomenon. Themes are "knots in the webs of our experiences around which certain lived experiences are spurs and thus lived through meaningful wholes" (van Manen, 1997, p 9). A thematic analysis refers to uncovering the theme(s) that are embodied in the transcribed interviews.

This study used van Manen's (1997) selective or highlighting approach to do a thematic analysis. The selective approach identifies key phrases by highlighting, underlining, or circling those phrases that appear essential or revealing about the phenomenon. Once themes have been identified from the data they become part of a collaborative analysis by both the researcher and participant in follow up interviews. Both the researcher and the participant review each theme collaboratively and ask if the theme captures what the experience was really like? Therefore, not only does this reflection of theme(s) lead to a deeper understanding and re-orientation to the phenomenon but validates the researcher's findings that the interpretation is reflective of the participant's lived experience (van Manen, 1997).

Following thematic analysis, the researcher attempts to describe the lived experience through writing and rewriting. Writing and rewriting allows the researcher to distance him/herself from the lived experience and objectively reveal the existential structures of the experience through reflection. While writing and rewriting, it is crucial that the researcher remain orientated to the phenomenon under investigation. All of the researcher's efforts should be put forth to gain a greater understanding of the lived

experience, as opposed to being distracted with abstraction of the experience, entertaining speculations, or becoming disinterested and preconceived opinions (van Manen, 1997).

The final research activity outlined by van Manen is balancing the research by considering parts and wholes. At various intervals the researcher steps back and considers the overall text and the how the parts contribute to the final text.

### *Methods*

The following section provides a brief overview of the participants including recruitment and selection of participants, data collection, data analysis, credibility, and ethical considerations. The methods used allowed the researcher to work with the participants and thus come to a better understanding of the organ donation experience.

#### *Participants*

Five individual family members who had donated their loved one's organs in the province of Newfoundland and Labrador were interviewed. A family member was defined as the individual who is listed as the next of kin on the deceased's chart and who has signed the organ donor consent form. Eligibility criteria for the participants in the study included: (1) able to communicate fluently in English; (2) mentally competent enough to allow him/her to give informed consent and to understand the purpose of the study and participate actively in the interview; (3) older than 19 years of age, since interpretation of the phenomenon by adults is often perceived differently than children; (4) a family member who has donated a loved one's organs within the last three years,

since this time frame would allow for the participants to give a vivid description of the “lived” experience; and (5) living in the same household as the deceased to enhance the understanding of this “lived” experience.

### *Recruitment and Selection of Participants*

After ethical approval was obtained from both the Human Investigations Committee (see Appendix A) and the Health Care Cooperation of St. John’s (HCCSJ) (see Appendix B), the two Organ Procurement Coordinators (OPC) within the HCCSJ were approached to assist me in contacting potential participants. The OPC made the initial contact with the participants by telephone and requested the family member’s participation in the study. If the individual agreed to participate, her name and telephone number was released to me. I then contacted each participant and gave an introduction to the study and the purpose of the study. An opportunity was also given for the participants to ask me any questions that they might have prior to the interview.

### *Data Collection*

Data were collected through the use of unstructured interviews. The interviews were conducted at a time convenient for the participants. Three of the interviews were done at the participants’ homes and two were carried out in a private office. Prior to the interview, an explanation of the study and its purpose was given to all participants, followed by written informed consent (see Appendix C). The participants were informed that they were not obligated to participate in the interview and could withdraw at any



time. The original consent forms were locked in a filing cabinet. Confidentiality of the participants was also addressed. All the participants were ensured that they would not be identified at any point during the study and that the audiotapes would be destroyed once data analysis was completed.

The unstructured in-depth interviews were audiotaped and transcribed for data analysis. Since phenomenology centers on the meaning of the lived experience, research questions were not predetermined (see Appendix D). The unstructured interview gave the participants the opportunity to tell their "lived" experiences of what it is like to donate a loved one's organs in their own words, providing a greater insight into the nature of the phenomena (Morse & Field, 1996). Follow-up questions were used to clarify the participants' ideas, thoughts, and feelings in order to gain a fuller understanding of the "lived" experience of donating a loved one's organs.

The completed interviews varied from approximately 20 to 45 minutes depending on the data obtained. All participants were informed that a follow-up interview might be required to reflect, clarify, and add descriptions to the phenomena. Follow-up interviews were held with four of the five participants as described below.

### *Data Analysis*

In phenomenology, data analysis is initiated by immersion in the data as a whole. It requires reading, intuiting, analyzing, synthesizing, and reporting the data collected in order to develop a greater understanding of the organ donation experience (Morse & Field, 1996). Upon completion of the taped interviews, the written text was transcribed as

soon as possible and entered into a computer. The written accounts were compared with the audiotapes to ensure accuracy of the dictation. The audiotapes were then destroyed.

Using selective highlighting, significant statements and themes that were reflective of the "lived" experience of organ donation were underlined. Each narrative description was reviewed multiple times to confirm that all significant statements were taken into account. In each interview, specific quotes that supported and identified themes were grouped together. Finally, I reflected upon all five interviews together and the themes identified in an effort to gain a greater understanding of the essence of what the "lived" experience of organ donation is like.

Once I completed a thematic analysis, the themes were brought to my thesis committee for discussion and for verification that the identified themes were reflective of the participants' interviews. I met with my thesis committee multiple times during the data analysis process for guidance and assistance when writing the final research findings.

### *Credibility*

Credibility relates to the trustworthiness of findings in qualitative research. It is demonstrated when participants recognize the reported research findings as their own experiences (Sandelowski, 1986). According to van Manen (1997) findings of qualitative data are credible only when they are returned to the participants to confirm the interpretation. Thus, to ensure credibility of the data analysis typed interviews were mailed to the participants who were asked to confirm that the text reflected their

experience and that they could not be identified. Secondly, in follow-up interviews the analysis was presented to the participants and they were asked if they recognized the description of the phenomena as their own 'lived' experience, thus validating the reported findings.

Two of the follow-up interviews were conducted by telephone and two at the participant's home. Each interview lasted from 20 to 45 minutes. One participant could not be located by telephone and she was not re-interviewed. All of the four re-interviewed participants stated that they recognized the text as an accurate account of their organ donation experience. No additional comments were added. All of the participants felt that the identified themes captured the meaning of their organ donor experience; this validated the findings of this study. The participants reported that they found reviewing the written accounts of their interviews and the follow-up interview therapeutic.

Credibility was also ensured by meeting with my thesis committee members, one of whom has experience in phenomenology and one who has content expertise in acute care, to review and validate findings. Both committee members were given transcribed interviews and thematic analysis. I met with the committee members on a regular basis in order to reflect on data, reconfirm data analysis, discuss the meaning of written verbatim, and receive assistance on the writing of final text. An audit trail was completed illustrating the thought processes, decisions, and methods used by the researcher. Through the use of notes and self-awareness, bracketing was used to identify my notions and ideas about the phenomena and knowledge regarding the organ donation experience.

This helped ensure that the data analysis reflected the actual meaning of the “lived” experience of families who have donated a lived one’s organs rather than what I presupposed about organ donation.

### *Ethical Considerations*

Protection of participants’ rights is essential for any research conducted using human participants. Ethical approval was obtained by the Human Investigation Committee at Memorial University of Newfoundland and Labrador. Prior to being given access to participant’s names, additional approval was obtained from the Medical Advisory Board at the Health Care Corporation of St. John’s.

The potential risks and benefits of participating in the study were discussed with each participant. The only risk anticipated was psychological distress due to the sensitive nature of the phenomena under study. Participants who experienced any psychological distress were given the options to: (1) withdraw from the study, wherein the taped interview would be erased immediately, as was the case with one interview, (2) reschedule the interview for another time, or (3) take a break prior to recommencing the interview. I was prepared to offer the participants assistance in contacting available support services and I ensured that all participants were in stable condition after each interview.

One participant elected to withdraw from the study during her interview because of extreme emotional distress. I stayed with the participant and provided an opportunity for her to further talk about her concerns. I ensured that she was not emotionally distraught prior to leaving and offered professional support resources, and left her my

contact number. When I returned home from the interview I called the participant to ensure that she was not distressed. She assured me that although she was upset, she was coping well with the memories of her loss that had resurfaced during the interview. In the sensitive type of research such as I was conducting, I had to be prepared for such an emotional reaction and indeed had covered the issue of emotional upset in my ethics approval. When I telephoned I once again offered support resources and informed her to contact me if she had any questions regarding the interview or if I could be of any further assistance.

The participants were informed that there were no direct benefits for their participation in the study except that it may offer some therapeutic support. However, by obtaining a greater understanding of the “lived” experience of donating a loved one’s organs, health care professionals may be able to help develop strategies to support and meet the needs of families when they are experiencing this phenomenon. Secondly, data may emerge that identify factors that predispose one to donate their relative’s organs, providing insight into methods to increase organ donation rates in Canada.

Confidentiality was ensured for all participants. Confidentiality was guaranteed by: (1) using a code on the interview tapes and transcriptions so that participants would not be easily identified, (2) locking the taped interviews in a separate cabinet from the consent forms so that there are no links between names on the consent forms and the audiotapes, (3) providing the participants with a copy of the transcribed interview to verify that they could not be identified, (4) limiting access to the data to the primary researcher and the thesis committee members, and (5) removing gender of the two

paediatric organ donors because it may allow them to be identified. In the follow up interviews, all participants were asked if they felt that confidentiality had been maintained. All of the participants stated that they felt they could not be identified from their interviews.

## Chapter 4: Findings

What is the experience like for family members who have made the decision to donate a relative's organs? This chapter attempts to provide a greater understanding of this phenomenon through interviews with five women who have donated either their child's or spouse's organs. The findings are presented in three sections. The first section presents a brief overview of participants' characteristics. The second section describes the themes that emerged from phenomenological analysis of the participant's narrative descriptions. The third section discusses the essence of the experience.

### *Participant's Characteristics*

Five women who had donated their relatives' organs after death participated in this study. Three of the participants had donated their spouse's organs and two had donated their child's organs. Three of the participants were married and living with their husbands. One of the paediatric donors was a single mother, and one participant was separated from her husband. The ages of the participants ranged from 35 to 55 years. Two of the participants were retired, two were unemployed, and one worked as a service provider.

All of the participants' relatives had died sudden, unexpected deaths within the last three years. Two of the deaths were the result of cardiac arrest, and the others were the result of post-operative surgical complications, head trauma, and a sudden-onset illness.

### *Thematic Analysis*

A thematic analysis of the narrative descriptions of five women who “lived” through the experience of organ donation identified five essential themes. These themes helped me gain insight and a greater understanding of what life is like for family members who have donated their relative’s organs. All the themes are presented separately to emphasize certain aspects of the organ donation experience, but all are of equal significance and are interrelated. The five themes that were identified from my analysis included; (1) a struggle to acknowledge the death: this cannot be happening; (2) a positive outcome: wanting some good to come from the death; (3) creating a living memory: the deceased is living on; (4) buying time: I have to keep them alive as long as possible; and (5) it’s your decision: support networks make it easier. The integration of these themes led me to identify an overall essence of this experience as *creating a sense of peace*.

#### *A Struggle to Acknowledge the Death: This Cannot be Happening*

Essential to all participants’ experiences was the disbelief that accompanied their loved one’s death and then being placed in the position to make a decision about organ donation. This theme described the struggle of the participants to come to terms with the realization that their loved one was actually dead. All the participants in this study described the loss of their loved one as a continuous struggle to balance feelings of grief



with the reality of the death and the request for organ donation. The length of time between the injury or the adverse event and notification of death varied for the participants. While some participants were notified that their relative was dead within a few hours, other participants were notified of the diagnosis of brain death within 24 hours of admission. One participant described the experience as taking place over a period of five days.

It was apparent from participants' stories that none of them had anticipated the death of their loved one. All the participants described a sense of numbness, shock, and disbelief that their spouse or child was dead and frequently referred to the suddenness of the death. One participant expressed disbelief that such a routine surgery could result in death and said when she heard the news all she could think was, "God, this can't be happening." Another participant whose spouse collapsed from a cardiac arrest recalled a sense of confusion and vagueness surrounding being told her husband had passed away, and described the sequence of events as "happening too fast." A mother, despite being told her child was brain dead, did not believe that her child was going to die and assumed the child would be coming home. Another parent refused to believe that her child was dead, thinking that the doctors had "made a mistake."

Shock and disbelief of the death is associated with the family's inability to absorb information, and to ask pertinent questions about organ donation procedures and this was the case for my participants. Although they recalled being notified of the death and believed that they made an informed decision to donate, they described that they did have difficulty processing the information given at the time. The participants referred to a

“foggy period” where they vaguely recalled the sequence of events leading to the donation, such as how they were approached and the factual information they received. They described the whole experience, as being sudden and chaotic, suggesting an unequal balance between information provided and their ability to process it. This contributed to feelings of shock, disbelief, and a general sense of being overwhelmed by the experience as reflected in the following comment:

I am blurry because I was so upset so I cannot even remember how I was approached for [Relative's] organs. I know we were in a room. I do not know who approached me. I do not know what I was feeling . . . we were so upset and she explained the procedure or something.

A similar account from another participant suggested this feeling was fairly common:

I do not know who the person was who originally spoke to me about donation. . . . But I am sure they put it to me in a good gentle way . . . I am sure he explained it to me that day but things were not hitting home and whatever I got told that day did not stick with me very well.

It was not until after the donation that some of the participants started to ask questions on events surrounding the donation and brain death criteria. In the initial and follow-up interview a number of participants asked me questions pertaining to brain death criteria. Another participant was unsure about what part of the eye the cornea was, but remember this as a possible donation.

Although participants had some prior knowledge of organ donation that they had obtained from newspapers and television, they still referred to a lack of understanding of

the diagnosis of brain death. They described a conflict between an intellectual and an emotional acceptance of the diagnosis. Although they realized that their loved one was dead, they described an emotional struggle to accept the diagnosis. The participants attempted to identify clinical evidence of life to support their belief that their loved one was alive. The participants attempted to identify physical signs of life, such as breathing, a heartbeat, and body warmth, all of which were not associated with the traditional definition of death. The search for visible signs of life reflected the donor family's lack of understanding of the definition of brain death, their inability to process the information, and their disbelief in what had happened to their loved one. These signs of life were used as a means to confirm the existence of life, to deny the diagnosis of brain death, and to give them a sense of hope for a recovery. This is summarized in a participant's comment, "The heart is still beating but why isn't [Relative] alive."

Although all the participants did have some knowledge of brain death, the paediatric organ donors in particular did not grasp the significance of what it meant. These participants frequently questioned the validity of the diagnosis and its implications on their child's prognosis, as echoed in this comment:

They said that [Child] was brain dead and I said they were wrong and they could not be right. [Child] was just in a coma and how could you know the difference if somebody was in a coma or brain dead. Maybe I am just grasping at straws but if you poke somebody who is brain dead and poke somebody who is in a coma which causes a reaction? . . . Brain death and coma are difficult to distinguish because I was always told where there is a heart beat there is life . . . . They said that in their authority that brain death meant I guess as simple as it sounds, that [Child's] brain was dead. [Child's] heart was working but there was no function in this brain.

I do not know but does that make [Child] dead? How are they going to determine if [Child] is brain dead, if [Child's] heart is still beating?

Overall, all participants were shocked by the suddenness of their loved one's death. They described being overwhelmed by the very idea of the death and had difficulty processing information throughout the experience. Although they all consented to organ donation, many of them had difficulty emotionally accepting the death.

*A Positive Outcome: Wanting Something Good to Come from the Death*

This theme reflects the efforts of the participants to make something good come out of the death of their loved one. This is one of the main reasons why participants consented to organ donation. Prevalent throughout a large part of the participants' narratives were thoughts of wanting something good to come out of their spouse's or child's death. Despite the obvious tragedy of the deaths and the difficulty they had with accepting this death, the participants continuously referred to the positive aspects of the organ donation experience. The idea of helping another individual was identified as one of the main reasons influencing their decision to donate.

Almost all of the participants felt that the decision to donate was based on the fact that it would help someone else continue to live or to improve the quality of the recipient's life in some way. This feeling of "helping others" gave the participants a sense that their loved one's death was not in vain, but in fact was at least beneficial to another individual. The donation was perceived as giving some further meaning to the life of the

deceased and in some ways helped the donor to rationalize the death. All the participants reported a sense of comfort and peace from the donation.

Imagine being able to give somebody sight, to see through his eyes. . . . If you think about it he was giving somebody else sight and it felt good.

Just think about it . . . It [donation] could save somebody else's life or help somebody. . . . It happened for a reason and if there is anything any good to anybody why wouldn't you give so somebody could benefit from it.

Something so selfish back then turned into something so good because it did help four people and knowing that those four people are doing good makes my [Child's] death worthwhile.

The participants also described a sense of comfort derived from the fact that they were fulfilling the wishes of the deceased. They believed organ donation was something that their family member would have wanted, "It would have given him a lot of pleasure to be able to give somebody the gift of sight," and "I am sure my husband would have wanted me to do this." Another participant recalled a conversation with her spouse where they had been joking about organ donation. She stated in summarizing her husband's comments, "There would be no organs of any good to anyone after he had died." The very fact that some of his organs were used for donation made the experience more positive for the participant, and, for her, helped with her spouse's death.

Participants constantly referred to characteristics of the deceased that influenced their decision to donate their loved one's organs. These characteristics confirmed that they were making the right decision and that organ donation was something that the deceased would have wanted. One mother described her child as, "Having a kind and

giving nature ...we knew that [Child] would have wanted to help other people... [Child] was very kind and generous." Another parent stated, "If [Child] were alive [Child] would have given one of [Child's] kidneys that is how good of a person [Child] was." Another participant referred to a spouse as "a very giving" person.

The sense of a positive outcome was from the "giving" of the organ and knowing this giving was an attempt to help the recipient, it did not necessarily come from how well they knew the recipient was doing. However, all the participants talked about the recipients of their loved one's organs. Mixed opinions were expressed on whether they wanted contact with the recipient or not. Although some participants were unsure if they wanted any contact with the recipients, they felt that just knowing the recipient was "doing okay" gave them a sense of well-being and helped them deal with their loss. This information about the knowledge of the recipient's health and how the donation had changed their lives reconfirmed the participant's feelings of helping others and reinforced that they had made the right decision. It also gave the participants a visible sign that their efforts were worthwhile and thus gave them a sense of gratification. The recipients were seen as being given another chance at life, an improved quality of life, or the return of physical functions (i.e. sight). A participant who received a letter of thanks from a recipient described it as, "Giving me a sense of peace, making it [the donation] worthwhile" and helping her get through the Christmas holidays. Another participant felt strongly that she would have liked some contact with the recipients and knowing with some greater certainty that they were doing fine. She felt this would help her better

deal with her loss. In a letter to a recipient, a participant summarized the significance of the news of how a recipient was doing:

I know you may not understand but knowing your continuous improvement makes it worthwhile. You are a few years younger than my dad but when we received the news that [Child] helped four people I cannot begin to tell you how good it felt for me and my family. My Dad is so proud and we have gotten so much peace from it. . . . I thank you for the card and the letter it took me to a place that I really needed to be.

Overall, a large part of the participants' narratives focused on the positive outcomes of the donation. Participants not only reported a sense of comfort and peace from knowing that their loved one's death helped another, but felt that it gave some meaning to the death. They also felt a deep satisfaction that they had followed the wishes of the deceased.

#### *Creating a Living Memory: They Are Living On*

Memories of a deceased family member are sustaining to those who are left behind. It is a way to assist them in the grief that follows a loss, such as, death. While most of these memories are private or shared with other family members, many times after death, we search for ways to promote these memories or make them more public, for example, making donations in memory of a loved one or having something named in their honour if a public figure. For the participants I interviewed organ donation was a means of having a positive memory related to their relative. This theme reflected the belief of the participants that by donating their loved one's organs, it helped keep the

memory of the donor alive. A common idea that emerged through the narrative descriptions was that by donating a loved one's organs the participants ensured that in some sense this person was still "living on" through the recipient. The idea that the donor was not "really dead" brought a sense of peace to the participants and helped them deal with their loss.

The fact that their relative's organ(s) still functioned, although in another person's body, was viewed as evidence that "a little piece" of their loved one was alive, and represented a living memory of the deceased. The creation of a living memory was viewed as a positive aspect of the experience and had a significant influence on the participant's decision to donate as echoed in these comments:

In our minds we thought that it would keep [Child] alive in somebody else. So, that was our main reason for donating. . . . It was just that [Child's] memory or parts or [Child] were still alive.

The thought of parts of [Relative] going on still living, that is what helped the family to donate [Relative's] organs. . . . We thought that it would keep [Relative] alive in somebody else. So that was basically the main reason for donating . . . just that [Relative's] memory or parts of [Relative] were still alive and that is the bottom of why . . . That was my idea of donating plus that it was very helpful for a lot of people.

This "living memory" was a good reminder of the deceased's life and ensured that the some characteristics of the donor were still alive. It also confirmed the benefit of the donation, which was one of the main reasons influencing the decision to donate. One participant stated that she felt like she could talk about her spouse like he was still alive and that made her feel good.



I can talk about [Relative] like he is still here and I guess in a way parts of him are....There was still a part of him that was not going to be dead. I was thinking and feeling that he was not going to be dead.

Overall, the concept of “living on” was fundamental in helping the participants deal with their loss and gave them a sense that in some ways their loved one was not really dead, but in some way was continuing to live through the recipient. This creation of a living memory had a significant impact on the decision to donate and the family’s ability to cope with the actual death of the person.

*Buying Time: I have to Keep Them Alive as Long as Possible*

This theme summarizes the efforts by some of the participants to keep their loved one alive as long as possible. The participants’ who donated their children’s organs described a concept of “buying time.” By consenting to organ donation their child would be left on life support longer. Thus, the family had “bought” more time to confront the diagnosis of brain death, time for family members to come to terms with the death, and to say good-bye to the deceased. A mother explained her decision to donate her child’s organs as a means to “buy time” to prove that the diagnosis of brain death was wrong. She recalled that life support would be disconnected unless she had consented to organ donation. Since it would take the transplant team five hours to reach the hospital she believed it would be enough time for her child to wake up from a coma, and enough time to show that the physicians were wrong, that her child was not brain dead. This reaction of “buying time” represented the denial of one mother to accept the death of her child and

a plea to extend life support measures in a desperate hope that the child would recover.

She summarizes her efforts to buy more time in the following comment:

The one thing that swayed me was that I knew that it would take those people from [City] five hours to come and take those parts and I said OK. Well, I thought there is nothing wrong with my [Child]. [Child] is just in a coma and is going to wake up anytime and tell these doctors that I am going home with Mom. . . . It never did happen but it gave [Child] another five hours to show that those doctors had to be wrong. It just could not be true.

Another parent had similar thoughts of “buying time.” By consenting to organ donation her child would not be disconnected from life support as quickly as quickly as if she did not agree. This was a conscious strategy to give the family time to say good bye to the child and come to terms with the death as reflected in her statement, “It was like a car accident when you die instantly, like you never got to say goodbye to [Child].” Even though the participant had accepted the prognosis of brain death, she felt that as long as her child was on life support the child was still here, on earth, with the family. She recalls that the decision to donate, “Kept [Child] here with us a bit longer.” It was not until after the funeral that the realization that her child had passed away started to emerge.

The extra time that parents had “bought” with their children when they consented to organ donation allowed an opportunity for the parents to relive the events prior to the tragedy and to perhaps start coping with their loss. During this time the parents reflected on their role as parents. The death of the child was viewed as a result of their failure as parents to protect them. Their narratives reflect a sense of self-blame rooted in the belief that their negligence contributed to their child’s death. One parent blamed herself for not

making her child take a helmet outdoors to play, which resulted in a head injury when riding a friend's bike. She questioned why she did not think that her child would ride a friend's bike. Another mother cried as she wished that she had taken her child to the hospital when the child had complained of vague flu-like symptoms. She felt that she had waited too long before seeking medical attention. These feelings of self-blame contributed to the constant search for why their children died and the constant replaying of the events that led to the diagnosis of brain death. By "buying time" the parents were given the opportunity to start and make sense of the events prior to the death, to clarify their role in the tragedy, and to attempt to redefine their role as a parent.

The failure to protect their children was reconfirmed by a sense of powerlessness and lack of control over their child's care when the attending physician advised them that the decision to disconnect life support was inevitable and may not be the family's decision. This was reflected in these parents' statements, "They were not going to give me a choice any ways" and "I always thought that you had a choice to terminate life. I never dreamed that the doctors could go over your head." The parents felt that they were being stripped of their legal parental rights and moral obligations to protect and nurture the child as echoed in the following comment:

I said what if I do not want the life support taken away, what if I want it left there. He said that might not be your decision. I guess the doctors were going to make the choice of taking away the life support, it was out of my hands. I was not allowed to make the choice there.

The last efforts of the parents to preserve their child's life and protect them from harm were to first deny the diagnosis of brain death and secondly, to consent to the

donation in order keep them alive as long as possible. In summary, the idea of buying time for the parents was an attempt to bargain for time for their child to recover from the injury and time for the family members to accept the death. By "buying time," the parents were given more time to come to terms with their loss, time to process the information provided, time to relive the events prior to the death, time to identify their roles as parents, and time to reflect on the implications of their decision prior to dealing with the reality that their loved one had died. This time in itself, perhaps, was a way to cope with their loss. However, as noted, only two of the participants were parents.

*It's Your Decision: Support Networks Make it Easier*

The participants in the study frequently spoke of both professional and family support networks as having an impact on their organ donation experience. Professional networks included doctors, nurses, and organ procurement staff (OPC). Family networks were their immediate family. In some instances they mentioned friends helped as well. The majority of participants referred to family and friend support networks as a positive feature of the experience. Professional support networks were described as contributing to both positive and negative aspects of the experience.

Family and friends were identified by all of the participants as being the main source of support. Several participants identified certain family members and friends as being very supportive and described them as, "a tower of strength." A participant described the very presence of the immediate family as supportive and helpful in making the decision to donate. Several participants described the decision to donate as a

collaborative family effort similar to this participant's description, "I spoke to my other children and my husband and we all agreed that it would be a good idea." A participant who received a lot of support from her family spoke of approaching each family member individually to ask their opinion on organ donation. However, she stated that she had already made the decision to donate prior to approaching the family. For her it was a personal decision. Including the family in the decision-making process was perceived as being respectful and polite as reflected in this statement:

My family was standing around and I said what do you think, whether they agree or disagreed did not really matter because I knew that I had five hours, but it was still nice going to my family.

Although the very presence of the family was viewed as supportive by all of the participants, they believed that the decision to donate was ultimately their decision alone. One participant spoke of this solitary approach, "It was a decision that I had to make myself, nobody could understand what I was going through."

Only one participant described the interaction with some family members as not supportive. She described her in-laws' initial lack of support of her decision to donate. She remembered them saying, "Why put him through anything else" and stated in referring to her husband's family, "a few of them were not too fussy." This lack of support was attributed to their limited understanding of medical terminology and not realizing, "how important it is to donate." Despite this, other members of this same family, who had stayed with the participant during the experience, were perceived as very supportive.

For another participant the support of her friends had a significant impact on her experience. She recalled the great amount of support that she received from her husband's friends. Being a part of this social circle she was in was viewed as a type of support and provided an opportunity for the participant to continue some of the activities that she and her husband had engaged in prior to his death. This aided in the grieving process. Just being able to partake in these activities maintained the memory of her husband and represented the life that they had together.

The participants acknowledged the interaction with health care providers as important and as having an impact on their experience. Professional networks were described as having both positive and negative effects on the organ donation experience. Several participants voiced dissatisfaction with the lack of opportunity to be involved in decision making regarding their relative's care and not being informed of their relative's condition or of the medical procedures carried out.

A participant who was struggling to understand how the death could have happened spoke of the lack of information concerning her spouse's deteriorating condition and the explanation of ongoing medical treatment, "I really have to wonder about the medication he was getting, nothing was explained along those lines. . . . I knew that his blood pressure went up, did something drive it up or whatever?" She continues saying, "I was not told anything. . . . it seemed like if I asked questions nobody wanted to answer them."

Similar feelings were voiced by another participant who felt that lack of medical care coupled with a poor explanation of her [child's] condition contributed to her anger

and disappointment towards health care providers. She described being left in the waiting room while her [child] unknowingly was moved to intensive care. In addition to this, she and her husband were mistaken for the parents of a different child and, thus, they received no information on their [child's] condition. Finally, the participant was notified that her [child] was brain dead by telephone. Upon arrival at the hospital, she was also notified that the attending physician had left the facility. A sense of abandonment was echoed in her comments summarizing the experience:

The doctor he was gone, he was not there he did not wait for us to come out or anything. We tried to get a little information out of the nurse that was attending to [Child]. So we stayed there that night. All we knew was that [Child] was still in a coma, they were keeping life support on [Child], and [Child] was becoming brain dead. . . . And that was when they asked us if we wanted to donate [Child's] organs. . . . They did not tell us that [Child] was dying. I felt like they were putting me off. . . . I was let down. . . . You put your trust in them and then get let down. . . . [Child's] breathing stopped several times and the nurse did not call the Doctor. I do not think that [Child] should have been left with the nurse to attend to when [Child] was in that severe condition.

Several participants referred to the support they received from health care professionals who were required to play the dual role of caregiver to the donor and support personnel for the family. A participant referred to health providers as "very supportive and doing everything that they possibly could to help me at that time." Another participant described care given to her husband as "excellent."

Less frequently mentioned was the support the nurse provided to the organ donor families. There was only a single participant who referred the nurse as having a

significant impact on the experience. Nursing care was viewed as trying to make the participant aware of the loved one's deteriorating condition and prepare her for the loss.

Simple gestures were seen as acts of support, as summarized in these comments:

There was one nurse who knew that it was grim. I was just bubbling with enthusiasm and positively just coming out of my ears. I was just constantly repeating myself. She was trying to let me know to be prepared for the worst so I would not have such a hard fall. She was doing it in little ways like remarks of negativity. . . . Like there has been no movement and I would get really upset and mad.

This participant reflected on a similar incident where the nurse attempted to prepare her for possible outcomes of a head injury:

There was the lady from [the] Emergency Room who was in charge of head injuries that said I had to look at it rationally. She sat me down and said this may happen just put it in the back of your mind. We are all praying that it doesn't, but just put it there. She brought me facecloths. I mean she was working in the Emergency Room too, but she was extremely good, making sure that I was alright.

Although participants did not recall specifics regarding their interaction with Organ Procurement Coordinator's (OPCs), both of whom are nurses, they described the experience as positive. The OPCs were described as caring individuals who provided donor families with support, information on their relative's condition, and the organ procurement process.

I do not know what [OPCs] looked like . . . I was so confused I really do not remember. But I do remember that they were really nice to me.



Another participant voiced similar thoughts:

[OPC] was wonderful . . . . When they were taking [Child] to the OR that night we had to say our good-byes to [Child], [OPC] was there and [OPC] was really supportive. [OPC] was explaining to us how the procedure was going to take place and [OPC] let us know that they were not going to cut [Child] up and discard [Child] or anything. That the surgery was going to be done like any other surgery, that was good to know cause you wonder what they are going to do with [Child].

Many of the participants remained in contact with the OPC(s). The OPCs were viewed as a critical link to the recipients, providing up to date information on their conditions. One participant stated:

I was really glad that [OPC] was there to explain all of that and even after it was done, before and during you could always call [OPC] . . . I call [OPC] every year just to find out how everything is going with the recipients.

In summary, participants described their support networks as having both positive and negative effects on the organ donation experience. Participants acknowledged the emotional support provided by informal networks as helping them cope with the loss and reconfirming their decision to donate. The information and emotional support provided by the health professionals was critical in helping the individuals in their struggle to deal with the reality of the loss and provided information required to make an informed decision. Dissatisfaction resulted from the lack of communication and information provided by some health care professionals.

### *The Essence*

The themes that were developed from the participants' narrative descriptions were the struggle to acknowledge the death, positive outcomes from the death, creating a living memory of the deceased, buying time and the significance of support networks. It is the integration of these themes that led me to identify an overall theme or essence of this experience as *creating a sense of peace*. The participants' descriptions of the journey to create a sense of peace enabled myself, and I hope the readers of this text, to gain a greater understanding of what this experience was like for the individual family members who donated their loved one's organs.

The narrative descriptions represented the disruption in the participants' everyday "lived" sense of peace and their struggle to restore it. This struggle to create a sense of peace was manifested in the participants' descriptions of being shocked and of having feelings of disbelief that their relative had indeed died. This period was filled with questions surrounding the validity of the diagnosis of brain death, the inability to comprehend information and poor recollection of events surrounding the organ procurement process. Several of the participants expressed hope for a full recovery as they denied the death in order to maintain a sense of temporary peace. The struggle to create a sense of peace was threaded throughout all the participants' narrative descriptions and lead to the emergence of other themes in an effort to cope with the death, start the grieving process, and restore a peaceful balance.

In order to create a sense of peace, all of the participants felt the need to make something good come out of the death. Thus, they searched for positive outcomes of the death. Positive outcomes were identified as helping another individual live, improving the recipient's quality of life, and fulfilling the wishes of the deceased. These positive outcomes not only contributed to feelings of peace, but also reconfirmed that the participants had made the right decision and gave some meaning to the death. By focusing on the positive outcomes, the participants tried to re-establish a sense of order and balance in their lives.

The participants who had donated their child's organs described a traumatic disruption in their inner peace. These participants struggled with feelings of self-blame, powerlessness, guilt, and denial as they attempted to restore a temporary sense of peace by "buying time." This temporary peace gave them time to accept the death, say their good-byes, and provided an opportunity to contest the diagnosis of brain death, in the hope of a full recovery. It also provided the foundation for reflection on the events, time to try and make sense of the death, and time to develop coping mechanisms to deal with their loss. This sense of temporary peace itself is a coping mechanism providing the parents with more time to deal with their loss.

Evidence of creating a sense of peace is rooted in the participant's efforts to create a living memory of their loved one. By creating this living memory, the hope that their loved one would be "living on" through the life of the recipient emerged. The participants believed that this living memory would be a constant reminder that the donor was still alive. This idea was significant in helping the participants deal with their loss. It created a

sense of peace in that they were able to create a living memory symbolizing the positive outcomes of the death and the life of the donor.

All the participants referred to their support networks and how these networks helped them cope with the death and organ donation experience. The sources of support most valued by the participants were family and friends, and health care professionals. In describing their experiences with support networks, participants highlighted those encounters where the nurse was in the role of the OPC. Family and friends were also perceived as providing emotional support. OPCs were viewed as playing the dual role of clinical expert, providing necessary information on procurement procedures, and psychological muse, providing emotional support. Support for the participants was viewed as a collaborative effort to create a sense of peace.

Individual family members who experienced the death of their loved one and the decision to donate their organs were often faced with a sudden unexpected loss that upset an existing sense of peace encompassing their everyday lives. This disruption forced them to participate in a struggle to restore the loss of peace and, thus, find meaning from their experiences. The solutions to restore this sense of peace are rooted in the participants' efforts to focus on the positive outcomes of the donation, buy time to come to terms with the death and to say good-bye, to create a living memory and finally, to draw on available support networks.

## Chapter 5: Discussion

This chapter is a discussion of the findings from the study. There are two aspects to this study. The first is to explain the findings by exploring the themes more fully. The second is to relate the findings to the literature on organ donation, and in particular to the literature on the family's experience with organ donation.

### *A Struggle to Acknowledge the Death: This Cannot be Happening*

This theme described the struggle of participants to acknowledge the loss of their loved one and accept the diagnosis of brain death. The participants of this study were overwhelmed with the idea that their loved one was dead, and described the experience as disbelief that their loved one had actually died. They found it difficult to accept the diagnosis of brain death and to process the information given. This was attributed to the suddenness of the death, and the age of the deceased, particularly in the cases of the paediatric donors. Responses similar to those participants in this study were reported in the literature. Other researchers have described individuals who have lived through the experience of organ donation as being overwhelmed with feelings of shock, disbelief, uncertainty, and disappointment (Pelletier, 1992; Pelletier, 1993b; Robertson, 1998; Shih et al., 2001b), resulting in difficulty accepting the diagnosis of brain death (Franz et al., 1997) and the inability to process and retain a large amount of factual information provided (Cleiren & Van Zoelen, 2002; Douglas & Daly, 1995; Riley & Coolican, 1999; Tymstra et al., 1992; Pelletier, 1992; Steed & Wagner, 1998; Shi et al., 2001b). The

struggle described by the participants is reflected in Frid et al's (2001) account of what they label the uncertain vigil and the arduous struggle.

While a large amount of the literature suggested a positive correlation between approach methodologies and organ donor consent (Culter et al., 1993; DeJong et al., 1998; Gortmaker et al., 1998; Helander et al., 1995; Kay & Barone, 1998; Klieger et al., 1994; Marisma & Escalante, 2002; Von Pohle & Linda, 1996) the participants in this study failed to support this relationship. The participants did not discuss approach methodologies as having a significant impact on their organ donation experience or their decision to donate their loved one's organs. The participants did not remember the specifics of who approached them, nor did they describe significant relationships between the actual setting where the request for donation took place or decoupling on their decision to donate. The events were described as being vague and foggy. In several cases it was not until the organs were retrieved for donation that the participants requested information about the medical condition resulting in their loved one's death, brain death criteria, organ procurement process, and organ distribution. This finding brings into question how "informed" the consent is when it comes to organ donation, at least for some of the participants.

The participants of this study described a conflict between the intellectual and emotional acceptance of brain death. The struggle to accept the diagnosis of brain death was rooted in their perceived definition of death. Despite being told that their relative was dead, visual signs of life, such as having a heart beat and respirations, confirmed the participants' belief that their loved one was indeed alive and had the potential to recover.

This conflict has been discussed in the literature (Frid et al., 2001; Franz et al., 1997; Pearson et al., 1995) and is attributed to a lack of understanding of the concept of brain death, which may result in refusal to consent (Franz et al., 1997). The findings of this study challenge this claim. Although the participants did identify a lack of understanding of brain death as one factor that inhibited acceptance of the death, they still donated. This is similar to the findings of Savaria et al. (1990) and Cleiren and Van Zoelen (2002), as well as other researchers who reported no association between the degree of understanding of brain death and consent (Frutos et al., 2002; Pearson et al., 1995; Siminoff et al., 2002). This finding suggests that when individuals make the decision to donate a thorough understanding of brain death criteria may not exist prior to giving consent. Although knowledge of brain death may have an impact upon their decision to donate it is not the most significant factor influencing their decision. The participants focused on traditional connotations associated with death rather than physiological evidence of brain death. It is not until they started to gain an understanding of the meaning of brain death later that they started to ask questions surrounding the physiological manifestations of brain death.

*A Positive Outcome: Wanting Something Good to Come from the Death*

This theme captured the participants' desire to want something good to come out of the death of their loved one. All of the participants associated the decision to donate with feelings of helping others, which is also reported in the literature (Bartucci &

Bishop, 1987; Exley et al., 2002; Painter et al., 1995). The idea of helping others gave the participants a sense of peace and comfort similar to that described by researchers investigating how organ donation hindered or facilitated the grieving process (Bartucci & Seller, 1986; Christopherson & Lunde, 1971; Fulton et al., 1977; Morton & Leonard, 1979; Pelletier, 1992).

Participants also reported that knowledge of the deceased's wishes and their personal characteristics had a significant impact on their decision to donate, as found in earlier research studies (Bartucci & Bishop, 1987; Burroughs et al., 1998; Cunningham, 1998; DeJong et al., 1998; Exley et al., 2002; Frutos et al., 2002; Martinez et al., 2001; Painter et al., 1995; Siminoff et al., 2001). The belief that organ donation was something their loved one would have wanted guided the participants' decision to donate. Common descriptions of the donor's personal characteristics, such as "caring" and "giving," reinforced the idea that they were fulfilling the wishes of the deceased. By fulfilling the wishes of the deceased and helping others, the participants were able to rationalize the death and give some meaning to the deceased's life, which in itself was seen as a positive outcome. Finally, the participants viewed the reports on the improved quality of life of the recipients as proof that they had made the right decision and had achieved a positive outcome of their loved one's death. This facilitated the participants' ability to cope with the loss of their loved ones, which was found by several researchers (Bartucci & Seller, 1986; Pelletier, 1992; Shanteau et al., 1992).



*Creating a Living Memory: They Are Living On*

One of the factors that clearly influenced a participant's decision to donate a loved one's organs was the idea of creating a living memory of the deceased. No reference was found in the literature specific to creating a living memory. The participants in this study believed that by donating their loved one's organs they were keeping a small part of the deceased alive, which was living on through the recipient. This idea that characteristics of the deceased were "living on" through the recipients has been briefly documented (Exley et al., 2002; Siminoff & Chillang, 1999; Steed & Wagner, 1998). There is little discussion on the significance of the concept of "living on" and its influence on the organ donation decision-making process.

The paediatric organ donor families in this study were more interested in knowledge of the recipients and exchange of information on their progress than the families of adult donors, a finding similar to that of another research study looking at paediatric organ donation (Weiss, Fortinsky, Laughlin, Alder, Mudge & Dimand, 1997). The paediatric organ donor families in this study had more frequent contact with the organ donor program and requested more information on the health status of recipients. This reflects the parent's continued need to ensure that their child is living on and that their memory remains intact. The information that the recipient(s) are doing well created a sense of peace and comfort for the families.

These two concepts were the main factors that influenced the participants' decision to donate. They contributed to the participants' attempts to create a sense of

peace and comfort and, thus, facilitated the grieving process. The idea that organ donation may facilitate the grieving process has been addressed in the literature (Bartucci & Seller, 1986; Fulton et al., 1977; Pelletier, 1992; Shanteau et al., 1992; Steed & Wagner, 1998).

*Buying Time: I Have to Keep Them Alive as Long as Possible.*

Another finding of his research study was the concept of "buying time." The narrative descriptions of the two paediatric organ donors in this study introduced the idea of consenting to organ donation in order to "buy time." This theme captured the efforts of the parents to buy time in order to dispute the diagnosis of brain death and to say good-bye to their child. No discussion in the literature was found related to this concept nor did any of the reviewed literature reference "buying time" as a coping mechanism. Only one research study briefly notes the lack of opportunity to say good-bye (Frid et al., 2001).

The findings of this research study suggested that paediatric organ donor families have a unique organ donation experience as compared to families of adult organ donors. This experience is expressed in their efforts to buy time. The paediatric families gave a traumatic account of the events that surrounded the death that emphasized its unexpected nature. They described strong feelings of disbelief, shock, and denial. They manifested their lack of understanding of brain death in the denial of the diagnosis and efforts to buy time. These participants expressed feelings of powerlessness, self-blame, and failure as a parent, invoked by their lack of participation in the decision to discontinue life support measures, and in their failure to protect their children from harm. The continuous effort to

buy time was viewed as a time to resolve these feelings, to try and gain control over their child's life, protect their child from harm, and identify the cause of the child's death. Similar responses with paediatric organ donors were reported in one other research study (Oliver, Sturtevant, Scheetz & Fallat, 2002).

*It's Your Decision: Support Networks Make it Easier*

This theme captured the significance of support networks in helping individual family members cope with their loss and providing support through out the organ donation experience. Participant's accounts of informal networks supported findings in the literature that identify family and friends as a core means of support through the experience (Frid et al., 2001; Pelletier, 1998; Shih et al., 2001b; Warren, 2002). However, the participants in this study described the influence of family and friends on the organ donation decision as limited, despite asking them their opinion on the decision to donate. The participants felt the decision to donate was their decision to make alone. In several accounts the participants had made the final decision to donate prior to approaching the family.

Physicians, nurses, and OPC were referred to as formal support networks. Several participants expressed dissatisfaction with the lack of medical care, poor communication, and information on their relative's condition. Similar findings were noted by other researchers (Pelletier, 1992; Warren 2002). Many of the participants describe the stress associated with dealing with health care professionals in a similar way as the participants in Pelletier's study. Information was communicated in an insensitive manner (e.g. "over the phone"), in terms they did not understand (e.g. "becoming brain dead"), and with little emotional support available (e.g. "I was alone when they told me"). However,

despite reported dissatisfaction with health care professionals, the participants still chose to donate their loved one's organs. This contradicted the literature linking dissatisfaction with health care professionals and refusal of consent (Siminoff et al., 2001; Martinez et al., 2001; DeJong et al., 1998, Weiss et al., 1997).

Comments from participants revealed that when formal networks were viewed as providing proper information, giving good medical care, and having a caring attitude they were perceived as supportive and viewed in a positive manner. Participants gave little reference to the role of the nurse only in the capacity of the OPC. These findings necessitate further research given the extensive literature on the impact of the nurses' communication skills on the organ donation experience (Ingram et al., 2002; Kiberd & Kiberd, 1992; McCoy & Argue, 1999; Molzahn, 1996; Molzahn, 1997; Pelletier, 1992).

The OPCs were seen as a critical link in the organ donation experience and as having a significant impact on the participant's ability to cope with the death, their understanding of the organ procurement process and in making the decision to donate their loved one's organs. The significance of the OPC in supporting families throughout the organ donation experience and their positive impact on organ donation rates has been documented in the literature (Cunningham, 1998; DeJong et al., 1998; Gortmaker et al., 1998; Marmisma & Escalante, 2002; Siminoff et al., 2001).

### *The Essence: Creating a Sense of Peace*

The integration of identified themes represents the participants' efforts throughout their organ donation experiences to create a sense of peace. Their everyday sense of peace was disrupted the instant they were notified that their loved one was brain dead. Although previously discussed literature described the feelings associated with the

disruption of the organ donor family's sense of peace there is a dearth of literature which refers to the efforts to create or restore this sense of peace. Reviewed literature briefly referred to the act of donating as giving the deceased relatives a sense of solace and comfort at a time of great loss (Douglass & Daly, 1994; Steed & Wagner, 1998), as facilitating the grieving process (Bartucci & Seller, 1986; Christopherson & Lunde, 1971; Fulton et al., 1977; Morton & Leonard, 1979; Pelletier, 1992; Shanteau et al., 1992), and as providing families with an opportunity for disclosure (Pelletier, 1993a). The identification of creating a sense of peace as the essence of five individual family members' organ donation experiences contributed knowledge to the existing body of nursing knowledge and necessities further qualitative research inquiry into this phenomenon.

### *Summary of the Discussion*

From an extensive analysis of the narrative descriptions of five individuals who have donated their relative's organs and a review of the literature on organ donation, I believe there are several key concepts that contribute to and support the existing body of knowledge surrounding organ donation. Firstly, the psychological distress described by the participants in this study is well documented in the literature. Not only were the participants in this study shocked at the diagnosis of brain death, but they also failed to process pertinent information given to them during critical periods.

Secondly, although the literature suggests a positive correlation between approach methodologies and donor consent, the participants in this study did not describe them as

significant in their experience. They vaguely recalled donor approach methodologies – who approached them, the timing of the request, or if the request was decoupled. The only reference to an approach methodology was the positive impact that the OPC had on their experience as a source of emotional and information support.

Thirdly, even though the participants in this study, as in the literature, described a lack of understanding of the concept of brain death, they did not identify this as the most significant factor in making their decision to donate. For the participants of this study, the main factors influencing their decision to donate were the positive outcomes of the donation such as helping others, following the deceased wishes, characteristics of the deceased, parts of the deceased are living on, and the fact that they were creating a living memory of the deceased.

Fourthly, a significant difference was noted between the adult donors and paediatric donors. Paediatric donors described the experience as more traumatic and unexpected. The parents denied the diagnosis of brain death and searched for physical evidence to support their belief that their child was not dead. This denial was rooted in the parents' efforts to buy time to initially dispute the diagnosis, followed by time to come to terms with the loss. A vast amount of literature exists looking at adult donors with little reference to paediatric organ donors; therefore, more research is required in order to gain a fuller understanding of the concept of “buying time”, which was a major theme emerging from the data on paediatric donors.

Finally, these individuals experienced a disruption in their everyday “lived” peace, which they continuously struggled to restore. All of the participants viewed organ

donation as a means to try and restore this balance by focusing on the positive aspects of the donation. There has been no reference to creating a sense of peace in the reviewed literature. However, the literature does acknowledge the solace and comfort derived from the donation, as well as its benefits on the grieving process.

## Chapter 6: Limitations And Implications For Nursing

The findings of this phenomenological study have significant implications for future nursing education, practice, and research due to the limited knowledge and insight into the individual family members who have donated their relatives' organs. This chapter will first discuss limitations to this research study. This is followed by a brief discussion of implications of the study for nurses in practice, research, and education. The chapter concludes with a summary of the study.

### *Limitations*

The goal of phenomenology is to describe a lived experience such as organ donation. It is this lived experience that gives meaning to the phenomenon as perceived by its participants. There are two limitations to this study with the first being the selection of participants. Given that the research findings suggested a difference between families of adult organ donors and pediatric organ donors, interviews with more paediatric organ donors may be required in order to gain more insight into this difference. Inclusion of more parents would help to ensure richness of the data, and perhaps lend greater support that I captured the meaning of the experience of organ donation for both adult and pediatric donor families.

The second limitation is that due to geographic confinements and time constraints, I was unable to work as closely with the participants as I would have liked to in order to ensure that I had obtained a full account of the participant's organ donation experience.



While every effort was made to have as much contact as possible, I would have preferred more extensive contact, even though telephone calls did help increase contact.

### *Nursing Practice*

The study provides valuable insights into the experience of organ donation, which I hope will assist nurses in planning and delivering care to family members who find themselves faced with the option of organ donation. Therefore, I believe the findings of this study have many implications for nursing practice.

Several of the participants perceived health care professionals as not being supportive. It is important for nurses to recognize the emotional conflict that these individuals experience and provide support to help them cope with their loss. Nurses can then develop therapeutic listening skills to help them gain a fuller understanding of the organ donation experience. The knowledge attained through listening to the stories of organ donors will help nurses identify and prioritize the perceived needs of these individuals and clarify any areas of ambiguity, such as brain death criteria. Nurses need to be aware of the significance of the decision to donate for the participants and assist these family members to focus on the positive outcomes of the donation in an effort to instill a sense of peace and to facilitate the grieving process.

Nurses also can increase their awareness of the different responses of pediatric organ donors and adult donors to the diagnosis of brain death. The participants who donated their children's organs had more difficulty accepting the death than participants who donated adult organs. They described feelings of powerlessness, guilt, self-blame, and failure as a parent. Nurses can help ensure that individual family members are invited

to participate in all decisions on the care of their loved one, giving them the opportunity to take charge of their loved one's destiny, thereby instilling some sense of control. This in turn, will help families create a sense of peace. Recognizing this difference can facilitate the development of a plan of care that is individualized and reflective of the individual's needs, based on the uniqueness of the experience and relationship to the donor.

Participants in this study frequently referred to a lack of understanding of brain death and medical procedures related to the inability to comprehend information given. Nurses must be able to identify knowledge deficits in these individuals and provide required information repetitively in a clear and concise manner, using language familiar to the individuals. Since many of the participants report a discrepancy between intellectual and emotional acceptance of brain death, nurses need to be able to explain brain death criteria and give time to the family members to work through this definition. Nurses must work with an interdisciplinary team to ensure families understand the clinical signs associated with brain death, such as having a heart beat and breathing, since many of the participants refer to these as clinical evidence of life, facilitating their denial of the death.

Family members who are faced with the death of their loved one and approached for organ donation described being overwhelmed with the entire experience and reported difficulty to comprehend information. Nurses can act as an advocate not just for the donor, but also for the donor family. Nurses will be able to help ensure that individuals faced with the organ donation decision understand the required information in order to

make an informed decision, receive that information in an appropriate manner, and have the information reinforced as required. This will support the donor families to cope with their loss and make decisions regarding their loved one's care.

Nurses need to take an active role in the development of quality assurance management approaches to monitor and evaluate on site organ donation strategies. Reflective of a holistic health care system, nurses need to help build multidisciplinary partnerships that encompass a framework for delivery of organ procurement programs. This framework is needed to ensure that organ donors and their families receive appropriate clinical and emotional management, as well as follow up bereavement services, as suggested by The National Coordinating Committee for Organ and Tissue Donation, Distribution and Transplantation (1999).

Since communication of bad news is a process which requires not only skilled communicators but a receptive audience, nurses must be able to determine the most appropriate time to approach the individual family members for consent. Nurses need to evaluate whether or not the relative's emotional state will affect their ability to hear and comprehend the information given, as described by the participants of this study. This is accomplished by approaching the family in a private setting at a predetermined appropriate time and asking the individuals to recapture their understanding of the information provided. By doing this, nurses are given the opportunity to identify any further needs of these individuals and to reinforce information provided.

Overall, if nurses are to plan and implement strategies to support individual family members who have donated their loved one's organs, they need to actively

participate in the organ procurement process. Only by participating in this experience will nurses develop the skills to assess and identify individual's needs and provide adequate information and support these families through the experience.

### *Nursing Education*

If nurses are to actively participate in the organ procurement process hospitals need to have clear policies and procedures that outline brain death criteria and a management plan for both the donor and their family. Nurses can be instrumental in establishing these policies and procedures and be part of the educational process to promote them. Not only would this help novice nurses feel more comfortable with organ donation, and hopefully increase their participation, but it would also ensure that all families receive the required information in order to make an informed decision.

Nurses need knowledge and skills in order to participate in the organ procurement process. Continuing professional development and employee orientation programs should include topics of death and dying, grief counseling, organ procurement policies and procedures, and brain death criteria. Organ donation should be included in nursing education at all levels and should be a required component of continuing professional development programs so that nurses can attain the level of clinical skills to maintain the donor and the therapeutic skills to support the family.

Novice nurses need to be given the opportunity to be mentored by nurses more experienced with organ donation. This increased knowledge base coupled with clinical experience will aid novice nurses in becoming more confident with organ donation,

developing therapeutic listening and counseling skills, providing support to organ donor families, answering any questions, and approaching families for organ donation thus increasing organ donation rates.

Finally, nurses need to become more active in public education in order to strengthen consumer knowledge, enable informed choices, and increase participation and support for organ donation. Public education is essential to foster a broader understanding of organ donation and increase organ donation rates. These educational strategies must be population-based and culturally sensitive (National Coordinating Committee for Organ and Tissue Donation, Distribution and Transplantation, 1999).

### *Nursing Research*

Findings from this study provide insight into the phenomenon of organ donation. However, further qualitative research is required to gain a deeper understanding of the struggle of donor families to create a sense of peace and to provide information that will assist nurses in planning nursing care for these clients. There are several areas of research that I believe are required in order for us gain insight into family members' organ donation experience.

Firstly, further research is needed about the donor families' perception of brain death and on the significance of understanding on the donation decision-making process. Researchers must focus on the family's perception of the definition of brain death and attempt to identify areas of conflict and ambiguity. This will allow us to gain a better understanding if it is the concept of brain death that contributes to reported feelings of

being overwhelmed by organ donor families or whether it is the idea that their loved one is dead, regardless of the origin of the cause. Further research in this area may help clarify the relationship between an understanding of brain death and the decision to donate.

Secondly, since that the concepts of “buying time” and “creating a living memory” are somewhat new to the existing body of knowledge surrounding organ donation. These concepts should be explored further through qualitative research. Research focusing on the significance of these two concepts, perhaps in the form of grounded theory, would facilitate our understanding of the organ donation experience. Grounded theory would help understand how these processes occur and the conditions under which they occur. We could also better understand variation in the processes and what influences the variation. This study suggests that “buying time” and “creating a living memory” are important in assisting family members in coping with the loss of their loved one and giving them a positive outlook on the organ donation experience. It is this ability to cope that restored a sense of peace in their lives. In order for nurses to play a supportive role, they need to have a complete understanding of these two concepts and their significance on the organ donor families. Also, since the majority of participants focused on the positive outcomes of the donation as the basis for their decision to donate, research into these outcomes is essential if nurses are to formulate care plans and strategies emphasizing these outcomes, with the goal being to increase organ donation rates.

Thirdly, studies are also needed to look at the experiences of both adult organ donors and pediatric organ donors in anticipation of different needs. This study suggests there is a significant difference in the experiences of adult and pediatric organ donors. Given that few researchers have included pediatric donors in their research, more research that focuses on the experiences of pediatric organ donor families is required to increase our knowledge in this area. This will help nurses develop a plan of care reflective of the donor family and their identified needs.

Finally, given that the literature overwhelming cites the importance of the impact of the nurse's care in assisting families deal with their loss and the organ decision-making process, further qualitative research into the perceptions of nurses regarding organ donation is required. This will help us identify further areas of nursing research, practice and education that require attention in order to increase the involvement of the nurse in the organ procurement process, and perhaps increase organ donation consent rates.

### *Summary of the Study*

This phenomenological study explores the experiences of individual family members who have made the decision to donate their loved one's organs. It has attempted to answer the question, what is life like for families who have made the decision to donate their loved one's organs. From the data collected in five unstructured interviews, five themes were uncovered using van Manen's (1997) mode of inquiry. The five themes included; (1) a struggle to acknowledge the death: this cannot be happening; (2) a positive outcome: wanting something good to come from the death; (3) buying time: I

have to keep them alive as long as possible; (4) creating a living memory: they are living on; and (5) it's your decision: support networks make it easier. The integration of these themes represents the essence of the organ donation experience as creating a sense of peace.

The five themes and the essence were discussed in relation to the literature. The research findings have implications for nursing practice, education and research aimed at improving the experiences of family members who decide to donate the organs of their deceased relative. Limitations of the study were also identified.



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## Appendix A: Human Investigations Committee Approval Letter



# Memorial

University of Newfoundland

Human Investigation Committee  
Research and Graduate Studies  
Faculty of Medicine  
The Health Sciences Centre

1999 08 16

Reference #99.99

Ms. April Pike  
C/o Ms. S. Solberg  
School of Nursing  
Memorial University of Newfoundland,

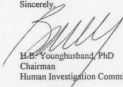
Dear Ms. Pike:

At a meeting held on August 12, 1999, the Human Investigation Committee reviewed your application originally entitled "Organ Donation: The Lived Experience". The Committee granted approval of the application.

The Committee is of the understanding that this study will concentrate on the experience of one individual member of each family.

With respect to the consent form, the Committee requested some specific modifications, which have been outlined on the attached. Please forward a copy of the revised consent form to the HIC Office.

Sincerely,

  
H.B. Younghusband, PhD  
Chairman  
Human Investigation Committee

HBV:jglc

C Dr. K.M.W. Keough, Vice-President (Research)  
Dr. R. Williams, Vice-President, Medical Affairs, HCC  
Dr. S. Solberg, Supervisor



St. John's, NF, Canada A1B 3X6 • Tel.: (709) 737-6974 • Fax: (709) 737-5033

SUPPORT



## Appendix B: Health Care Corporation Approval



October 14, 1999

Ms. April Pike  
 c/o Dr. S. Solberg  
 MUN School of Nursing  
 Health Sciences Centre

Dear Ms. Pike:

Your research proposal *HIC 99.99 - Organ Donation: The Lived Experience* was reviewed by the Research Proposals Approval Committee (RPAC) of the Health Care Corporation of St. John's at its meeting on October 7, 1999, and we are pleased to inform you that the proposal has been approved.

This approval is based on the understanding that it has the necessary funding and that it is being conducted at the Organ Donor Program site only. Additionally, the Committee requires a progress report to be submitted annually.

If you have any questions or comments, please contact Lynn Purchase, Manager of the Patient Research Centre, at 737-7283.

Sincerely,

A handwritten signature in cursive script that reads "Pamela Elliott".

Pamela Elliott  
 Vice President  
 Patient Care Services

mh  
 c Ms. Lynn Purchase  
 Manager  
 Patient Research Centre

## General Hospital

300 Prince Philip Drive, St. John's, Newfoundland, Canada A1B 3V6 Tel. (709)737-6300 Fax (709)737-6400

MEMS: General Hospital • Lunenburg Child Health Centre/Children's Rehabilitation Centre • Leonard A. Miller Centre  
 St. John's Mercy Hospital • The Salvation Army Grace General Hospital • Dr. Walter Hemplow Health Centre • Winfred Hospital

## Appendix C: Consent Form

FACULTY OF MEDICINE - MEMORIAL UNIVERSITY OF  
NEWFOUNDLAND  
AND  
HEALTH CARE CORPORATION OF ST. JOHN'S

Consent To Participate In Bio-medical Research

TITLE: The Experience of a Family Member who Consented to Donate a Deceased Relative's Organs.

INVESTIGATOR: April Pike BN RN  
Telephone : 709 364-3708

You have been asked to participate in a research study. Participation in this study is entirely voluntary. You may decide not to participate or may withdraw from the study at any time.

Information obtained from you or about you during this study, which could identify you, will be kept confidential by the investigator. The investigator will be available during the study at all times should you have any problems or questions about the study.

1. Purpose of study:

This study will explore the experiences of family members who have made the decision to donate a loved one's organs. The objectives of this study are to gain a greater understanding of: (a) what life is like for these family members, and (b) the needs of family members, which may help health care professionals to assist and support the families while they are involved in the organ donation experience.

2. Description of procedures and tests:

You will be asked to recount your experience of donating a loved one's organs. The interview will be tape recorded, with your permission, and carried out at a time and place of your convenience. Your identity will be kept confidential at all times through out the research process, and in the final text description of your experience.

3. Duration of participant's involvement:

The expected interview time is one to two hours, however you may take as much time as you need to recount your experience. A second interview may be requested so that you may clarify/explore ideas, thoughts and feelings gathered from the initial interview.

4. Possible risks, discomforts, or inconveniences:

The only anticipated risk of participating in this interview is that it may be upsetting for you to talk about the death of your loved one. If you experience any distress you may stop the interview and reschedule it for another time, or you may withdraw from the study. You will be giving up approximately one to two hours of your time for the interview

5. Benefits which the participant may receive:

There are no direct benefits to you from participating in this study. However any information obtained may assist health care professionals to develop strategies to support and meet the needs of families who are faced with organ donation.

6. Liability statement:

Your signature indicates your consent and that you have understood the information regarding the research study. In no way does this waive your legal rights nor release the investigators or involved agencies from their legal and professional responsibilities.

Signature Page

Title of Project: The Experience of a Family Member who Consented to Donate a Deceased Relative's Organs.

Name of Principal Investigator: April Pike BNRN

To be signed by participant

I, \_\_\_\_\_, the undersigned, agree to my participation or to the participation of \_\_\_\_\_ (my child, ward, relative) in the research study described above.

Any questions have been answered and I understand what is involved in the study. I realise that participation is voluntary and that there is no guarantee that I will benefit from my involvement.

I acknowledge that a copy of this form has been given to me.

(Signature of Participant)

(Date)

(Signature of Witness)

(Date)

To be signed by investigator

To the best of my ability I have fully explained the nature of this research study. I have invited questions and provided answers. I believe that the participant fully understands the implications and voluntary nature of the study.

(Signature of Investigator)

(Date)

Phone Number

Assent of minor participant (if appropriate)

(Signature of Minor Participant)

(Age \_\_)

Relationship to Participant Named Above

## Appendix D: Interview Guide

### Initial Statement:

I am interested in gaining a greater understanding of what the experience was like for you to have made the decision to donate (name of deceased) organs.

### Potential Clarifying Questions:

Could you please tell me about your decision to donate (deceased name) organs?

What were the main factors influencing your decision to donate (deceased name) organs?

Could you describe your experience with health care professionals and their impact on your decision to donate?

Did you have a good understanding of the term brain death?

How did you feel about donating (deceased name) organs?

Where there any individual's who helped you make the decision to donate (deceased name) organs?





