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A Family Member's Experience of Cadaveric Organ Donation

by

Brenda Lynette Kindleman ©

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of Master of Nursing.

Faculty of Nursing

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled *A Family Member's Experience of Cadaveric Organ Donation*, submitted by *Brenda Lynette Kindleman* in partial fulfillment of the requirements for the degree of *Master of Nursing*.

Dr. Marion Allen

Dr. Lillian Douglass

Dr. Herb Northcott

Date April 12, 2000

Abstract

In order to understand family member's experience of cadaveric organ donation, in-depth interviewing of nine participants was undertaken. Data analysis demonstrated that donor family member's progress through four distinct phases of the organ donation process: *Work of Waiting and Vigilance, Work of Decision-Making, Work of Grieving and Healing*, and *Seeking Direction*. The *Work of Waiting and Vigilance* is characterized by activities, which assist family members to cope with the death of their loved one and the consideration of organ donation. The *Work of Decision-Making* includes tasks of seeking and gathering information, considering influencing factors, and weighing pros and cons of organ donation. The *Work of Grieving and Healing* begins immediately following the decision to donate a loved ones organs. *Seeking Direction* occurs throughout the organ donation process and refers to the family member's need for direction and guidance from healthcare professionals to facilitate smooth progression through the organ donation process.

Dedication

To everyone who has agreed to donation of a loved one's organs. Thank you for your courage, faith, and intense compassion for others when you are faced with the loss of a family member. As well, thank you for the "gift of life" you gave so selflessly so transplant recipients could have a second chance at life.

Acknowledgements

I wish to extend my sincere thanks and gratitude to the nine individuals who agreed to participate in this study. Your selfless sharing of your tragedy has profoundly influenced my understanding of the donation process, and I will endeavor to convey your experiences to others, as you so desired.

Second, I wish to thank the members of my thesis committee, Dr. Marion Allen, Dr. Lillian Douglass, and Dr. Herb Northcott for all their support, encouragement and availability. It was a great pleasure working with you on this study.

Third, I wish to thank my family and friends who never failed to ground me when I lost sight of my goal and ensured my return to reality. A special thanks to my husband Terry, whose unwavering support, love, and patience kept me focused and devoted to the study.

Lastly, I wish to thank the National Kidney Foundation of Canada, The Alberta Association of Registered Nurses, the Faculty of Nursing Internal Allocation Fund, and the Mrs. Moritz Educational Scholarship without whose financial support, this study would not have been possible.

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Chapter 1: Introduction

The purpose of this research study is to explore and describe the family member's experience of cadaveric organ donation. In this chapter, I will describe the genesis of the research study and its significance to nursing practice. Chapter two will substantiate the need for the research study from a theoretical and empirical perspective.

The Quest

The idea for this research study arose from my clinical nursing practice. I worked for many years in a Neurosurgical Intensive Care Unit and had the privilege of working with numerous family members who had agreed to organ donation of a deceased loved one's organs. Often I would counsel the family on the organ donation process, answer questions, provide the necessary documents to be signed, and offer emotional support as these individuals attempted to cope with the death of their family member and deal with the organ donation process simultaneously. I was often left feeling that I should have done more for the family, but had no conclusive ideas as to what would improve the donation process. I believed I had a great deal of experience and knowledge of organ procurement. However, I had little or no understanding of the family members' experience of this process. My contact with the donor and family members ceased when the donor was taken to the Operating Room. I was often left with many unresolved questions: Did the family members have any regrets about organ donation? Could the organ donation process be improved in any way? Was the information provided to the family members sufficient, or were there other questions or areas of concern that should be addressed?

In an attempt to understand the family member's experience, I worked with an Organ Procurement and Exchange Program as part of my clinical practicum in my Master of Nursing program. The role of the organ procurement coordinator is to assist family members by facilitating the consent process and acting as a resource person throughout the donation process. Other responsibilities include coordinating organ retreival, educating the public and healthcare professionals about the organ donation process, and assisting the healthcare professionals in identifying and maintaining a brain-dead patient for organ donation (Albert, 1994; Malecki, 1987). Also, organ procurement coordinators follow up with the donor family with written correspondence, telephone calls, and yearly memorial services. I observed the organ procurement coordinators engaged in, and responding to, numerous family members' inquiries concerning their experience. Months, sometimes years, after their donation experience, family members often had thoughts, questions or unresolved concerns regarding their donation experience. The organ procurement coordinators were instrumental in assisting the individual to effectively resolve these outstanding queries.

In my quest to understand the family member's experience, I also went to the literature to review what was known about this experience. I discovered that there was very little theoretical and empirical literature concerned specifically with the donor family's experience of cadaveric organ donation.

Thus, the impetus for this research study came from my clinical nursing practice, my experience with the Organ Procurement and Exchange Program, my personal desire to understand the cadaveric donor phenomenon, and recognition that there was scant theoretical and empirical literature to guide current nursing practice. Without a clear understanding of the donor family member's experience of the organ donation, little can be done to improve the organ donation process. Therefore, it is my hope that the findings of this study: improve our understanding of the organ donation process; improve the quality of nursing care provided to donor families; facilitate a positive donation experience for donor family members; and lastly, enhance society's understanding of this process to facilitate individual discussion and consent to organ donation in the future. As well, future research questions generated from this study may foster a better understanding of cadaveric organ donation, thereby improving nursing care for both the donor and the donor's family.

The next step in conducting this study was to complete an in-depth literature review to determine more fully if other researchers had explored the organ donor family members' experience. If so, did a gap exist between clinical practice and implementation of research findings, or was there in fact insufficient knowledge in this area? Chapter two details a review of the literature and substantiates the need for research in this area.

Chapter 2: Literature Review

Prior to initiating this research study, I conducted a review of the literature on organ donation and transplantation to determine what was known about the donor family members' experience of cadaveric organ donation. The purpose of this review was to determine what was known about the phenomenon under study, identify if any gaps in knowledge existed, and lastly, to determine if there was a need to conduct this research study. Using key terms such as *organ procurement*, *cadaveric organ donation*, *transplantation*, *voluntary altruism* and the *gift of life*, a review of the literature listed in CINAHL, MEDLINE, ERIC, and PSYCHLIT was reviewed. A vast quantity of literature on organ and tissue procurement and transplantation exists. This literature mainly addresses medical interventions and advancements, procurement and transplant team responsibilities, and legal, ethical and moral issues of procurement and transplantation. I then narrowed my literature review to sources that specifically dealt with the problem of concern guiding this study, and the population of interest, namely, family members of cadaveric organ donors. The literature review begins with a brief overview of organ procurement and transplantation, proceeds to the voluntary altruism and gift giving, and then to literature specific to the experience of organ donation.

Overview of Organ Procurement and Transplantation

In the last three decades, the medical and scientific community has made extraordinary progress in the area of organ transplantation. With the advent of immunosuppressant therapy (Albert, 1994; Veatch, 1989), refined surgical procedures (Bartucci, 1987), blood and tissue typing for donor/recipient compatibility (Barizza, 1990), and improved organ preservation techniques (Bartucci, 1987), organ transplantation is an efficacious (Caplan & Virnig, 1990), cost-effective (Bartucci, 1987; Rosner, et.al., 1990) life-saving medical treatment for people suffering from end-stage organ failure (Abbott, Keown, & Stiller, 1987; Barizza, 1990; CNA Position paper, 1988). However, organ transplantation has become a victim of its own success. The demand for organs far exceeds the supply, resulting in the death of thousands of people suffering from end-stage organ failure (Caplan & Virnig, 1990; Childress, 1992; Kluge, 1989; Siminoff, Arnold, Caplan, Virnig, & Seltzer, 1995; Smith-Brew & Yanai, 1996). The only hope for these individuals is organ transplantation.

Organ procurement occurs from living and cadaveric organ donors. Subsumed under the living donors are living related donors (i.e., parents, siblings), emotionally related donors (i.e., friends, spouse), and voluntary donation by altruistic strangers (Daar, 1992). Living donors can only donate paired organs such as a kidney, lung, or portions of the liver. Cadaveric organ donation occurs when the deceased (i.e., via a donor card, driver's license, health care card) or next-of-kin have consented to organ donation following a catastrophic injury, which results in brain death (Allen, Joyce, & Sutherland, 1997; Childress, 1986; Dougherty, 1993). Cadavers can provide all perfusable organs such as the heart, lungs, liver, kidneys, and pancreas, as well as tissues, such as corneas, heart valves, pituitary gland, bone, and skin. However, in order to donate the aforementioned organs, the donor must be declared brain dead and kept on mechanical support in order to maintain organ viability. At present, cadaveric organ donation supplies the largest number of organs for transplantation.

The Uniform Human Tissue Gift Act in Canada and the Uniform Anatomical Gift Act in the United States have been enacted to facilitate organ donation (Dickens, 1985). These acts enable individuals to consent to organ donation via an organ donor card; or, in accordance with the deceased's wishes, the next-of-kin may consent on behalf of the deceased (Gideon & Taylor, 1981; Veatch, 1989). The intent of the organ donor card is to encourage individuals to make a personal voluntary altruistic gift of their organs and tissues upon their death (Kleinman & Lowy, 1992).

Voluntary Altruism

Many healthcare professionals, bioethicists, and society in general perceive voluntary altruism to be the optimal means of organ procurement. However, voluntary altruism is failing, resulting in a critical shortage of organs. An extensive review of the literature revealed numerous possible reasons for the failure of voluntary altruism. A synopsis of these findings is as follows: failure to educate the public and healthcare professionals about the process of organ procurement (Abbott, Keown, & Stiller, 1987; Abbud-Filho et al, 1997; Childress, 1992; Horton & Horton, 1993; Lowy & Martin, 1992; Prottas & Batten, 1989; Salahi et al., 1998; Younger, 1992); perceived unfairness and mistrust of the medical establishment (Caplan & Virnig, 1990; Kiernan, 1987; Peters, 1991); religious, cultural and philosophical beliefs, values and attitudes which prohibit organ donation (Abouna et al.,1990); superstitions and fear regarding mutilation of the body (Jonsen, 1989; Prottas, 1992); lack of incentives for the organ donor and family (Daar, 1992; Garcia, 1997; Peters, 1991 & 1997); healthcare professionals' negative attitudes regarding organ donation (Sophie, Salloway, Sorock, Volek, & Merkel, 1983), and medical disinclination to care for organ donors (Kiberd & Kiberd, 1992; Mahar & Strong, 1989; Matten et al., 1991; Schutt & Henne-Bruns, 1997; Sophie et al., 1983; Stark, Reiley, Osiecki, & Cook, 1984; Younger, 1992).

The literature clearly reflects the negative factors associated with cadaveric organ donation, thereby inhibiting the success of voluntary altruism. Many of these factors could be eliminated with education aimed at dispelling the negative beliefs, attitudes, and misconceptions of cadaveric organ donation (Siminoff et al., 1995). Nurses are in an excellent position to foster voluntary altruism. By sharing their personal experiences and knowledge of the organ donation process, nurses can dispel many of the family's fears and negative feelings, thereby assisting the family to agree in favor of organ donation (Hart 1986; Watson, 1991).

The Nurse's Role in Cadaveric Organ Donation

Nurses are excellent candidates to educate the public and other healthcare professionals as they are usually the first healthcare professional to identify and care for potential donors (Albert, 1994); and they have the practical knowledge to provide continuous assessments of the donor to ensure organ viability (Mahar & Strong, 1989). As well, nurses can facilitate a positive donation experience for family members by providing emotional and factual support as they proceed through their donation experience (Albert, 1994). A positive donation experience in the hospital will sustain these positive feelings long after the experience has ended (Lange, 1992).

As one can see, there exists a tremendous need for healthcare professionals in general, and nurses in particular, to attend to the serious problems associated with organ procurement and exchange. Without the altruistic act of organ donation, countless individuals suffering from end-stage organ failure will die. Perhaps if we understood what the cadaveric organ donation experience was like, many of the reasons why voluntary altruism have failed could be rectified. Appropriate interventions could then be identified to effectively facilitate and encourage voluntary altruism in the future.

A Family Member's Experience of Organ Donation

Very few quantitative and qualitative research studies have been done on organ donation from the family member's perspective. Soukup (1991), using a correlational design, looked at the relationship between the perceived stress of the organ donation process of a brain-dead family member and the following situational variables: type of family decision-making, isolated versus accommodation or consensus; time between suspected and declared brain death; age of the donor family member; if the donor's preference for donation was known; if the heart was a donated organ; and the family members' immediate participation in post-death bedside customs.

The findings of this study suggest that the degree of perceived stress increases when the family is not aware of the deceased's donation preference, and when family participation in immediate post-death bedside customs is low. There was a nonsignificant correlation between the family stress and the other four variables. The findings of this quantitative study were significant; however, the researcher noted that at the conclusion of the interview, all participants spontaneously shared with the researcher what their organ donation experience meant to them. Although not formal findings of this quantitative study, informal discussions with the researcher at the conclusion of the home interviews revealed clinically relevant information. A brief synopsis of this information is as follows: family members perceived a post-donation discussion about their donation experience as very meaningful; words such as "cadaver", "harvested organ", used by healthcare professionals, triggered feelings of distress among family members; family decision-making concerning organ donation is easier when the deceased's wishes are known; the family's death experience was made more difficult if the organ donation process was delayed; confusion concerning the actual time of brain death; hospital billing and organ donation coverage; unrestricted donation of all organs, tissues and bone versus organ-specific donation; concern about the time between consent of organ donation and actual organ procurement; and the importance of follow-up communication from or about the recipients. The findings of these interviews revealed a wealth of unsubstantiated data about the family member's experiences of cadaveric organ donation. The author noted that further qualitative research was required to fully understand the experience of organ donation from a family member's perspective.

Pelletier (1992) also studied the stress experienced by organ donor family members. A retrospective exploratory research design was used to explore what nine family members perceived as the most stressful aspects of organ donation during each stage of the process, namely, Anticipation, Confrontation, and Post-Confrontation stages. The most stressful situations associated with the Anticipation stage centered on the threat to the family member's life and interactions with healthcare professionals. Stress in the Confrontation stage was associated with the actual organ donation process, namely, the diagnosis of brain death, giving consent for organ donation, and waiting for the completion of organ procurement. Stressful situations in the Post-Confrontation stage included discontinuity in patterns of living, loss of a significant relationship, and poignant reminders.

Despite several study limitations, including the small sample size; self-reporting by family members; looking at organ and tissue donations, rather than organ donations specifically; and the limited generalizability of the study interview tool, the study findings suggest several strategies to improve nursing practice. These strategies include: working collaboratively with other healthcare professionals to identify potential donors, assisting family members to make an informed decision about organ donation, facilitating communication between family members and the healthcare team, and offering follow-up support in the form of home visits, telephone calls, and letters of acknowledgement from recipients who benefited from their loved one's organs and tissues.

Bartucci (1987), in a descriptive study, examined the donor family's overall feelings about their organ donation experience. A mailed questionnaire was used to elicit family members' responses. The findings of the study suggested that most donor families have positive feelings about organ donation because of their desire to help others and to make something positive come from their loss. Because a questionnaire was used, rich descriptive data that could have been obtained by an interview were lost. Other limitations of the study include the small sample size (34 people) and a homogenous study population. In addition, the participants responded to the questionnaire only once, regardless of when the organ donation took place.

Overall, organ donation has been viewed as a positive outcome to a tragic loss of a loved one (Bartucci, 1987; Morton & Leonard, 1979; Pearson, Bazely, Spencer-Plane, Chapman, & Robertson, 1995; Simmons, Fulton & Fulton, 1989), despite the perceived stressfulness of the organ donation process (Pelletier, 1992: Soukup, 1991). As well, findings suggest that the grieving process was made easier as organ donation gave some meaning to the loss of a loved one (Bartucci & Seller, 1986; Pearson et al., 1995; Pelletier, 1992). Despite these positive findings, cadaveric organ donation is still not readily agreed to, thus perpetuating the on-going organ shortage. What is required is an understanding of the donation experience from the family's perspective, their thoughts, feelings, and attitudes in their entirety. Greater understanding of this experience would facilitate improved nursing care by specifically addressing areas of concern in current practice.

Summary

The paucity of literature and research done on the experience of cadaveric organ donation, as perceived by family members, substantiates why it is essential to explore this unstudied topic. Pelletier (1992) eloquently stated "unfortunately, after making the decision to donate, most organ donor families slip into anonymity" (p.90). Consequently, their input and expression of their experience is lost, as is the information they could provide to improve the quality of care nurses and other healthcare providers give to future donor families.

Statement of the Problem / Research Question

The purpose then of this study was to explore and describe family members' experiences of cadaveric organ donation. The findings of this study have the potential to improve and/or enhance the quality of nursing care given to organ donors and their families, now and in the future. The need for this study has clearly been established. The research question guiding this study was:

What is the immediate family member's experience of cadaveric organ donation?

Chapter 3: Conducting the Research Study

Selecting the Research Methodology and Design

An exploratory, descriptive design was used to answer the research question posed for this qualitative study. Qualitative research is used: when little is known about a phenomenon; when the researcher is interested in the " emic", or the participant's perspective of an experience; and when the intent of the research is to explore, describe and understand a particular phenomenon of interest (Field & Morse, 1985). Based on the aforementioned points, a qualitative method was the most appropriate research methodology to answer the research question guiding this study for several reasons. First, there exists a paucity of previous research dealing with a family member's experience of cadaveric donation. Second, a clear understanding of the emic perspective was the primary focus being explored in this study. Lastly, the intent of the research study was to explore, describe and understand the little known phenomenon of cadaveric organ donation from a family member's perspective.

Obtaining the Sample

A purposive or purposeful sample is one in which potential participants are selected, based upon their expertise, knowledge, and/or experience with the phenomenon of interest; and who will either enhance, substantiate, or refute emerging themes, or theory (Field & Morse, 1985). Thus, the researcher selects participants based upon the needs of the research study (Morse, 1991). A purposive sample allows the researcher to identify and select participants who will reflect upon, and verbalize what their experience means to them. The sample selection process begins with selecting participants who have a broad understanding of their experience (Morse, 1991). Once potential themes emerge, participants are selected who have specific knowledge, and expertise concerning the identified themes. Finally, participants who have had a negative or atypical experience are interviewed so that the researcher has a clear understanding of the range of possible experiences with the particular phenomenon studied. In qualitative research, concurrent sampling, data collection and data analysis are done in order to ascertain the "richness" of the data and to address any identified gaps in the emerging themes.

Primary selection is one means of facilitating the researcher's control over the "quality" of participants interviewed (Morse, 1991). With primary selection, the researcher has established a rapport with potential participants, has knowledge of which participants would be the most knowledgeable, receptive and the most likely to agree to participate in the researcher study (Morse, 1991). The organ procurement coordinators were instrumental in assisting me with primary selection as an adjunct to the purposive sampling procedure. During my senior practicum, I had the pleasure of meeting many individuals who would be excellent participants. These individuals expressed interest and enthusiasm in the research study, were excellent historians, were very willing to share their experience and were people with whom I had established a strong rapport.

Potential participants included any male or female family member of a cadaveric organ donor who met the following inclusion criteria: 1) able to speak and understand English; 2) have the cognitive ability to reflect upon and clearly express his or her experience; 3) 18 years of age or older; 4) be an immediate family member of the organ donor, who had been involved in the process of organ donation; and 5) the immediate family member's organ donation experience must have occurred within 6 to 12 months. The specified time frame of 6 to 12 months was chosen as I felt that, as time elapses, memories of the participant's experience may become less clear and details of the experience may be forgotten; yet, still providing the participants with enough time to begin their grieving process. All participants were able to understand English and could clearly verbalize their emotions, thoughts, and knowledge of their organ donation experience in order that I was able to understand their narrative. As well as a means of obtaining a homogenous sample, the participant was an immediate family member (parent, child, or sibling) directly involved in the process of a cadaveric organ donation.

Concurrent purposeful sampling, data collection and data analysis occurred throughout the research study (Morse, 1991). Participants who met the inclusion criteria were selected. The first two participant interviews were immediately transcribed. Analysis of the transcripts resulted in the identification of emerging themes, commonalties and differences between the participants' experiences, gaps in the description of their experiences, and several preliminary hypotheses. Next, I attempted to select participants who could substantiate or refute the emerging themes, data gaps, and preliminary hypotheses. Lastly, I attempted to identify participants who had experienced a negative or atypical case to broaden the scope of the data.

Although every attempt was made to implement the aforementioned sampling strategies identified by Morse (1991), numerous roadblocks to this process inhibited my success. The identification of potential participants proved to be the greatest hurdle. Prior to commencing the study, I met with all organ procurement coordinators to explain the study in depth. Written handouts were provided to the organ procurement coordinators during my initial meeting and reviewed at our regularly scheduled monthly meetings. The written information provided included the following data: a synopsis of the study; a list of the inclusion criteria; suggestions for a good participant, namely one who is "articulate, reflective, and willing to share with the interviewer" (Morse, 1991, p. 127); a description of the interview process; my availability; contact telephone numbers for myself and the thesis supervisor; the study timeline; and a copy of the Letter of Introduction (Appendix A), the Information Letter (Appendix B), and the Consent Form (Appendix C). The organ procurement coordinators used this information to assist me in identifying suitable participants. It was quickly determined that not only was it difficult to identify suitable participants via medical chart reviews by the organ procurement coordinators, the post-donation time frame of 6 to 12 months severely restricted the participant sample pool due to the critical shortage of cadaveric donors during this time frame. It was necessary to extend the time frame to 18 months post organ donation. This time frame was still recent enough to ensure that the participants could clearly recall specifics of the event, yet allowed sufficient time for the participant to reflect on their experience and recover from the intense grief of losing a loved one.

Potential participants who met the inclusion criteria were contacted by telephone by the organ procurement coordinators. The intent of this initial contact was to inform the individual that a research study was being conducted to explore and describe the immediate family member's experience of the organ donation process, and would the family member allow the researcher to contact them with more information. If there was an affirmative response, the respondents received by mail a Letter of Introduction and an Information Letter from the researcher (Appendices A and B). Those individuals interested in participating in the study could contact me by telephone, or return their reply in a self addressed, stamped envelope. If no verbal or written reply was received within 2 to 3 weeks, it was assumed that the individual was not interested in participating in the study. No further attempt was made to recruit those individuals. This process was continued until a sufficient purposive sample was collected.

With the initial telephone contact by the potential participant, I explained the time commitment required to participate in the study and the number of interviews required (a minimum of two). As well, I answered any questions or concerns the potential participant had. After verbal consent was obtained, the participant was given the option of scheduling an interview, at his or her convenience, or he or she could elect to contact me at a later date, in order to deliberate upon their decision to participate in the study. The opportunity to reflect upon the decision to participate allowed potential participants to ensure that this decision was right for them, as well as ensuring that no form of coercion had precipitated their decision. If the individual responded by mail (Appendix B), I then contacted the potential participant by telephone, and the aforementioned information was provided. Of the nine participants in the study, seven responded by telephone, and two responded by mail.

Over the course of the study, approximately 15 individuals were contacted. Nine agreed to participate in the study, six declined. Of those who declined, one individual wanted to conduct the interview immediately by telephone. When it was explained that that was not possible, as the recording equipment, etc., was not set up, the individual stated that he did not want to participate. Two other individuals stated that they did not feel that they had the energy to discuss their experience as they were still grieving the death of their loved one. Lastly, three of the potential participants declined to participate and no reason was offered.

The sample was comprised of nine participants. It was difficult to specify the required sample size, as it was dependent upon the adequacy of the data obtained (Morse, 1991). Morse defines adequacy as the "sufficiency and quality of the data obtained" (p.135). Thus, data were assessed in regards to its relevance, completeness and whether data saturation was achieved. Data saturation was noted at the conclusion of the first interview with the seventh participant. The remaining two participants were used as secondary informants. Secondary informants were used to validate, challenge or refute the evolving themes or categories that emerge from the final data analysis. As well, the secondary informants assessed the accuracy and validity of my interpretation and understanding of the research findings.

Description of the Sample

Participants were purposefully selected in regards to heterogeneity in age and gender. Other variables that were considered when purposefully selecting participants included when the experience of organ donation occurred, if they were fluent in English, if they were good historians and if they were willing to share their experience with the researcher. The purposeful selection of participants was difficult due to the scarcity of organ donors during the time of this study. For seven of the participants, the date of organ donation in relation to the first interview ranges from 10 to 16 months, with the average being 13 months. For the first and ninth participants, the timeframe from the organ donation to first interview was at 2.5 years and 5 years respectively. These two participants were selected to participate in the study for several reasons. Both participants were excellent historians, were extremely eager and personally requested to participate in the study, and both were extensively committed and involved in the organ procurement program. Demographic characteristics of the study participants and characteristics of the organ donors are summarized in Tables 1 and 2, respectively.

Table 1 Sample Characteristics: Biographic Data (n=9)

Participant Characteristics	**Statistics**
[α]Age (Years)	Range: 29 - 48 Mean: 40
Gender	
• Female	8
• Male	1
Relation to Organ Donor	
• Mother	7
• Father	1
• Wife	1
Time of Organ Donation in Relation to First Interview (Months)	
(Participants: 2-8)	Range: 10 – 16 Mean: 13
(Participants: 1 & 9)	Range: 35 – 60 Mean: 47.5

[α] At time of first interview

Table 2 Donor Characteristics (n = 10)

Donor Characteristics	**Statistics**
[α]Age (Years)	Range: 1 - 46 Mean: 14.6
Relationship to Participant	
• Son	7
• Daughter	2
• Husband	1
Cause of death	
• Motor Vehicle Accident	3
• Unknown	1
• Suicide	1
• Accident	4
• Complication of Severe Chronic Disease	1
Organs donated	
• Heart	6
• Lungs	2
• Liver	7
• Islet Cells – Pancreas	4
• Small Bowel	1
• Kidneys	20
Tissues donated	
• Heart Valves (sets)	3
• Skin	1

[α] At time of death

Data Collection

The primary data collection tool was a semi-structured, open-ended interview (Field & Morse, 1985). The open-ended interview is a process that facilitates the participants' expression of their experience in an inductive manner, from a broad generalized scope to a more defined specific focus. Open-ended questions, and if necessary probe questions, facilitated the researcher's interview agenda, as well as allowed the participant sufficient freedom to explore and describe personally significant facets of their experience. Concurrent sampling, data collection and data analysis resulted in changes in the type and focus of the interview questions. The nature of the opening question was general in order to elicit the participants' unique perception of their experience (Appendix D). This approach allowed the participants to share their unique perspectives of their experience in its entirety. Based upon the participants' response, the questions became quite specific in order to clarify or substantiate prior responses, or to encourage the participant to elaborate upon a prior comment (Rodgers & Cowles, 1993). A pilot interview was done prior to the onset of the study. A pilot interview provided an opportunity for my committee chair to critique the effectiveness of my use of self to facilitate the participants' free expression of their experience. The pilot interview was without serious error or problems.

The initial interview with each participant took approximately 1 to 2 hours. If the interview took longer, a brief recess was suggested in order to prevent participant-interviewer fatigue. A brief recess was required only once out of 18 interviews. The first interview with the first participant in the study lasted approximately 2.5 hours, and a recess proved to be necessary and beneficial to both parties, as it allowed each of us an opportunity to reflect upon the interview and explore and expand upon the significance of several facets of the participants' experience that may have been otherwise overlooked.

The interviews took place at a date, time, and place convenient for both the participant and myself. The ideal setting was comfortable, quiet, accessible and free from any distractions.

Locations used included the Organ Procurement Agency's conference room, a private office in the Faculty of Nursing, the participant's home, or my home. Of these four locations, the private office in the Faculty of Nursing was the most frequently used as it was the most convenient site for the participants, as well as being the most neutral, non-threatening location. Five participants shared with me that they had not been in or near the hospital since their organ donation experience occurred. Returning to that environment would cause unnecessary pain and grief. Thus, the Faculty of Nursing site was near the hospital, yet its proximity to the hospital was not a concern for the participants, as they did not have to enter the facility to access the faculty office.

When the participant was from somewhere other than within the city limits, a telephone interview was conducted. Although not ideal, as salient data such as non-verbal behaviors were lost, a telephone interview did suffice. Two participants were interviewed by telephone. The telephone interviews were conducted at a time that allowed for little or no interruptions by either party, generally between 0700 – 1000 hours. Salient non-verbal behaviors heard during the interviews, such as lighting a cigarette, blowing their nose, and crying were extensively documented in fieldnotes during and after the interview. These behaviors were validated with the participant and their significance was clearly documented.

A second interview was scheduled at a mutually convenient date, time, and place, and was conducted in person, or by telephone, depending upon the participant's preference. The second interviews did not take as long as the intent was to clarify, elaborate upon, or validate my understanding of the emerging themes and categories from the data. On average, the second interviews lasted 1 hour. With the exception of the two telephone interviews, all second interviews were conducted in person, even when the option of a telephone interview was offered. This option was offered because four of the seven in-person interviews required the participants to drive 30 – 90 minutes to the city. All four participants declined this option as they indicated that they were most comfortable sharing their experience in person. Sharing their experience in person allowed them to reflect and share with an objective, interested person. Participant comments included "no, I like meeting with you and talking about my experience, it's been so helpful"; "...it's been great to talk to someone [about organ donation], as I always feel like the family thinks I should be over this..." Thus, the interviews were very cathartic in nature for the participants.

The timeframe for the second interviews occurred within 1 to 4 months of the first interview. The second interview allowed the participant to clarify, elaborate upon, validate or refute my analysis of identified themes, or phenomena identified in the first interview. It also provided an opportunity for the participant to reflect on the information provided in the first interview. In many cases, the participant would then spontaneously share rich descriptive data about their experience, which he or she deemed important, that was not fully explored in the initial interview, or that was felt to be of interest to the study.

Field notes were compiled immediately upon completion of each interview. Field notes included brief notes written in a notebook at the onset and conclusion of each interview, or recorded via a mini tape-recorder and transcribed. The purpose of recording field notes at the onset and conclusion of each interview was to ensure that all relevant data obtained before, during and after each interview was documented, thereby ensuring that no data was lost to memory. Field notes are the researcher's objective, descriptive account of what occurred during the interview (Field & Morse, 1985). Relevant or salient observations regarding the context of the interview, participant non-verbal behavior and appearance, or any interaction, which may have interrupted the interview, were recorded (Rodgers & Cowles, 1993). Thus, field notes supplement the data collected throughout the study, and form a valuable tool to assist with describing and understanding the participant's experience. As well, field notes provide a succinct audit trail for possible replication of the research study (Field & Morse, 1985), and establish the trustworthiness of the study (Rodgers & Cowles, 1993).

Analytic, methodological, contextual and personal response documentation was recorded in the form of memos and in journal format, as suggested by Rodgers and Cowles (1993). My subjective thoughts, emotions, insights, and queries were recorded in a personal journal. I was then able to identify possible biases or assumptions that could impede exploring and describing the emic perspective of the participant's experience of cadaveric organ donation. As well, a personal journal facilitated exploring my own ideas, hypotheses, and thought processes which occur during concurrent data collection and analysis. This documentation assisted in providing a detailed audit trial to substantiate the rigor of the research study (Rodgers & Cowles, 1993).

The instruments used in this research study included a short biographical data form (Appendix E) and myself, as the researcher. Allender (1986, cited in Youge & Stewin, 1988) states that as researchers "we interact with and are an integral part of what we study" (p. 62). Lipson (1991) calls the interaction between the participant and the researcher "reflexivity", whereby each participant shares personal insights in order to understand the true meaning of the other's experience. The biographical data form assisted me in understanding the participant's experience by identifying such information as when the organ donation took place and the relationship of the participant to the organ donor. This information had a direct bearing on how the participant interpreted his or her experience. This information was useful in understanding how these variables influenced similarities and differences in the findings.

Data Analysis

The intent of an ethnographic analysis is to discover how members of a defined group organized their cultural knowledge (Spradley, 1979). The primary purpose is to explore and describe the participant's (emic) experience, rather than imposing the researcher's (etic) perspective of what he or she perceives is occurring. Thus, an ethnographic analysis is a "search for the parts of a culture and their relationships *as conceptualized by informants*" (Spradley, 1979, p. 93). In order to facilitate an ethnographic analysis, continuous feedback between data collection and analysis is essential. Completed participant interviews were continuously reviewed and compared with other interviews in order to identify commonalties, differences, and emerging themes. Field notes, memos and my personal study journal were also consulted. An inductive data analysis, as outlined by Hammersley & Atkinson (1983), was done. The biographical data form was analyzed, using descriptive statistics to determine the mean, range and frequency of the data.

After several participant interviews were transcribed, the transcripts were read numerous times in order to become familiar with the content. Line-by-line analysis of each transcript resulted in identifying common concepts, themes, incongruencies, contradictions, and surprising or puzzling data (Hammersley & Atkinson, 1983). Emerging concepts, identified either by the participant or by myself, evolved into patterns and categories. At this stage, 'sensitizing concepts' were identified (Blumer, 1954, cited in Hammersley & Atkinson, 1983). Although not well defined, sensitizing concepts assist in identifying emerging theory as well as provide the impetus for further data collection. Examples of sensitizing concepts that emerged from the participants' first interviews include hope of recovery prior to a physician sharing the catastrophic nature of the brain injury, long periods of waiting, and assembling a support network. These sensitizing concepts were written in the left-hand margin of the transcript, highlighted with a marker and then flagged with post-it notes® for easy access and retrieval. The right-hand margin of the transcript was used for comments or reminders about the sensitizing concepts. For instance, further clarification, elaboration, or validation from the participant were required in order to fully understand a data query. In addition, these comments assisted in identifying follow-up questions for the participant at the second interview.

The next stage of the data analysis involved identifying 'definitive concepts'. Definitive concepts were well-defined concepts identified by specific characteristics and attributes (Blumer, 1954, cited in Hammersley & Atkinson, 1983). Definitive concepts can be categorized and emerging theoretical scheme (linkages between concepts) can be developed. The strategy used to facilitate this process is Glaser and Strauss's (1967) 'constant comparative method' (cited in Hammersley & Atkinson, 1983). Using this method, each portion of the data was examined, and its relevance to other categories was noted and compared. This process allowed the range and variation of each category to be mapped in the data, with patterns mapped in relation to other categories. Examples of definitive concepts identified in the data include: the concepts of work of waiting; seeking information, identifying influencing factors and weighing the pros and cons of organ donation; making sense of the loss; seeking public acknowledgement of organ donation; and making sense of their donation experience.

The final step in the data analysis was the identification and development of typologies. Lazarsfeld and Barton (1951, cited in Hammersley & Atkinson, 1983) state that by specifying the dimensions, attributes and characteristics underlying the typology, the researcher can then systematically consider the phenomenon subsumed in each category and its relationship to other defined categories. The four typologies identified and defined in this study are the Work of Waiting and Vigilance, Work of Decision-Making, Work of Grieving and Healing, and Seeking Direction. A detailed discussion of the attributes and characteristics of each of the aforementioned typologies will be addressed in chapters five through eight respectively.

Diagrams and flow sheets were used to display these evolving categories and the interrelationships or linkages between the categories. I found this a particularly useful strategy as it allowed me to visualize the relationships between concepts and illustrated the dynamic movement between categories. Another useful strategy to assist in data analysis was the use of written memos. Memos are thoughts, queries, and insights identified throughout the process of data analysis. They tie together pieces of data to illustrate linkages, define categories, and refine codes (Miles & Huberman, 1994).

Peer and colleague review, as well as discussions with the members of the thesis committee, were conducted periodically throughout the data collection and analysis process to ensure that the data analysis was accurate and unbiased. These forms of member validation assist in checking the accuracy and validity of the study findings (Sandelowski, 1993). In addition, two secondary informants reviewed the findings of the data analysis and validated these findings. Sandelowski (1996) stated that a qualitative study is credible if the descriptions of the participants' experiences are accurate and "that the people having that experience would immediately recognize it from those descriptions or interpretations as their own" (p.28).

Reliability and Validity

Steps taken to ensure rigor. Based upon the work of Guba and Lincoln (1981, cited in Sandelowski, 1986), Sandelowski developed a framework to assess the issue of rigor (reliability, validity, and objectivity) in qualitative research. Credibility, fittingness, auditability and confirmability are the four criteria identified in Sandelowski's framework.

Credibility (internal validity) is achieved when a participant, or another person with a similar experience, can read a description or interpretation of the research findings and immediately recognize their own lived experience. In order to achieve credibility, the researcher's reflexivity becomes central to data collection. The researcher is the tool or instrument by which data collection and analysis occurs. Strategies used to determine the credibility of this study included: 1) a review of the pilot interview by my thesis supervisor to critique the quality of the interview and determine the adequacy of my interview questions and skills; 2) a critique of all documentation (fieldnotes, personal journal, and memos) done following the pilot interview, and throughout the research process, as this material was used to supplement the richness or "thick" data obtained from the participants' description of their experience; and lastly, 3) discussions with thesis supervisor to identify all potentially inherent biases, assumptions or subjective feelings identified in my personal journal which may affect the credibility of the research findings.

The fittingness, or the applicability of qualitative research is the ease by which the research findings "fit" into a context other than this study's situation; when other people see the research findings as relevant, meaningful, and applicable to their own experience; and when the research findings "fit" the data from which it was derived. Strategies used to facilitate the fittingness of the research study included using exemplars that reflect the richness of the described experience, as well as the aforementioned credibility strategies.

Other strategies that were used to ensure that the credibility and fittingness of the research study included: 1) constant comparison and concurrent purposeful sampling, data collection, and analysis to facilitate the exploration and description of the experience of cadaveric organ donation; 2) secondary participants' critique of the research findings to validate, challenge or refute my understanding or interpretations of the participants' experience; 3) periodic peer and thesis supervisor review of the concurrent data collection, data analysis, and documentation (analytical, personal, contextual and methodological) to assist in identification of biases and assumptions which may distort the accuracy of the findings (Rodgers & Cowles, 1993); 4) triangulation of methods (biographical data form, semi-structured, open-ended interviews, and all interview transcripts, fieldnotes), and sources to determine and possibly confirm the research findings (use of two secondary participants to confirm the study findings) (Corner, 1991; Knafl & Breitmayer, 1991); and 5) review of the transcript with the audio tape to ensure the accuracy of the typed data.

Auditability, or consistency of qualitative findings, is determined by the audit trail left by the initial researcher. If another researcher can clearly understand the directions taken by the initial researcher and arrive at similar, not contradictory, conclusions, then the criterion of rigor, namely auditability has been met (Sandelowski, 1986). Strategies to ensure that auditiability was met have been alluded to, namely that an audit trail clearly illustrates the decisions made to affect the research findings. Documentation (analytical, personal, contextual and methodological) done throughout the research study was painstakingly kept to substantiate any changes that occur during the research (Rodgers & Cowles, 1993). Constant comparison and concurrent data collection and analysis also assisted in maintaining rigor in this study.

Confirmability refers to the research findings themselves, and is accomplished if the credibility, fittingness, and auditability of the research study have been established (Youge & Stewin, 1988). Strategies used to facilitate the confirmability or neutrality of the research findings include: 1) recording a well documented audit trail; 2) triangulating data sources and data collection procedures to determine if there is congruency of findings among them, and 3) using secondary participants to validate, or refute the research findings (Sandelowski, 1986).

Ethical Considerations

Prior to commencing the study, ethics approval from the University of Alberta Hospital and the Ethics Review Committee of the University of Alberta Faculty of Nursing were obtained. Numerous strategies were identified and incorporated in the study's design to ensure the participants' human rights were protected throughout the research study. These strategies are described below in relation to informed consent and access to participants, confidentiality, anonymity, and risks versus benefits.

Informed consent and access to participants. Prior to the onset of the first interview, the Information Letter and the Consent Form were read to the participant to ensure that he or she was aware of the reason for the research and their rights as a participant. These procedures prevented the researcher from directly or indirectly behaving in a coercive manner and ensured that participants were aware of their rights. These rights included the right to withdraw from the research study at any time without consequence, the right to ask questions concerning the research, and the right to be informed of any inherent risks or benefits that may be incurred by participating in the research study (Field & Morse, 1985). All participants were given my telephone number and that of thesis supervisor so that any questions or concerns could be addressed promptly at any time.

If the individual chose to participte in the research study, written consent was obtained prior to the first interview. Two Consent Forms were signed, one for the participant, and the other for myself. The signed Consent Forms were stored in a locked drawer for the duration of the research study. The Information Letter and the Consent Form were written at a grade 8 level, as determined by Right-Writer® computer program, to facilitate the participant's understanding of the written research study material.

Potential participants could respond to the Information Letter and Letter of Introduction either by telephone or a written reply via the self-addressed, stamped envelope. If the potential participant replied by telephone, a detailed description of the purpose, data collection method (interview and biographical data form) and time frame required to complete the two interviews was explained. If the telephone respondent was willing to participate in the study, verbal consent was obtained by telephone. Prior to the onset of the first interview, the participant was asked to read and sign the written Consent Form (Appendix C). If a respondent replied by mail, the individual was telephoned and the consent process was repeated in the same fashion for both verbal and written consents. If no verbal or written reply was received within 2 to 3 weeks, it was assumed that the individual was not interested in participating in the study. No further contact between myself and the potential participant occurred. If the interviews were conducted by telephone, verbal consent was audio taped on a separate tape, and was stored along with the written consents in a locked drawer. If the participant desired a copy of the written consent form for his or her records, the participant's address was obtained, and a Consent Form was mailed promptly.

Confidentiality and anonymity. Confidentiality of the transcripts was maintained throughout the research study. With the exception of the transcriber, and thesis committee, no other individuals had access to the raw data. The aforementioned individuals all maintained this information in strict confidence. I was the only individual with access to the participants' transcripts, audiotapes and consent forms. The transcripts and audiotapes were stored separately from the consent forms. All study documents and materials were secured in a locked file cabinet and will be stored for at least 7 years, as per University policy.

The research findings contain data collected during subject interviews and are presented in this thesis and in papers for future publication and conferences. Participants' anonymity was protected using the following strategies. First, pseudonyms were used throughout the study and in the final research report. Secondly, no exemplars were used which would identify a particular participant. Thirdly, code numbers were assigned to each participant and their corresponding transcripts and audiotapes, thus no identifying data appeared on the raw data (transcripts, field notes, and biographical data form). The master list of these codes, linking the participant to the data, and the signed consent forms were secured in a locked drawer, away from the data. At the conclusion of the study, the master list was destroyed.

Risk/benefit issues. Although there was no inherent risk to the participants associated with their participation in the study, it was possible for feelings of pain and anguish associated with the death of their family member to be experienced during interviews. As participants share their organ donation experience, feelings of sadness, loss, and grief did occur. If a participant had any concerns or problems with the feelings evoked by sharing their experience, they were referred to an appropriate individual or agency (i.e. Family Counselor, Psychologist, Pastoral Care etc.). To my knowledge, no participant needed to access these resources at any time during or after the research study. At the onset of the first interview, each participant received a list of community grief and bereavement support groups, as well as telephone contact numbers of pastoral services and counselors at the hospital with whom they could discuss their feelings, should the need arise.

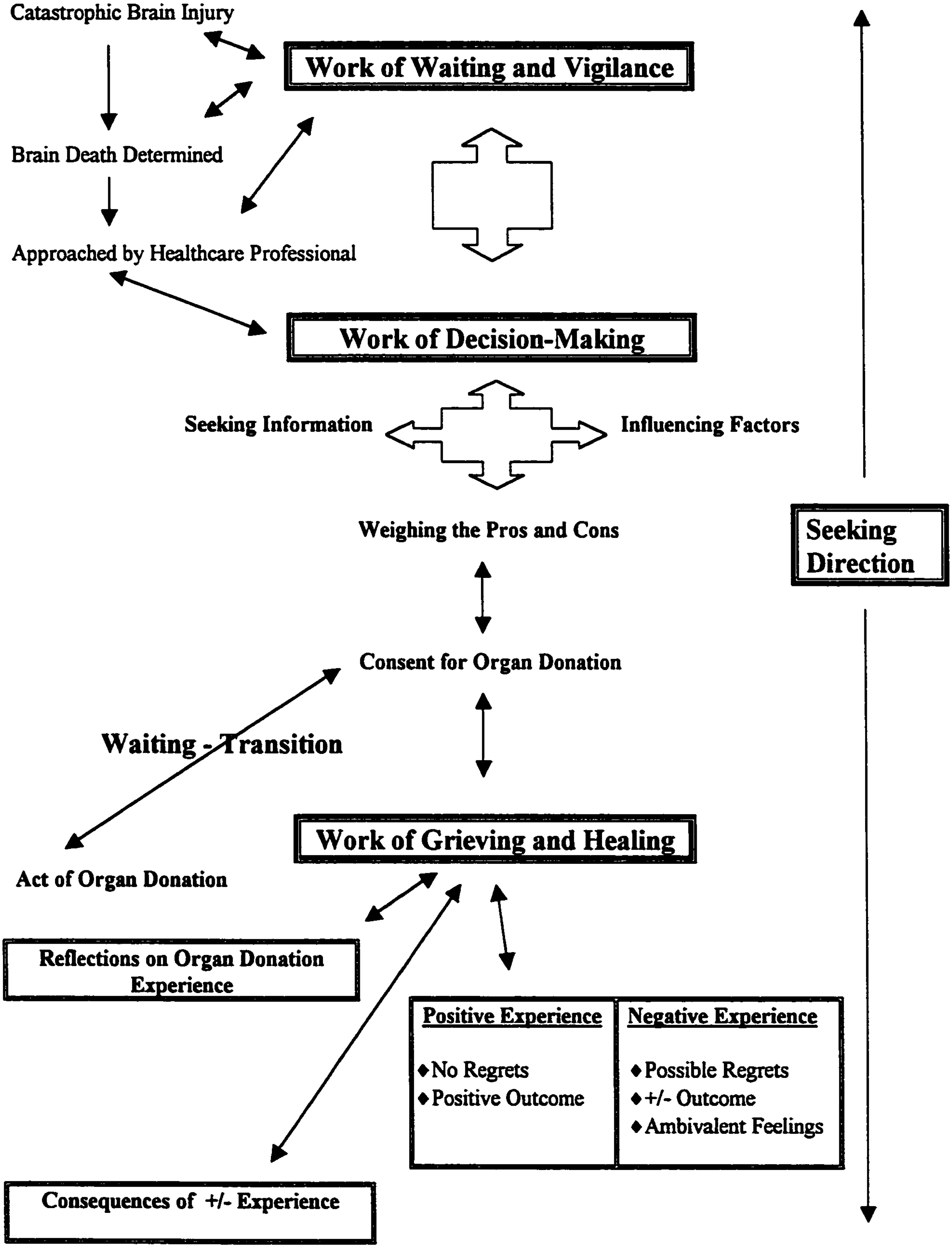
A possible benefit of the study, as perceived by the participants, may be a sense of relief to share their experience with an objective, empathetic, active listener. As well, sharing the findings of this study will improve nursing knowledge and nursing care for future donor family members.

Chapter 4: Overview of the Study Findings

The findings of this study were identified through concurrent data collection and analysis of eighteen interviews over a 12-month period. Continuously revisiting the raw data and keeping meticulous field notes was a time-consuming and laborious process. Many times I felt overwhelmed by the vast quantity of data and the seemingly endless process of analysis. However, with each interview, the participants' stories began to sound "familiar" as the commonalities and differences of each experience were clearly noted. Key concepts, emerging themes and finally four typologies were identified and characteristics of each clearly defined. These typologies outline stages or phases of the family members' experience of cadaveric organ donation. The four phases identified include the Work of Waiting and Vigilance, Work of Decision-Making, Work of Grieving and Healing, and lastly, Seeking Direction (See Figure 1). In this chapter, I provide a brief overview of the four phases of the cadaveric organ donation. In chapters 5, 6, 7 and 8, characteristics of each phase of this process are identified and described in detail.

Throughout the finding's chapters, participants' experiences are shared with the reader in the form of illustrative excerpts from the interview transcripts. These excerpts have been meticulously edited to remove extraneous information, improve grammar, maintain participants' anonymity, include pertinent non-verbal behavior and clarify meaning and context (Morse & Field, 1995). Any clarifications added to the excerpts have been inserted in square brackets. In other cases, I have taken the liberty of arranging sentences that were not spoken together but yet share a similar theme. The researcher has the "narrative license to arrange words or sentences together that were not necessarily spoken together or in the same sequences as in the original transcribed text" (Sandelowski, 1994, p. 481). This strategy captures the richness of the participant's experience and facilitates the reader's understanding of the research findings.

Figure 1. The Four Phases of Cadaveric Organ Donation



The phases of the cadaveric organ donation process are the Work of Waiting and Vigilance, Work of Decision-Making, Work of Grieving and Healing and lastly, Seeking Direction. These phases described activities that facilitate the progression through the participant's organ donation experience. The term work implies "activity designed to achieve a particular purpose and requiring an expenditure of considerable effort" (Webster, 1991, p.1132).

Work of Waiting and Vigilance

Despite how the participant's family member sustained a catastrophic brain injury resulting in brain death, participants all shared a similar beginning to their stories. The participants arrived at the hospital and were immediately told of the severity of their family member's brain injury. As a result, all experienced varying degrees of both emotional shock and hopefulness. Emotional shock was characterized by feelings of denial, disbelief, fear, anger, and a sense of numbness and unreality. Combined with these feelings was the hope for the survival and recovery of their loved one.

During this time, participants experienced long periods of waiting. I have defined waiting as a state of readiness or anticipation of some expected event to occur (Webster, 1991). Therefore, "waiting" implies a dynamic state, a state of physical, emotional, and spiritual readiness to act. Examples of the type and nature of waiting experienced by the participants included: waiting for the brain death test results, waiting to hear news or talk to the healthcare professionals, and waiting in the emergency or intensive care waiting rooms to see their loved one.

The Work of Waiting and Vigilance characterizes activities that assist family members to cope with the reality of the situation. Activities include assembling a support network composed of family, friends, clergy, and community support agency personnel; enacting rituals defined by one's belief system; dealing with a multitude of feelings, thoughts and emotions associated with emotional shock and coping with the declaration of brain death. This phase is key to the participants' successful completion of the cadaveric organ donation process.

Work of Decision-Making

Once brain death was suspected and/or confirmed, the physician approached the family members about organ donation. The organ procurement coordinator was then notified, and was available to provide information, answer questions, and support the participants with the decision-making process. Subsumed within the Work of Decision-Making are the tasks of seeking and gathering information, considering the influencing factors, and weighing the pros and cons.

Seeking and Gathering Information

Seeking and gathering information is a very important component of the decision-making process. In order to give informed consent, participants required all pertinent and necessary facts and information about the act and process of organ donation. Questions that were frequently asked by the participants included: how is brain death determined? Are the results of the brain death tests conclusive evidence that my loved one is dead? Can my loved one feel any pain? Which organs and/or tissues can I donate?; how long will the organ donation process take? What happens to my loved one's body before, during, and after organ donation?

These questions assisted participants to understand and make sense of their cadaveric organ donation experience. As well, the answer to the questions provided the knowledge necessary to make an informed decision. Physicians, nurses, and the organ procurement coordinator were instrumental in facilitating the decision-making process of the participants. A trusting rapport between the participants and the healthcare professionals was established and fostered with open, honest, and candid communication. As well, an empathetic, caring demeanor by healthcare professionals assisted the participants to seek the information they required.

Considering the Influencing Factors

There are numerous influencing factors that either facilitate or hinder the work of decision-making. Influencing factors are unique, personal, and timely variables that participants considered when making his or her decision to donate a family member's organs. These factors are affected by one's knowledge, beliefs and values. Influencing factors identified in this study include: one's previous experience with organ donation, either directly through a past organ donation experience, or indirectly via the media (television, newspapers, magazines, etc.); an awareness of the loved one's wishes regarding organ donation through family discussions or personal conversations; signed driver's license, healthcare card, or organ donor card; quality of life issues; altruistic act; if the loved one's death was perceived prior to the physician declaring the individual brain dead; premonitions or dreams of the family member's death.

Weighing the Pros and Cons

Weighing the pros and cons occurs when making any decision. The decision must be based on information obtained and with consideration of all influencing factors. This process can be facilitated by discussions with significant others, family, friends, clergy, and the healthcare professionals. Once all facets of the work of decision-making are considered and weighed, an informed decision was made, and the participant consented to organ donation.

Work of Grieving and Healing

The work of grieving and healing begins after the participants agreed in favor of cadaveric organ donation. Once the healthcare professionals receive the consent for organ donation, family members were given as much time as possible to remain with their loved one. Some participants left the hospital after saying good-bye to their loved one. Others shared that they stayed by their loved one's bedside until the donor was taken to the operating room. This was strictly the participant's personal choice. Some of the tasks identified in this phase include making sense of the loss, seeking public acknowledgment of the organ donation, and reflecting upon the organ donation experience.

The participant's experience was perceived as either positive or negative, depending upon the ease in which the cadaveric organ donation process occurred, the time component required to complete the process of organ donation, and lastly, the availability of the healthcare professionals, especially the organ procurement coordinator. Typically, a positive organ donation experience would be described as one in which the donation process progressed in an orderly, timely fashion. A negative experience would include long delays, little or no contact with healthcare professionals, and perceived disinterest by healthcare professionals. As a result, the participant experienced ambivalent feelings and regrets about their decision to consent to cadaveric organ donation. The consequences of a negative experience include a delay in the participant's grief work and unresolved thoughts and feelings about the organ donation experience. Conversely, a positive experience has the following consequences: the participant is a strong advocate of cadaveric organ donation; the participant has the desire to increase organ donor awareness by sharing the positive nature of their experience; the participant may choose to maintain contact with the organ procurement agency to ascertain the welfare of the organ recipients; and the participant experiences comfort knowing that some unknown person is living a better quality of life as an organ transplant recipient. As well, a positive organ donation experience facilitates effective grief work and healing following the death of a loved one.

Seeking Direction

Seeking direction occurs throughout the organ donation process. Seeking direction refers to the participant's need for specific guidance throughout the organ donation process. Healthcare professionals provide clear, succinct, simple directions to donor family members to assist them to cope with this new experience. One participant suggested a step-by-step "recipe" of the expectations, actions, and behaviors that were expected of her during her donation experience. She wanted the healthcare professionals to tell her what to expect and when to expect it.

Role expectations were identified and shared with the donor family members in order to facilitate an easy progression through the phases of the cadaveric organ donation. The donor family member role expectations include: establishing and maintaining open, direct communications with the healthcare professionals; seeking answers to questions that facilitate their understanding of the act and process of organ donation; being honest with the healthcare professionals by informing them of their needs such as requesting short, simple, and frequent explanations of the healthcare professionals' activities; and requesting information about the routines of the intensive care unit, in order to spend as much time as possible with their loved one.

Movement through the phases of the cadaveric organ donation was not linear in nature, as illustrated by two-way directional arrows (see Figure 1). The participants revisited phases at various points in their cadaveric organ donation experience, and although they were primarily in one phase at a time, they were sometimes functioning in one or more phases simultaneously. For example, the participant would be assembling a support network (Work of Waiting and Vigilance) while attempting to identify and understand their role and responsibilities associated with their cadaveric organ donation experience (Seeking Direction). The dynamic movement through the phases of cadaveric organ donation was influenced by numerous factors. For ease of presentation, each phase of the cadaveric organ donation process will be described in the next four chapters, commencing with the Work of Waiting and Vigilance (see Table 3 for a synopsis of the elements in the process).

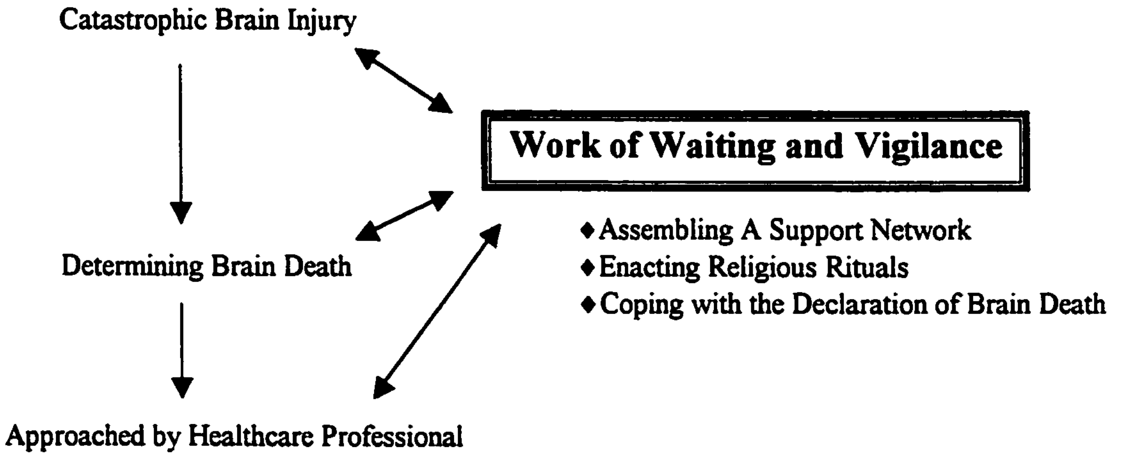
Table 3 Elements of the Four Phases of Cadaveric Organ Donation

Chapter 5	Work of Waiting and Vigilance
	Assembling a Support Network
	Enacting Religious Rituals
	Coping with the Declaration of Brain Death
Chapter 6	Work of Decision-Making
	Seeking and Gathering Information
	Type of information provided by healthcare professionals
	Communication style of healthcare professional
	Terminology
	Availability of healthcare professionals
	Identifying Influencing Factors
	Previous organ donation experience
	Awareness of deceased's wishes concerning organ donation
	Signed Driver's license, healthcare card or organ donor card
	Quality of life issues
	Altruism
	Parts of loved one to live on in others
	Perceived death prior to confirmation of brain death testing
	Premonitions, dreams, and déjà vu
	Weighing the Pros and Cons
	Consent for Cadaveric Organ Donation
Chapter 7	Work of Grieving and Healing
	Making Sense of the Loss
	Seeking Public Acknowledgement of Organ Donation
	Reflections of the Donation Experience
	Consequences of the Cadaveric Organ Donation Experience
Chapter 8	Seeking Direction
	Seeking Directions – Insights and Suggestions
	Understanding Role Expectations

Chapter 5: Work of Waiting and Vigilance

Work of Waiting and Vigilance is the first phase of cadaveric organ donation (see Figure 2). The antecedent to this phase is a catastrophic brain injury sustained by a family member of a participant. Motor vehicle accident, suicide, or other forms of accidents all caused severe brain damage that resulted in brain death of a family member. Once told of this tragedy, participants all experienced varying degrees of both emotional shock and hopefulness.

Figure 2. Components of Work of Waiting and Vigilance



Emotional shock was characterized by feelings of denial, disbelief, anger, and a sense of numbness and unreality. These feelings and emotions were not experienced in any particular order, nor were they all experienced by each participant; they varied in intensity among the participants; and they were not necessarily specific to organ donation, but rather to the impending death of their loved one. When asked, participants were unable to identify feelings and emotions specific to either the impending death of their family member or the request for organ donation. All experienced emotional shock in this phase, regardless of the trigger. One participant shared:

> At first, I felt denial. When I went to the hospital I was thinking no, he's coming home and everything's O.K.…I just felt sick and then all of a sudden I was really, really calm. I thought, oh boy. Then you know…I knew in my heart [that he died]. (09)

Other participants shared feelings of anger:

> It was about the third day and I got mad at [son], like not mad at him but [upset about his condition], "you've got to wake up" and I started to cry and got his arm all wet. (08)

> I felt quite angry then. I don't know if that's a common feeling but I felt really angry with someone. Just angry that the whole thing had happened....I think I felt really angry with the doctors. Maybe I had them too much on a pedestal but I was angry that they couldn't do anything. Nobody knew what had gone wrong and so for them then to be asking me for something from him [organ donation], I just felt like no way. Just let him be....Maybe that's even something that you are going to feel, that's a natural reaction...(02)

Factors that influenced the participants' emotional shock included: whether they witnessed or were involved in the accident that injured their family member; if there was a time lag between when the injured family member and when the rest of the family arrived at the hospital; and if the participant felt it was necessary to temper his or her feelings so as not to alarm other members of the family by the intensity of his or her emotional reaction. One participant felt it was her responsibility to remain calm and not alarm the other family members, in essence to protect them from the harsh reality of their loss:

> I was so numb and thinking how in the heck is the rest of the family going to handle this [son's death]? Like he's got a brother, sister, dad, and grandma he was very close to and how, what am I going to do now, that's when I started going into the protective mode, like how's everybody else going to handle this? (07)

Another participant shared how important it was for him to remain in control of his emotions and feelings. He felt he needed to stay in control, in order to provide support for his family. He stated:

> I wanted to get really mad a couple times....I was holding on to [my emotions], the way I would react or the way I didn't act for the family. Cause I had to. Or I felt I had to....You take a piece [son] that integral in the family you think that the whole family's going to fall apart....I was worried about all kinds of stupid things. Um, so if I'd have given free reign to my emotions, I don't know whether or not I wouldn't have been mad at the doctor [for not saving my son]. But I wasn't going to allow anything to [happen], I felt that if [son] had to die, then we'd act in a dignified manner. (08)

Associated with feelings of emotional shock, participants also expressed their hopes for their loved one's survival and recovery. However, many of the participants sensed the seriousness of the injury and perceived that there was very little hope for survival. Participants shared:

> It was obvious right from the very beginning that his injury was extremely serious. When we were in the hospital in the evening after we'd taken him to emergency, the doctors immediately told us that it was very, very serious injury and seemed to be preparing us for the worst right from the beginning...within a matter of hours we understood there was very little hope. (01)

> As the days went on, we were told that he [son] could have some motor damage and we came to accept that and then it got to the point where we were told that they didn't think he was going to even make it downstairs in the elevator [for a CAT scan]...we said our goodbyes prior to them doing the final CAT scan and we knew it was pretty bad....I think he [doctor] understood when he saw me that we were prepared for the worst....He [doctor] told me that he [son] had all the stroked areas [in his brain] and that there was no hope but he would do this one final test to confirm what they already knew, to confirm brain death. (08)

> Every part of you is screaming for some hope [becomes emotional] so you really do need someone to say there isn't any. (06)

Even though the participants were able to sense that there was no hope for their loved one's survival, it was difficult to perceive this reality because their loved one appeared to be "well". Their loved one was warm to touch with a pink complexion, their chest was rising and falling with the cycles of the ventilator, and the heart beat was seen on the cardiac monitor. This appearance suggested that, for all intents and purposes, their loved one was alive. This was very deceiving and gave the illusion that their loved one was going to recover. A tremendous amount of "work" by the participant was required to understand the reality of this situation.

> He looked like he was sleeping....I remember that the doctor saying that they'd have to leave the machines on for a little while and even though he was dead that the machines would be on and there wouldn't be a big change in the way he would look, and of course he looks like he's alive because he's breathing. (02)

It was very clear that this phase of the cadaveric organ donation was extremely emotionally taxing for the participants. Experiencing intense emotions and feelings associated with the emotional shock and the hopelessness of their loved one's fatal brain injury was emotionally, physically and psychologically draining. Most of the participants experienced this intense emotional shock over periods of days, while they waited as their loved one's condition steadily deteriorated. Long periods of waiting were very typical during this phase.

> There's a lot of waiting. You wait for one test and another test and another test....I think what you've got is a paradox because at first, you're just waiting and waiting and time is going so

> slowly. You're waiting for one test [brain death tests]. You're waiting to see what the situation will be in the morning. And then suddenly it's okay, [brain death] has been determined. Now it's rush, rush, rush, rush. I understand the necessity for the rush yes, but perhaps if people were prepared ahead of time [about organ donation] as we were, then, there wouldn't be so much of a rush afterwards [after confirmation of brain death and consent to organ donation]. (01)

Waiting is defined as "a state of readiness or anticipation of some expected event to occur (Webster, 1991). Thus, waiting is a dynamic state, a state in which the participant was prepared to act, physically, emotionally, mentally, and spiritually. Activities typically accomplished during these long periods of waiting included: assembling a support network, enacting religious rituals, and waiting for completion of the brain death tests and coping with the declaration of brain death.

Assembling a Support Network

Assembling a support network was the first task of the Work of Waiting and Vigilance phase. Typically, participants had family and friends with them during the hospitalization of their loved one. Other key individuals who offered support included: victim services, RCMP, city police, pastoral care, co-workers, intensive care nurses and physicians, and the organ procurement coordinators. These individuals were instrumental in assisting the participants to cope with the impending death of their loved one, as well as provide support when family members were offered the opportunity to consider organ donation.

> I mean that whole day and that whole night after the accident, there must have been 50 people walking in and out of the ICU [intensive care unit]. I mean they [ICU nurses] were just wonderful. They were just very supportive. The doctors were wonderful. The pastoral care was excellent. I even had [CITY] Victim Services, two ladies were with us all night. They sat with us. They got us coffee. They gave us quarters for phone calls. And they still phone. They still phone us to get an up date [on how we're doing]. ...They go through the RCMP, it's all volunteers and some of them have been [in our situation]....Like this one lady I met; she lost her son in a car accident and he was AGE and he was killed. He was hit by a drunk driver and now she volunteers to go out and help families, it's so wonderful. (05)

> The RCMP's were also there and they had talked to my husband. Then the constable told us that if there was anything that they could do, like make local or long distant calls, for us that they were there for us so we had lots and lots of support, and that helped a lot. (09)

> Everyone was very kind. I thought they [nurses and physicians] were very kind and sensitive to our needs. I thought they couldn't have been better, absolutely couldn't have been better....Well, I'll tell you, the nurses in both cases I thought perfectly fulfilled the role which they were assigned....They [nurses] kept him clean. They kept care of his body....I saw them doing their checks [assessments]. They did them all properly and correctly and on the hour, when they were supposed to be done. It comforted me a lot to see the physical selves of the boys getting taken care of. While they were doing that, I felt very much that they nurtured me emotionally. They were there for me....I felt that the nurses that cared for our sons really did a perfect job, both for our boys and for me....They were very, very good examples of what a nurse ought to be, I thought. (04)

> I was really impressed with the nurses caring for my sons. I felt like she was my friend and she's somebody who really had empathy for us. I think I had an opener mind to something she would have said than to other staff that I hadn't seen doing direct care for my sons. (04)

Another participant shared at great length about the support she received from family, friends and co-workers. These individuals were instrumental in assisting the participant to work through the Work of Waiting and Vigilance, as well as the other three phases of cadaveric organ donation.

> Well, I'll tell you that before this happened in my family I never knew what a strong family I had. You know, you tend to take your family and your friends and the people around you for granted. You think of your co-workers as nice people but they're co-workers and you think of your family as sort of being there but you don't understand what a bond of love really is until you have something like this [death of sons / organ donation] happen and they come to you and they give to you in ways you would have never dreamed. I've said it in my own head and I've even said to other people, I think that emotionally you feel like you're flat, that you can't lift yourself up but it's by the strength of everybody around you and their caring that lifts you up....It was the strength of those people around me that just kept me going for the longest time....We were overwhelmed and just really comforted by how many people cared about what happened to us. It was amazing to me, absolutely amazing....I had all kinds of people reaching out to us and trying to help us any way they could. (04)

The majority of participants felt the organ procurement coordinator was absolutely indispensable, extremely supportive, and offered an emotional bond that the other healthcare professionals did not provide.

> Well, [Organ Procurement Coordinator – NAME] was wonderful. She was able to make an emotional sort of bond, forge that bond immediately and for me that was extremely important. You certainly had the impression that it was someone who really genuinely cared, who had an understanding of what you were going through, and was able to take your cares, your concerns into consideration, to walk you through the whole [organ donation] process, and to answer questions. (01)

> The next day some of the family and the parish priest came back and waited with us. A person from the [organ procurement] program came and talked to us about organ donation. She

> explained the procedure. She was so compassionate and wonderful and it made us feel good about our earlier decision to go ahead with the donation. (09)

Two participants shared stories of individuals that were not supportive and in fact caused the participant extreme emotional pain. Journalists invaded the participant's privacy and disseminated information concerning the family member's accident without permission from the participant. This caused the participants to experience severe stress and feelings of powerlessness.

> He [son] told me that some journalists had been phoning the house and I was <u>extremely</u> upset. And this was after the doctor in emergency room had said, do you want any media announcements made? We said no. For us this is something very private, very personal. We don't want anything done, anything said. But one of the things that really upset me was there was a report in the newspaper the next morning. It didn't mention my son by name but they had their information from one of the ambulance people. It was one of the ambulance people who had informed the press...and I didn't think it was right, but I was not in a state to do anything about it at the time. You can get upset about things like that and if you're feeling emotionally well you can go and tackle them and say what the hell do you mean? You had no business doing that sort of thing but when you're not emotionally well, it's too much. (01)

> The night we came home and my husband was really tired, he went to sleep and I stayed up. I turned the TV on and it [son's accident] was on the news, you know how the media is. I didn't know that. I just put on the TV and then they were saying about [the accident], and I'm listening and I couldn't believe it. All I wanted to do was scream at them and say you don't know the whole [story]. You guys don't know anything. I was angry. I was so upset. I didn't know about it....The paper out here asked us if they could do [a story]. We said fine...they said exactly what happened, that he [son] was in an [accident] and that it was still under investigation and they [family members] were angry and my husband, I think that's how he felt. He was just drained and he said listen, that's exactly what happened, what's the difference? But when it's on TV, I felt like screaming, they [journalists] make it sound so cold and hard but I thought they don't know us. They don't know anything. They don't know what we've been through. They don't know that something good has happened out of this [organ donation]. They don't know anything. I was just angry. (09)

Another participant shared that she felt the intensive care nurses were not supportive of her or her family members. She felt that she spent a great deal of time waiting for the completion of tests, and as a result spent long periods sitting and waiting in the intensive care unit waiting area. As a result, she felt that the staff were not available to her, did not provide a supportive environment, and did not care about her emotional well-being.

> It seemed like we'd sit there and sit there and sit there, like what's going on in there? [Intensive Care Unit]. We finally took it upon ourselves to go in and see what was going on. He was in a little area by himself. The nurses weren't there doing anything. He was just there. There was

> no doctor. There were no nurses. We went back two or three times or we'd go and then we'd let the kids go or the aunt and the cousin go...But any time I was there, there was never a nurse in attendance or a doctor. Like all they're doing is waiting, waiting....Like they're obviously not doing [anything]. Yes, they had the respirator on him and they had monitors on him, but nobody knows what's going on, or doing anything either way. (07)

One participant felt that her daughter was not given sufficient time to say good-bye to her father. She felt she was an intruder when visiting at the bedside because the nurses were busy doing the necessary donor care without allowing the family privacy and time with their loved one. As well, she thought the nurses should have been more aware of the family member's intense grief and feelings.

> You knew that they [nurses] were busy and I know my daughter shared with me, she said they couldn't even wait. You know, I was trying to say goodbye to dad and they were busy doing this and doing that and I think she was feeling like I'm trying to say my goodbyes here and you're rushing around doing this even though it had been explained to us that it was important to get these samples and to do these things...I guess in that state it was important to say, you aren't in the way. We have to do this to keep his organs viable. In her young mind it was we have to get on with our work...It would be something to say to the [nurses] to say to families, please feel [free to stay as long as you like] and I'm only here [to give the necessary care], I'm sorry if I'm intruding on your time but in order to make this work we have to do this as soon as possible and just what you're doing is reaffirming to that person that they're not an intruder and you're not disregarding their feelings. (06)

Enacting Religious Rituals

The second element of the Work of Waiting and Vigilance is to reflect on one's personal belief system and enact religious rituals that provide comfort. Pastoral care offered spiritual support and guidance when the participant felt that prayer would give them the solace they were looking for.

> I changed to RELIGION when my husband and I got married but I was raised RELIGION and my husband wanted to have the priest come in; actually it was the nurse's idea, but she asked me and I said yes. Get the priest to come in because I knew my husband would want that. He [priest] had us all join hands and pray for a miracle, and I thought to myself like I'd pray for a miracle. I haven't been a person who has ever believed in miracles. I think that you're on this life and you're out there taking your chances, and a miracle is good luck, but in this case I prayed for a miracle. I hoped for a miracle, because I knew he [son] needed a miracle, when we joined hands I thought there might be a miracle. There might be a miracle, it might happen, you know, because you want it so bad. (04)

> We're from a RELIGIOUS background so it's funny, you know, because I had so many different feelings [about organ donation], I thought good Lord...I kept thinking about the end

> times and they say in the Bible how you're reunited with your body and I said to my dad, but her body will be missing parts....Dad said it has nothing to do with what you've done. What you've done is given other people life, a chance at a good life, and it's true....I don't know how people could get through something like this without having faith or a belief [system], you know, I know I'll be reunited with her one day and I know she's with me so I take a lot of comfort from that. (05)

Another participant shared that her daughter was baptized prior to her being declared brain dead. The participant stated that it was important to her family that she be baptized; thus pastoral care was instrumental in enacting this service.

> I never had her baptized. Except for that night [before she was declared brain dead] they [participant's family] had her baptized. It was kind of tradition. I don't know if I requested it or if my husband did....And then I guess the finality of [her death]. It really didn't seem important but yet I guess it was important for other family members to have it done. (03)

In almost all cases, pastoral care was offered to the participants. This form of support was helpful for many of the participants. However, depending on the participant's beliefs and ethnic customs, pastoral support may be of little or no assistance to the participant.

> We were asked if we wanted any clergy and we said no. Because we're not religious people and the last thing we needed was really just platitudes, O.K. You could pray but we didn't want the religious prayers. There's a difference to our way of thinking. (01)

Coping with the Declaration of Brain Death

The final element of this phase of Work of Waiting and Vigilance is waiting for the declaration of brain death. This was a very difficult experience for all participants. Once the brain death testing was completed and confirmed, the physician then approached the participants about considering organ donation. Often, the organ procurement coordinator had been notified prior to the completion of the second brain death test, and was then available to the participants as a resource person to assist them with their decision-making process.

> When he came back up [from CAT scan], he had four stroked areas in his brain, his brain had impacted with his skull so we knew then [that he was brain dead]....Then they did a dye test [cerebral angiogram] and an electrical test [EEG – electroencephalogram] again and nothing was working so we knew he was brain dead...I think he [physician] understood when he saw me that we were prepared for the worst and then he asked [about organ donation]. He [physician] told me that he [son] had all the stroked areas and that there was no hope but he

> would do this one final test, but it was just basically to confirm what they already knew, to confirm brain death and then he asked [about organ donation]. (09)

> They [doctors] mentioned it [organ donation] to us then, and then they contacted the person from the [Organ Procurement program] and that person waited actually until they had pronounced him dead before they went through the intricacies of [the organ donation process] with us. But it only took a short time after because it was all kind of set up before he was pronounced dead. (04)

When faced with a very traumatic incident, emotional shock can be so overwhelming that the family members are unable to cope with the reality of the family member's death. In this instance, they do not understand the significance of brain death testing, nor believe in the conclusiveness of these findings. In this case, they do not understand that their loved one is dead, that there is no hope for recovery or survival and consideration of organ donation would only be offered by the physician if brain death was confirmed by the brain death tests. The ambiguity in this situation caused the participant to experience tremendous feelings of confusion and very negative feelings about her organ donation experience in general.

> They [physician and nurse] took my daughter and I into a room. They didn't give us much hope and then they talk to us about organ donation. [Became very emotional]. I guess as soon as they brought up if we would consider organ donation, I mean at that point it wasn't really clear in my mind that he wasn't going to survive. That was kind of the indication that I think I'm getting the message here that he's gone....And you're in a state of shock, and I was having these terrible feelings....All I knew is it didn't feel very good at all, which confused me because you're supposed to feel good when you [agree to] donate a loved one's organs and I didn't feel good. I didn't feel good at all and it was because I didn't know what was happening....I needed someone to say he's gone. Yes, he is. Like look me straight in the eye and tell me that. And even if the doctor has told me that, or now maybe that's my own personal way of coping, but when I look back at how confused I was even though they were probably telling me....Maybe they had to tell me ten times instead of five, you know. (06)

Once the waiting is over and brain death declared, the participants are then given the opportunity to consider organ donation. The work of decision-making begins when participants explore their thoughts and feelings about organ donation. Chapter 6 will identify and explore the tasks subsumed within the work of decision-making phase which include: seeking and gathering information about the organ donation process; identifying and exploring all pertinent influencing factors that assist in determining one's understanding of the donation process; and lastly weighing all pros and cons associated with the donation process.

Chapter 6: Work of Decision-Making

Decision-making is an integral component of the cadaveric organ donation process. Participants are given the opportunity to consider organ donation on behalf of a brain-dead family member, yet the decision is not an easy or straightforward one. The difficulties in making decisions at this time were twofold. Firstly, participants were just told of the death of their family member and were experiencing intense grief and a profound sense of loss. As well, the death of the family member was unexpected, usually, although not always, resulting from a traumatic event, such as an accident. In several instances, the accident involved more than one member of the family.

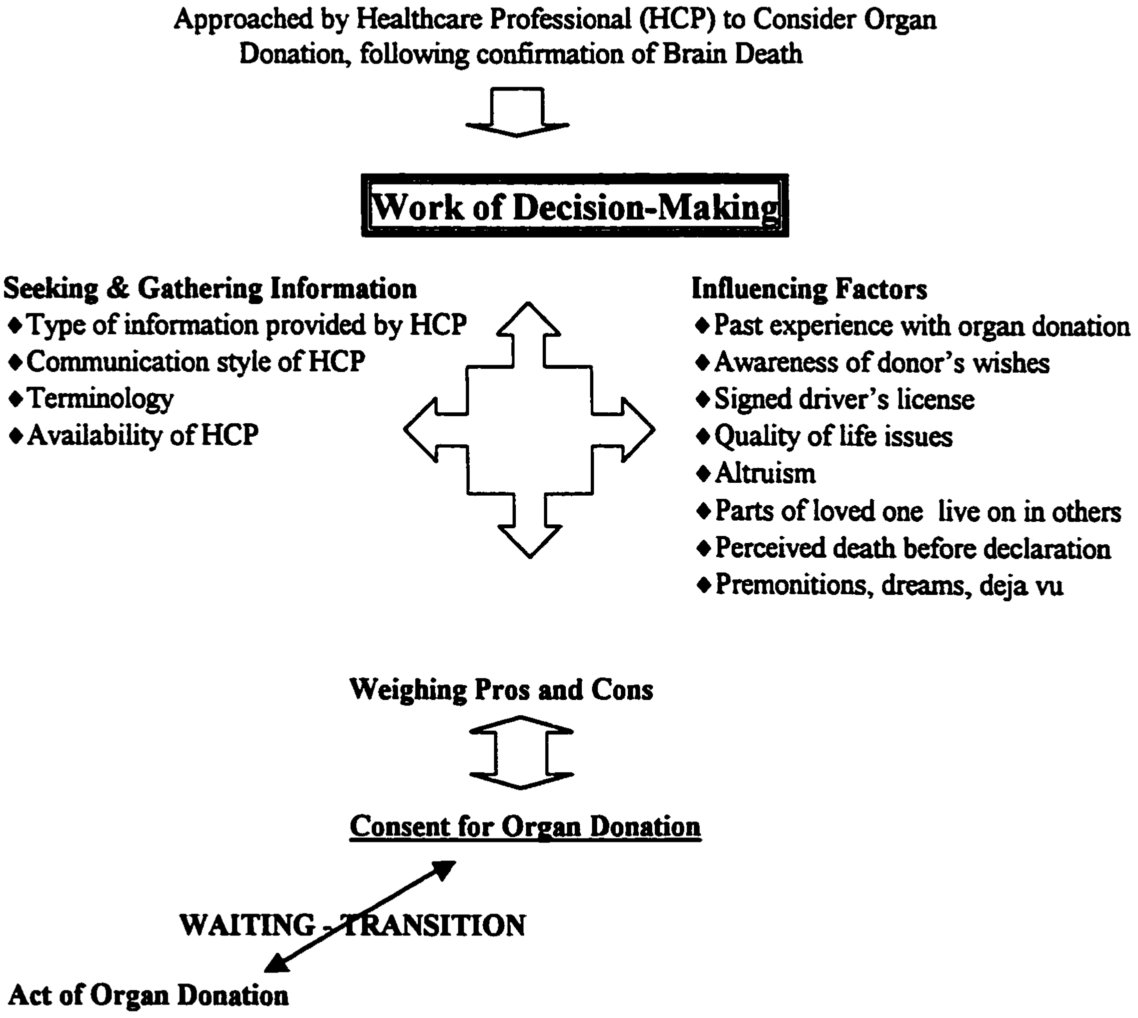
> The RCMP came and he told me that there was a motor vehicle accident involving my family but he didn't tell me how serious. He just told me that my kids were O.K.. that they were in the ambulance and my husband was being airlifted to the [Name of Hospital]....My son was fine....I think I probably waited, oh, it was a good hour and a half before I even knew about [my husband] or [daughter]....My husband was in a coma, on a respirator so they took him away [to ICU], and we proceeded up to the pediatric ICU. We waited probably another half an hour before the doctor would come out. When he came out he told me that she had a severe head injury, a blow to the head and that there was no response, she was on a respirator....I kind of knew that it was pretty bad for her and at the same time I didn't know about my husband either because I mean we went in to see her. It was just awful for me because she [pause], there was no life. At that point she was still all covered with blood and she was so cold, ice cold. So they start heating her up and they said they'd give it some time. Maybe as they raise the body temperature there would be brain activity because at that point there was no brain activity. And so throughout the course of the night there was really no change. They did different tests, the water tests in her ears [one of the brain death test] and there was no response....We had a meeting with the doctors and they had said that she was brain dead, and that was when they brought up organ donation....I don't know if it was shock or what, but I didn't want to make that decision right away. I wanted [husband], I wanted it to be a joint decision. So then we agreed we would wait to see if he was going to come out of [his coma] because they had him so heavily sedated that he wasn't responding. So then they eased up on the medication, morphine or whatever they were giving him for pain to see if maybe he would come around. They tried that, but then my sister came to me and said that [daughter] was, her organs were starting to fail a bit, that we couldn't wait to make a decision....I signed [the consent form for organ donation] and I went that night to say good bye and it was like I knew. She wasn't there, so I mean it was a hard decision [becomes slightly emotional]. (05)

Secondly, the opportunity to consider organ donation must be done in an expeditious manner so that organ viability is ensured. Thus, many participants experienced a sense of urgency when making their decision. One participant shared:

> NAME [organ procurement coordinator] came back and said, "Well, I've got to get you to sign the papers [consent form]. It's got to be done soon because everything's going to be shutting down shortly. Like it's not your choice anymore. It's the body shutting down. It's got to be done." (07)

It is within these constraints that decision-making takes place. The Work of Decision-Making is composed of three tasks, seeking and gathering information, identifying influencing factors and weighing the pros and cons [see Figure 3]. Each of these tasks will be identified, explored and then examined in relation to each other.

Figure 3. Components of Work of Decision-Making



Seeking and Gathering Information

The reality of their loved one's death and the simultaneous request by the physician for organ donation is an overwhelming experience that confounds the participants' ability to attend to even the smallest amount of information. Emotional shock further clouds the participants' ability to think clearly and understand any information shared by healthcare professionals.

> I think it started just as a yes/no decision [regarding organ donation]. Like it's, it's such a blur. And it's hard to think because you are thinking about what's the best thing for your child, and it's hard to think about other people at that time, you know....It's so clear in my mind, yet the events that happened aren't. I don't know how to explain it really. (02)

Many of the participants shared that the physician prepared them for the imminent death of their loved one prior to exploring their interest in organ donation. This provided an opportunity for the participants to understand the concept of brain death and eliminate any lingering doubts as to the finality and permanence of brain death. The importance of understanding the concept of brain death cannot be overstated. Without a clear understanding of this concept, the participant had ambivalent feelings about their organ donation experience.

> I didn't feel like it was clearly explained to me that they had determined that he was brain dead; because of what was happening, they were going to do this [test – EEG] and see if there was any [brain] activity. So I guess the point of determining [that brain death was confirmed was very ambiguous], I felt very unconvinced that are you sure that there is [no brain activity]. I didn't feel like anyone explained [becomes emotional], we did this test and [it was conclusive]. (06)

Type of information provided by healthcare professionals. During this phase, the task of gathering information started with a healthcare professional, usually either the physician or the organ procurement coordinator, discussing with family members what the organ donation process entailed. The type of information provided at this time included a brief description of brain death tests, findings of these tests, which organs and tissues could be donated, different tests that were necessary to determine which organs could be retrieved, the necessity of continuing mechanical support measures to ensure the viability of the organs and tissues, and the logistics of coordinating the O.R. and the surgical retrieval of the organs. Although participants stated what information was provided, almost all of the participants were unable to reiterate what the specifics of this information included; yet the majority of the participants felt they were given sufficient information to make an informed decision about organ donation.

> What I remember more than anything is that I hadn't realized how much of the body could be used and for what. From everything that you hear about heart transplants, liver transplants, kidney transplants, but there was a research project that required a section of the small bowel, skin donation and of course, cornea I knew about. But all these other things, not maybe immediately transplanted into the body but for research purposes, and do you want this or that or the whole gamut or what. I certainly wasn't prepared for that and I was a bit taken aback. I guess I just wasn't prepared because I knew about the organ transplants, but I wasn't aware of all these other things. (01)

> All I remember is that the doctor said that they couldn't harvest the organs until the boys were pronounced officially dead. And then he [doctor] said that they would be kept on the ventilators and whatever they had to do to keep them alive until such time as the O.R. time could be scheduled. And at that time when the organs were harvested, they [organs] would be immediately transported by plane to whatever location where the recipient [lived]....I remember them saying that they didn't know for sure what organs would be usable because in the case of motor vehicle accidents, sometimes there's trauma that isn't readily apparent before the official time of death and in [son's name] that was true....They did say that they did x-rays for the heart and lungs. A lot of them, I think they might have used some of the tests that had already been done to determine the injuries of the boys...[and] what they might potentially be able to use. And beyond that as far as [what] information [was provided] I think that was about all. (04)

The majority of participants felt overwhelmed by the choice of organs and tissues that could be considered for donation. Because of their limited knowledge and understanding of organ donation, considering the numerous choices was overwhelming, very disturbing to consider, and difficult to discuss. Several of the participants shared these thoughts:

> I certainly wasn't prepared for that [selecting organs and tissues], and I was a bit taken aback....It's a horrible analogy but it's almost like going into a restaurant and looking at a menu, you know. [she chuckles]....And I guess when it came to a point we just said well, what the hell, one part's the same as any other part and it's for perfectly good, ethical, medical purposes so whatever is needed, [take it]. (01)

> We were told that NAME, because of the extent of his injuries that with the exception of his brain everything else was working and functioning well. He'd been on life support for the four days. ...and he had been on the heart monitor and the [ventilator] so nothing had happened to any of his organs. They specifically mentioned heart, kidneys, liver and actually his eyes but I refused that because I didn't want them touching his eyes. It's strange because they had not mentioned his lungs. At that time, it was an oversight because about two hours after we got home from the hospital the hospital called and said, "You know, we're really sorry to bother

> you but we forgot to mention the lungs, may we add them to the list?" And they took my permission over the phone, so they did discuss the various organs. (08)

Subsumed within this organ and tissue selection process, several of the participants shared that they felt very strongly that their loved one's eyes or corneas not be procured. When asked why the corneas were more significant than any of the solid organs, participants shared that the eyes mirrored their loved one's spirit and personal essence.

> NAME's eyes were like marbles and the nurses, when he was born, called him bright eyes and I loved his eyes and I just didn't want them to touch them....It was a totally irrational personal thing but it seemed to me that his eyes were always him to me. (08)

> When she [organ procurement coordinator] was talking about all the different organs they could take, I was thinking, don't take his eyes....Because NAME would say, "Mom, how in the heck do you know what I'm thinking, or [what I'm up to] I look in your eyes, NAME. Everything's told by your eyes." I'm sitting there when she's going through this list, they can use the corneas and [I'm thinking] please don't take the eyes. But is it wrong or is it going to sound ignorant if I say please don't take his eyes? Take anything you want but please don't take his eyes. So in the end I didn't say anything, [I said] take what you want or take what you can....There was too much swelling for the eyes to be used and I thought oh small blessings, somebody's actually watching out for me. (07)

One participant did not fully understand how the corneas were procured. She thought that if the corneas were retrieved, her loved one's physical appearance would be altered. The participant felt that if a healthcare professional had explained the retrieval process that she would have consented to corneal donation after all.

> So once we had decided that yes, we were going to do this, we then had to decide what we wanted to donate. Just the eyes were a bit of an issue...I didn't want him to look marred or anything. I've since learned that actually with cornea donation, the whole eyeball [is not taken] out so that would have helped me at that point if someone had said [that], if I could have understood that a little more...Because we were openly saying we were worried about how he looked. (06)

Several participants shared that they were not concerned about mutilation of the deceased's body because of the information provided by the healthcare professionals. The organ procurement coordinator was instrumental in explaining the surgical procedure to the participant. Her assurance that their loved one would be treated with respect and dignity was reassuring and soothed any fears the participant had about the donor's body being disfigured.

> NAME [organ procurement coordinator] was finalizing her talk with us telling us...she'd stay by his side to assure that there was no mutilation of the body, that it was a nice clean surgical incision and that he'd be stitched back up...She assured us that he would be treated with respect. (07)

Seeking and gathering information is facilitated by several pertinent behaviors of the healthcare professionals, namely communication style, terminology used and availability. The participant's perception of these healthcare professional behaviors will be explored in detail, and their influence on the participant's decision-making process will be explored.

Communication style of healthcare professionals. Participants all shared that their understanding of information gleaned from healthcare professionals was directly influenced by how the information was presented. Healthcare professionals who developed a rapport with the participant facilitated the participant's understanding of the information imparted. Any hesitancy, vagueness, or less-than-candid communication by healthcare professionals caused participants to experience feelings of uncertainty about the information that was shared. Such uncertainty, as noted in the quote below, led to the decision-making process becoming more agonizing.

> The emergency room doctor was trying to make us aware of the reality [of son's life-threatening injuries]. He was very thoughtful, very considerate and he had one hell of a job having to get families to the realization of the seriousness of a situation like that....Then the Neurosurgical resident came and talked to us and he was very sort of cut and dried in his manner....I don't want to criticize him because, God. Here we are in the small hours of the morning, a very taxing job that he'd just been doing but he was more distant whereas the emergency room doctor was sort of making a bit more emotional contact with us. I think for his [Neurosurgical resident] own sake, which I can understand entirely, he needed to just be very professional, very cut and dried and sort of see in the morning sort of deal. (01)

> The nurses said that there wasn't really much hope. To me he was gone. There was no question about it. Now how am I going to get everybody else to see this because all evening his dad would say, "Well, the doctor said if." You know if he happened to wake up or survive this he would be a complete vegetable. He'd never walk. He'd never talk and he [husband] kept hearing if this happened instead of, he's gone. I saw he [son] was gone and my husband heard 'if'. You know, if he woke up, he'd be this, he'd be that. So there was this chance they had to hold out for....I mean I don't know how long we could have kept him on a respirator or functioning but [NAME - organ procurement coordinator] ends up coming in at three or four in the morning and saying, "Well, it's not your choice anymore, that the body is shutting down and there's not going to be any control of it" and that's when I think it started to come easier for [my husband] to say, "Yeah, O.K." Just saying no, he's gone [brain dead] so now let's let him go, sign whatever we have to sign, do what we have to do. It's done. (07)

Conversely, a strong rapport and candid communication by healthcare professionals gave the participants a feeling of confidence in the healthcare professional and the information that was shared.

> The doctors were very candid with us the entire time. Even when I came first into the emergency, they just as gently as they could told me that his injury was a fatal injury and I knew what that meant and then, like during the day I saw him move and I would say to the nurse, "Do people ever come back from an injury like this?" And she would say, "No. No. They never do" and so I knew he was in a transition between life and death and the doctor came about three o'clock in the afternoon and said to us that NAME had no chance of recovery, that his brain injury was too severe and would we consider organ donation. (04)

> Dr. [NAME] who was one of the doctors that was in the pediatrics unit with [son's NAME]....I liked him particularly because he let us know all along, he told us straight up that he wouldn't return to us a brain-dead child and he wanted us to know that if he felt it wasn't worth it, he wasn't going to continue any longer with operations or being on life support for months and months....He was straight up honest. He explained to us what the things on the machines meant, that is the pressure in his head [Intracranial Pressure – ICP] and that was very comforting at times because in the early stages it was at three or four, and anything under twenty is really not a concern. I remember all that and then it started to climb up and he'd say we have a drain and we can drain [the fluid in his brain]....We just knew because we were following the ICP levels and the pressure had gone up from a low amount to hit a 100 at one point so we knew it was pretty bad....He told me that he had all the stroked areas [in his brain] and that there was no hope but he would do this one final test but it was just basically to confirm what they already knew, to confirm brain death and then he asked [about organ donation]. (08)

Terminology. Terminology used to describe the process of cadaveric organ donation can be upsetting and very disturbing to participants. The use of terms which foster feelings of unpleasantness inhibit the participant's ability to attend to the pertinent information imparted by healthcare professionals. Some participants felt that the term "harvesting organs" was a very impersonal, cold and unfeeling way of describing organ procurement.

> It's [terminology] very cold. Very medical. Not really putting a face to it. Not really attaching human feelings to it. (03)

> I hate the word 'harvesting'. You use it when you're culling out the weakened animal in husbandry. I probably wouldn't have noticed but I know that the word 'harvesting' wasn't used. Those words, that depersonalizes your child or your loved one quite a bit...Actually it's not only unsettling. It would be just totally insensitive. Because [it reduces your loved one] to a piece of meat. [half chuckles] I think I'm not the only one that's probably strongly against terminology like that. (08)

Although not used by healthcare professionals, the term was familiar to the participants via personal knowledge and the media. However, some participants used the term "harvesting organs" themselves as a means of describing their experience. In these cases, none of the participants felt uncomfortable with this terminology.

> It [terminology] sounds a little bit cold. It's not a personal thing. Personally, it doesn't bother me a bit because my son is dead. His body is just a shell. If someone harvests what's left for someone else's benefit, to me that all that's [important]. The organ is no more my son than this placemat is. That's just a part of him and if somebody else can use it, it's just like if your car breaks down and the carburetor's good in the old one [you switch parts], right. To me it's [terminology] not offensive at all. But it may be offensive to some people who haven't had any medical talk [used] around them. (04)

The terminology most often used by healthcare professionals to describe the organ donation process included organ donation, organ retrieval, and organ procurement. Of interest is that the majority of participants felt that the terminology used by healthcare professionals was appropriate, sensitive and non-threatening.

> The people were very careful how they approached us. They were very careful in how they phrased it, that they wanted us to consider donation and they were very careful in asking, like presenting to us that they didn't want to put any pressure on us....I thought that they were absolutely perfect as far as tact and diplomacy and trying very hard to be considerate of our feelings. I don't think anyone could have done better than the people that we dealt with. I thought they were just wonderful. (04)

> Procurement was used. I didn't have a problem with procurement. Donation was used the most. (08)

Availability of healthcare professionals. Availability of healthcare professionals also facilitated the participants' seeking and gathering of information. The majority of participants perceived the healthcare professionals desired to be available to assist them in coping with their situation, providing the necessary information to make an informed decision about organ donation, and to answer any questions that they wished to ask. Several participants stated:

> They [healthcare professionals] stayed out of our face unless we asked them for something, but they were always there in case we needed something [from them]. I just have nothing but good things to say about them. (04)

> They were wonderful. And they took the time, like everybody you talked to seemed like they had the time for you, which was good and even to share little things, they were just great. (09)

A helpful strategy used by the organ procurement coordinators to ensure that they were available to the participants was to provide a business card with telephone numbers where they could be reached. This strategy encouraged the participants to access the coordinators as resource persons when and if they had any questions concerning their organ donation experience. Many of the participants shared that they did call the coordinator with questions and that it was nice to have that resource when the need arose.

> They [organ procurement coordinator] gave me a business card that if I had any questions I could phone there. And I did phone one time that I had a question. I can't remember what my question was, and she answered it, and that was sufficient for me. (04)

> I do contact the [Organ Procurement] program twice a year. [I like to inquire] about how the kids [recipients] are doing...It makes me feel wonderful...It's usually around MONTH when the accident happened, and around Christmas time...I felt really grateful for the information...(09)

One participant felt that a business card from the organ procurement program would have been a valuable resource. She did not receive this resource as no organ procurement coordinator was with her during her donation experience. Thus she had no idea who to contact to follow up on results of the organ donation.

> It would have been nice if when they did [the surgery], if they told us this organ or that organ was used, a phone call from the coordinator or someone would have made me feel a little bit better sooner on. By the time I got that letter, I was almost angry. Like gee, what did they do with it [organs]? Did they use it? Didn't they? I didn't really have a [business] card. Who could I phone and ask that of? I didn't, to tell you the truth, I don't even remember who the doctor was. I didn't even know the doctor's name. That's maybe another thing, that if someone's [situation could] give a business card that you can have someone to give them so you can look at calling later. (06)

Influencing Factors

Influencing factors are unique, personal, and timely variables that the participants must take into consideration when making their decision about organ donation. These factors are influenced by the participant's knowledge, beliefs and values concerning organ donation. Influencing factors identified in this study include: the participant's previous experience with organ donation, either by a previous donation experience or indirectly through the media; knowledge of the loved one's wishes concerning organ donation; signed driver's license, healthcare card, or organ donor card; quality of life issues, altruism, knowledge that parts of their loved one would live on in others; the perceived death of the loved one prior to completion of the brain death test, and if the participant experienced any premonitions or dreams of the family member's death.

Previous experience with organ donation. Previous experience and knowledge of organ donation came in many forms. Some participants had family members who had shared their experience of cadaveric organ donation that occurred years prior to the participant's current situation. Another participant agreed to organ donation on behalf of her sons when they were killed within six weeks of each other. The previous donation experience was very positive in nature and facilitated her quick decision in favor of organ donation for her second son. Others had knowledge of organ procurement and transplantation via the media in the form of television specials and newspaper and/or magazine articles. All information gleaned from these experiences was instrumental in assisting the participants to make an informed choice in favor of organ donation. Participants shared:

> Well, I followed the stories in the newspapers [about organ donation and transplantation] and was always interested in them. I remember Christian Bernard and the first heart transplant. I've always been interested in medical things....I'd read these stories about transplants and organ donation and I'd think oh gee, just imagine being in that situation, never dreaming, of course, that one day I would be in that situation. (01)
>
> I have an aunt that lost a daughter 25 years ago and she was AGE. It was also a car accident....She gave her daughter's organs up for donation too. She was brain dead as well....So that really had a lot of [influence on my decision], she was really good to talk to. (05)
>
> Not quite 6 weeks after our first son was killed, our second son was killed instantly in an [accident]. He was very badly injured...They pronounced him dead...and they didn't even know if they could keep him alive to harvest the organs....They got the lady [organ procurement coordinator] so fast, they were very sensitive to the fact that we'd just gone through this less than 6 weeks before. (04)

A social consciousness concerning the shortage of organs needed for individuals suffering from end-stage organ failure also influenced several participants' decision in favor of organ donation. The participants shared past experiences of individuals who required organ transplants, and because no organs were available, these individuals died. This experience had a profound influence on the participants' decision to agree to organ donation.

> I can still remember when [daughter] was only 3 weeks old, we were in the CITY and I had seen a little guy in the pediatric [bed] beside her....We had been back and forth for probably a 3-month period and I remember seeing the same little guy. They had told me what was wrong with him, that he just needed a liver...[He was so] vibrant and alive then. Coming back and forth to the ward and seeing [the drastic change in him]. We came back a week after he passed away. They had pictures of him up on the [wall]. I was devastated....All this little guy needed was a liver. (03)

> Well, I'm a nurse so I knew about organ donation....A person that's healthy doesn't really realize how much an illness like a kidney or liver disease will keep somebody from enjoying the simplest things [in life]....Being in the hospital, you see people who are going to die because they can't get a [organ] donation, and they would live for years and years if they had it [organ donation]. (04)

Awareness of deceased's wishes concerning organ donation. One of the influencing factors that had a profound effect on the participant's decision to agree to organ donation was when the deceased's wishes concerning organ donation were known. Several of the participants had discussed organ donation with their family members, and that discussion resulted in the family members signing their driver's license. One participant shared:

> When my sons got to the age of [obtaining their] drivers' licenses, I told them [to consider signing] the back of their license so that in the event they were injured their organs could be donated. Both of them had done that. And so I know that [organ donation] was something that they would want. (04)

Other participants shared that their personal views on organ donation and that of their spouse were instrumental in deciding in favor of organ donation. Certainly when the donor was one's child, it was necessary for the participant to reflect on his or her own feelings and beliefs concerning organ donation. These personal beliefs and values were then used to guide the participant's decision to consent to organ donation on behalf of the deceased child.

> We'd always had a kind of social consciousness when it came to helping out and things like that but I don't think we'd ever, we'd never discussed losing a child. We had discussed with each other in terms of whether or not we would donate organs so we both knew that the other one was going to do that, so it wasn't too much of a stretch [to consent to organ donation on behalf of his son]. (08)

All participants in the study had signed either their driver's license or their healthcare card. Thus, the participants were already strong advocates for organ donation for themselves, and this choice then influenced their decision to agree to organ donation for their loved one.

> They [physicians] asked if we wanted to consider it [organ donation] and I had no hesitation in saying yes because it is something that our whole family had been very supportive of....When we had our license renewed, we had both discussed [organ donation] and we've always been strong advocates so for us it wasn't a difficult decision. Like this is something that he or I would want to do. (06)

Quality of life issues. Several participants shared concern about a loved one's quality of life if he or she lived with a grossly debilitating brain injury following their accident. Thus, the issue of quality of life for their loved one had a tremendous impact on their decision-making process. In one case, the participant felt that it was one of the deciding factors in favor of organ donation. She stated that she could not imagine her son living with gross physical and mental disabilities, with no hope of recovery and no quality of life.

> I think for us we'd always sort of talked about the quality of life type of issues...I don't want to have a long, lingering death. The heroic measures type of thing, you know. To have some of these people being kept alive for years and years and years and for what? That is not life, by my definition, granted. But certainly the feeling for us was that would be unacceptable. My husband always said to me "Well, if I'm ever in that situation pull the plug on me. [chuckles] Don't worry dear, I will!" So I think some of those issues were already fairly well defined for us, and we weren't going to [allow] that sort of thing....It's never easy. I think maybe because it was a brain injury that might have made it [decision to donate son's organs] easier...But knowing what the implications are of a severe brain injury, I felt, and my husband felt, the same way. To have someone survive a very serious brain injury might be worse than death because that person is not the person you have loved and cared for all those years. I think maybe that can be an even bigger adjustment to make, a bigger challenge to face than the loss [of your loved one]. To see that person physically resembling your loved one but so altered and to know the kind of life that person was leading and to see the kind of life they will live [after the brain injury]. I think that would have been harder for us. If someone is paralyzed and in a wheelchair, their brain is still there. They still have their personality intact. They have challenges to meet but that person you love is there, is recognizable. They're [only] physically limited. I think the other way for me would be much, much harder. (01)

Conversely, another participant stated that both she and her husband felt very strongly that if their child's life could be saved, no matter what physical or mental disabilities were sustained as a result of the brain injury, that they wanted their son to survive.

> A doctor from emergency took my husband and I to a small room and explained the situation and asked us at that point if we would consider donating his [son's] organs. My husband indicated to him at that time that we would take him home no matter what condition he was [in], even if he was a "vegetable" or whatever...But he assured us that the situation was not good [son was brain dead]...so we decided that we would donate [his organs]. (09)

Altruism. Altruism is another influencing factor that had a profound influence on the participant's decision to agree to organ donation. All participants shared that they wanted very much to help another individual have a "healthy" life and to ensure that other people did not experience the pain of losing a loved one.

> We became aware that there were other people who were facing a potential loss too and that potential loss could be averted [by donating son's organs] so that's how we looked at it. (01)

> My family was strongly in favor of the donation. And everybody that had input back to me about it [son's organ donation] seemed to feel the same kind of comfort that I did, to think that some parts of our boys were going to make somebody else a healthier, stronger person. And it makes you feel better to know that you did good for somebody else...that somebody else was doing better on account of they got a donation from my son[s]. (04)

> I think it's because I felt like there was nothing we could do for him but if we could do something for someone else, if something good could come out of it, that if we could help someone else, if NAME [son] could help someone else, that would be wonderful....At the time you think well, there's nothing more we can do. If we can help someone else, why not? (09)

As well, many of the participants shared that it was important that something good come out of their tragedy. The participants felt that if another person could benefit from organs that were no longer required by their loved one, that it was important to share this gift of life to prevent the senseless suffering and possible death of others.

> NAME had no chance to recover, that his brain injury was too severe and [we were asked to] consider organ donation. Both my husband and I agreed immediately, that would be the thing to do because he was young and perfectly healthy. It seemed to us that some part of this tragedy ought to be made good for somebody else...We knew there would be no dissension and there has never been any. Both our daughters, and for that matter all our extended family, I think they've been glad for us and for their own selves too to know that our boys' death meant some life to other people. (04)

> [It was important] that he'd be able to help someone, some other child would still be alive based on the fact that he was dead...It's an awful thing that something totally unexpected or unforeseen can take a life and then you think that that life was completely in vain. Thinking that another child or another person could be helped takes away some of the emptiness. (08)

Another component of altruism is the belief that their loved one would want to help others if the decision was theirs to make. Participants shared that their loved ones were kind, caring, and giving towards others and that they would want to help others by agreeing to organ donation.

> NAME, was a very sharing child and even in death he was able to share [with others]. (08)

> I knew beyond any shadow of a doubt that if my boys were able to speak for themselves they would say, "Sure, give them away" because...we very much [wanted] to help people if [we could]. And I know both my boys were very generous and caring and giving people and I know without a doubt, and so did my husband that they absolutely would want some use made of their death if it was possible. There was no doubt in our minds it was the right thing to do. (04)

One participant shared that it was very comforting to know that other people would have a better quality of life from her son's generous gift of life. These feelings were confirmed in discussions with friends and family, as others also felt a sense of comfort from the act of organ donation.

> Everyone I [spoke to about my organ donation experience] seemed to feel the same kind of comfort that I did. To think that some parts of our boys were going to make somebody else a healthier, stronger person. And it makes you feel better to know that you did good for somebody else....It comforted me to know that other people were proceeding with their life, having an easier time in their life on account of my sons were able to contribute to them and it comforted me to know some good came out of it for somebody. (04)

> We tried to look at it that something good happened out of it [son's death]. I mean let's be serious, five children have a better quality of life because of my son, and that does make us feel good. (08)

<u>Parts of loved one live on in others</u>. Some participants shared that it was important to them to have their loved one live on in others. They felt that their child's life was so short and unfinished, and that parts of the child would then live on through the recipient. This concept assisted several of the participants to agree to organ donation for their child.

> At the time I just felt that if, I don't want to sound noble or altruistic, but I felt very strongly that some part of NAME [son] had to go on living. I don't feel that way now because obviously the organs that were donated belong to children that we don't even know and will never know but at the time I thought that this was one way of keeping him going. (08)

> It's [like you come] full circle. I mean when she passed away, it was so final. It's done. There's nothing more you can do and maybe because of those different experiences I hadn't gone through with her [going to school, friend's birthday parties] that I held on to that [organ donation], that it [her life] wasn't completely finished. She did go on. She did live. She does live on through [other children]. There are little parts of her out there somewhere. (03)

> [Organ donation] did make us feel good [because] we knew that another child was able to use part of our son. It made you feel like there was still a part [of him] alive...I don't know, it's something to hang on to, I guess. (02)

Perceived death prior to confirmation of brain death. When brain death was formally determined by brain death criteria and when the participant actually believed their loved one died could often be two different points in time. The disparity between these times has implications for the participant's perception of when healthcare professionals, specifically the physician and organ procurement coordinator, should approach the family about organ donation. Several participants felt that their loved one died long before the conclusion of the brain death tests. In this scenario, the participants unanimously believed that the organ procurement coordinator should have been available to the family to discuss the organ donation process, prior to the completion of the brain death tests. They felt that this time could be used to better understand the donation process, answer questions, and begin grieving.

> The doctors were very serious. They explained to us about brain swelling and lack of oxygen to the brain. Both of us have enough knowledge to understand the implications of all of that and what it means....I held my son's hand and I said it in front of the doctor. I said he's not here. I said he's gone. He's not here. I don't know what made me say that. It wasn't something that I'd consciously thought of. It was just the words came out of me....I think we understood completely that there was almost no hope at all....I don't think it was until the following morning, when we were waiting for the doctors and they were doing the tests for brain death, that the subject of [organ donation] was brought up....We talked to the physician again and he said, "Well, after the second test confirms that there's brain death, then we'll arrange for someone [organ procurement coordinator] to come and talk to you"....From my point of view, I would have liked to have been able to talk to her sooner, you know what I mean? I understand why it wasn't done but because we were already prepared for that [son's death] I would have liked to have had some of the information or someone from the [organ procurement] program come and talk earlier....[She – organ procurement coordinator] could

> have explained the way the whole system worked so that we understood what their role was [in the organ donation process]. (01)

> From the moment I saw NAME [son], I knew that he was gone because his eyes were so vacant. His eyes were always so bright and that's where all the spirit was. You could tell all his moves, all his thoughts through his eyes. So when his eyes were so vacant, I knew, to me he was gone already. But up there [CITY] they hadn't seen him but they had told us down here [TOWN] that they were sure that he was not going to survive. (07)

Another participant shared that even though her child was not declared brain dead, she felt she could have benefited from early intervention by the organ procurement coordinator. Additional time prior to the official declaration of brain death could have given her more time to consider all pertinent information, thereby eliminating the sense of urgency that she experienced.

> Maybe, even before the person was actually pronounced dead [doctors could approach you about organ donation]...because then you would have more time to think about it. I mean the doctor basically just said that there was no hope and that one test would tell us [confirm brain death]. I think we were prepared for the worst, as prepared as you can be but maybe that should have been the time [to approach the topic of organ donation]. (02)

Premonitions, dreams, and déjà vu. Although not everyone in the study experienced premonitions, dreams, and/or déjà vu, it is noteworthy to share some of the participants' thoughts and feelings about these occurrences, and to explore the significance of this influencing factor in relation to the participants' decision-making process. The participants who experienced a premonition, dream or déjà vu were very eager to share this facet of their organ donation experience with me. Often the participant was eager to know if other participants in the study had experienced these phenomena, or was their experience an isolated event. Of the nine participants, four shared their experience with these phenomena. One participant shared her dream:

> When we went up to the ICU, [pause] it was very, very difficult because I had a dream about a year before [the accident]. I had a dream of my son being in an accident and I was going to see him in the ICU and talking to the doctor and to walk in there...When I had the actual dream I'd woken up because my son had been out and he'd come home. He had woke me up because he'd had a small accident with the car. [chuckles] Oh thank God you're O.K., you're not hurt, you know. Oh, don't worry about the car, you know... So of course, I've always wondered if that dream was a premonition, you know, so to go in there and see this person just lying there motionless all bandaged up and the machines....You know, when you've never experienced that kind of thing before except in your worst nightmare [it's overwhelming]. (01).

This dream was obviously very frightening and very realistic to the participant. Then to experience the reality of these events approximately 1 year later was extremely difficult. The participant herself did not understand the significance of this dream, and in fact questioned if it was simply déjà vu, or a premonition of this event.

Another participant shared that she did not believe she had experienced a dream or premonition, yet she proceeded to explore an incident that occurred the day of her son's accident.

> On the day of the accident, he stepped [out of the vehicle] and said, "Mom, do you really think I'm the smartest kid you have?" and I looked at him and I swear there was a halo around his head. And I kind of flinched and looked away and he said, "Mom" and I looked again and I'm sure there was this glow of light around his head...Twice I looked at him and saw this halo, I just shook my head and looked away and thought jeeze that was strange... [When she was notified about the accident] it makes you wonder should you have done something about it...Maybe if you would have taken more notice well, that [it] was trying to tell you something that maybe you could have prevented the accident, you know, kept him home but [they] say everything happens for a reason. (07)

When I asked her the significance of this event, she felt that it might have been a warning to her to prevent the accident. She stated that there was really nothing she would have done differently that day, even if it were a warning because her personal belief was that everything happens for a reason: that perhaps her son's destiny was to be an organ donor.

Weighing the Pros and Cons

Weighing the pros and cons is the third task in the work of decision-making. Key facets of this phase include a review of all pertinent information and determining the significance of the influencing factors. One's personal beliefs, values, knowledge, and past experiences determine the relevance of the information obtained regarding organ donation. This information is then considered in light of all pertinent influencing factors. The result of this process is the weighing of pros and cons of cadaveric organ donation.

It goes without saying that all study participants decided in favor of organ donation. For some, the decision was spontaneous, occurring immediately upon request by the physician. However, others labored over their decision. In both scenarios, the process was the same. What was different was the degree of "work" the participant had to do to arrive at their decision.

The following excerpt is a synopsis of seeking and gathering information and identifying and considering the influencing factors. This demonstrates how the participant works through the tasks of the decision-making process to arrive at their decision to agree in favor of organ donation. The excerpts will compare the experience of decision-making, one being an "easy " decision, the other a "difficult" decision.

> It was obvious right from the beginning that his [son] injury was extremely serious...The doctors seemed to be preparing us for the worst right from the beginning...He was very thoughtful, very considerate, he made a bit of emotional contact with us....Within a matter of hours, we understood that there was no hope.... When we went up to the ICU, it was very difficult because I had a dream about a year ago, and I dreamed that my son was in an accident and I was going to see him in ICU. I've always wondered if that dream was a premonition, you know.... I held my son's hand and said he's gone....He's not here...The following morning we were waiting for [the completion] of the brain death tests and the subject of organ donation [was raised].... My husband and I had talked about it and we felt very comfortable with the whole idea of organ donation....When they had the second brain death test done, someone from the [organ procurement] program came and talk to us. [She told us about the whole organ donation process and what organs we could donate]...She was able to make an emotional sort of bond immediately and for me that was extremely important...She was someone who really genuinely cared, who had an understanding of what we were going through, she walked us through the whole process, answered our questions...[As well,] we talked about the quality of life issues, no heroic measures, people being kept alive for years and years and years, for what?....We were aware that other people were facing a potential loss too and that potential loss could be averted so that's how we looked at it....We wanted to make sure that there would be a positive outcome for somebody. (04)

This synopsis of a participant's experience identifies all the tasks of the work of decision-making phase. Seeking and gathering information about the organ donation process was accomplished through discussions with the physician and organ procurement coordinator. Candid, honest communication facilitated the participant's understanding of the organ donation process; as well, it helped in forging an emotional bond between the participant and the healthcare professional. Influencing factors identified by the participant included: knowledge and previous experience with organ donation, quality of life issues, altruism, perceived death prior to confirmation of brain death tests, and a premonition about the accident and son's admission to the

ICU. The significance of these influencing factors were weighed by the participant, and she felt that organ donation was important to ensure a positive outcome of this tragedy, as well as prevent others from experiencing the pain and grief of losing a child.

The decision-making process can be very difficult for the participant when the tasks of seeking and gathering information and identifying influencing factors are not completed to the participant's satisfaction, thereby precipitating ambiguous feelings about their decision. The participant still feels positive about the act of cadaveric organ donation but experiences unresolved feelings of confusion and perceives the decision-making process as having been very difficult.

> My husband had committed suicide, his heart had stopped beating for probably a half hour but they were able to revive him and as long as his heart was mechanically kept going he was O.K.…They did [this treatment] so we didn't really know how bad he was or if there was any possibility that he was going to survive, or in what state [he would be in]….They didn't give us much hope and then they talked to us about organ donation [becomes very emotional]. I guess as soon as they brought up if we would consider organ donation, at that point it wasn't really clear in my mind that he wasn't going to survive and that was kind of the indication that I think I'm getting the message here that he's gone. There was no [organ procurement coordinator], just the nursing staff…I had no hesitation in saying yes because it was something that our whole family had been very supportive of…During all the commotion, I didn't have my husband's driver's license where it actually showed that it was signed…We've always been strong advocates so for us it wasn't a difficult decision. Like this is something [that he would want to do]. It was so difficult [emotional]. Once we decided we were going to do this, we then had to decide what we wanted to donate. His eyes were a bit of an issue. I didn't want him to look marred or anything. I've since learned that for cornea donation, they wouldn't have taken the whole eyeball out so that would have helped me at that point, if I could have understood that. Because we openly were saying we were worried about how he looked...I kind of needed someone to say a little bit more, step by step, this is what we're going to do…The nurses were very considerate and they didn't rush us or pressure us in any way but it was that confusion, like I felt like what are we supposed to do now? I'm sort of waiting here [hospital]. I guess because you're in a pretty bad state and you kind of need someone to [guide you]. They didn't really explain to me that they would be taking his body over to the NAME OF HOSPITAL to get the organs. I guess I thought someone from the organ donation program was going to come and talk to us, I was waiting for someone like that I think that's what I was waiting for….I didn't feel like it was clearly explained to me that they had determined that he was brain dead...I felt very unconvinced that he was [dead]….We didn't have trouble making the decision to do it, like I decided that very quickly but it was this other business of not knowing what am I supposed to do now, or what are they doing to him or not hearing anything [which organs were retrieved, or how the recipients were doing] right away….You do feel good that somebody is benefiting but I guess I felt like the length of time for me [not hearing for 5 weeks which organs were retrieved] and a more personal thing [thank-you note from recipients] would have helped very much. …It's this protectiveness [emotional], the idea of organ donation even though I strongly, strongly believed in it and I

> know my husband did too, I didn't want them to mar his body and it was very important to know that he was [treated] with dignity. (06)

This participant experienced tremendous confusion about the organ donation experience for several reasons. The organ procurement coordinator's absence in this situation was very detrimental to the participant's understanding of the organ donation process. This lack of support precipitated feelings of protectiveness towards her husband's body, wanting to ensure that it was treated with respect and dignity, and to ensure that his body was not marred. In addition, she felt that she was not given sufficient information to understand the conclusiveness of the brain death tests. This lack of information caused her to experience feelings of uncertainty and a lack of conviction that he was indeed dead. Unresolved feelings or concerns about the organ donation experience will affect the participant's progress through the other phases of the donation process, that of Work of Grieving and Healing and Seeking Direction. These will be explored in detail in chapters 7 and 8.

Several influencing factors facilitated this participant's understanding of the organ donation process. Knowing her husband's wishes concerning organ donation, wanting to help others, awareness of quality of life issues, and her previous experience and knowledge of the organ donation process were instrumental in her decision to agree in favor of organ donation. It is important to note that the work of decision-making does not end once the consent for organ donation has been given. The work of decision-making ends when the act of organ donation actually takes place. Thus, there may be long periods of waiting between when the consent was obtained and the actual surgical retrieval of the organs. In this transition period between giving consent and the act of donation, the participant may revisit the tasks of decision-making and reflect on their decision. This transition period is very difficult, as the participants perceive that they are in "limbo" until such time as the surgery is complete. Thus, although the decision to donate a loved one's organs is done, closure of the event does not occur until the transition period ends with the surgical retrieval of the organs.

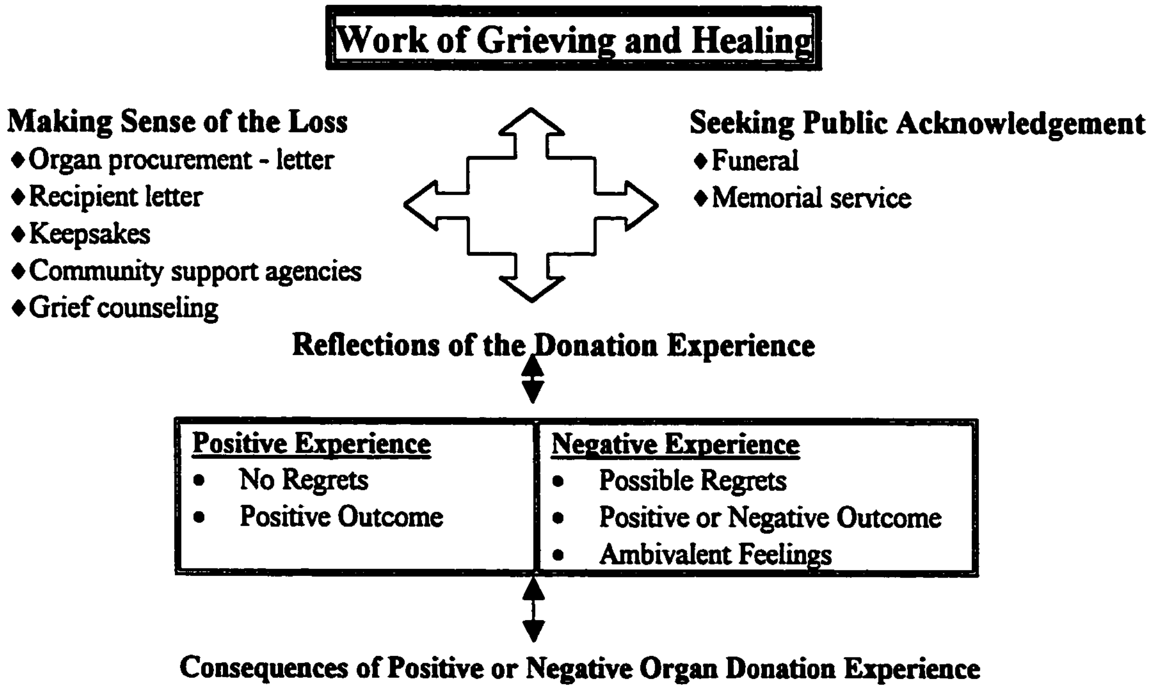
Consent for cadaveric organ donation

As one can see, the work of decision-making is extremely involved and requires a great deal of energy to complete the tasks of seeking and gathering information, identifying and exploring all influencing factors and weighing pros and cons of organ donation. For some, the decision was "easy" as the participants had a strong support network and past experiences; beliefs and values influenced and supported their belief in organ donation. For others, the decision was not as easy and required more effort to make. Yet, all the study participants felt very strongly that organ donation was a positive outcome to a very tragic loss and had no regrets about their decision to donate their loved one's organs.

Chapter 7: Work of Grieving and Healing

The work of grieving and healing begins as soon as the participant's loved one is declared brain dead and consent for organ donation has been obtained. This phase of the cadaveric organ donation process is composed of three tasks. These tasks include: making sense of the loss, seeking public acknowledgement of organ donation, and reflecting on the donation experience in its entirety [see figure 4]. These tasks require the participant to exert a great deal of time and energy on personal reflection of the event. This painful journey of poignant memories is cathartic in nature, as the participant gleans new-found hope for their future. But it is not without hazards, as self-reflection may give rise to conflicting emotions, unanswered questions, and unresolved issues. This is harmful only when the participant does not seek assistance in dealing with these feelings and unresolved issues. In the weeks and months following the donation experience, the participants sought assistance from several resources, including self-help groups, bereavement and grief counseling, family counseling, and the organ procurement coordinators.

Figure 4. Components of the Work of Grieving and Healing



Making Sense of the Loss

After consent for organ donation is obtained, participants experienced a dilemma as to whether they should stay with their loved one until he or she goes to the O.R. or should they leave the hospital as nothing further can be accomplished by them staying. This was an extremely difficult dilemma for several reasons. Firstly, participants felt that they were abandoning their loved one by leaving the hospital without them. This was a very common response from parents of child donors.

> Leaving the hospital was really, really hard. We were told that there was nothing else [we needed to do], I mean it was over. Go home. You know, you never left him anywhere but that particular day [you just walk out without him]. (09)

> I guess maybe once that test was done, I knew in my heart [she was dead]. There was nothing more I could do...It was the longest walk I ever took. To [walk] away from her [short pause]. To actually walk out of the room...It was very hard. (03)

As well, the uncertainty of when the participant would see their loved one again was very unsettling. Because many of the traffic fatalities were medical examiner cases, the body was not sent to the funeral home until after an autopsy was performed. This delay heightened participants' anxiety and uncertainty about the organ donation process.

> We didn't know how much time [organ procurement took] so we didn't plan the [the funeral]. He was declared at noon on Tuesday and we'll have the funeral on Saturday. We found out that the body was sent down here early Wednesday morning. We could have had the funeral on Thursday or Friday but we didn't know nothing about what was going on. We presumed that we had to give them time....[We would like to have known about what happened after the surgery] like he's going to be in surgery for 2 hours, and it takes another hour at the medical examiners and then we would have known that Tuesday they're done with him. He can come home. (07)

Coping with these difficult and ambiguous situations after the recent death of a loved one is extremely stressful. Added to this stress is the uncertainty of the specific details of the organ donation process. In many of the cases, participants did not have the emotional energy to ask about the specifics of the procurement process nor what care was required for their loved one's body. These factors inhibit the participant's grieving process, as there was a perceived time lag between the actual death of the loved one and when the deceased is delivered to the care of the funeral home. The organ procurement coordinators were able to diminish this stress by calling the participant at the conclusion of their loved one's surgery. This established the exact moment when the organ donation process was completed, thereby giving closure to the event. Participants were then able to concentrate on their grief and deal constructively with the necessary task of making definitive funeral arrangements.

> NAME [organ procurement coordinator] told us when they were starting the surgery. And she phoned again when it was completed. It was the middle of the night but we said don't worry. We wanted to hear....I felt that he was at peace. (01)

An atypical case occurred when the organ procurement coordinator was not available to the family. As a result, the participant did not receive any follow-up information about which organs had been retrieved for 5 weeks post-donation. This delay in hearing from the organ procurement coordinator caused the participant to experience ambiguous feelings concerning her donation experience. She still believed that helping others was a wonderful outcome to her tragedy, but she did not experience the joy that other participants felt. She believed a call by the coordinator at the conclusion of the surgery would have been helpful as it would confirm to her that her ordeal was over, inform her of which organs were procured, allow her to make the necessary funeral arrangements, and initiate the work of grieving and healing, namely, making sense of her loss. In addition, this would have facilitated a sense of closure to her ordeal far sooner, rather than a month later. She stated:

> A lot of people think it was a really good gift to share and I share in that but I didn't feel any overwhelming [sense of joy]...I was happy but I think I needed to know that sooner when it was more difficult, you know, to have made that decision and we did it....I was contacted by the hospital, I don't even remember who contacted me and said did I have a place to take the body after and I hadn't even thought, like it just seemed so quick. I didn't know what to do [pause]. So I guess if I had got a call, then that would have really helped....You just don't think about those things [funeral arrangements] and what happens....I think it would have been helpful if one of the organ [procurement] people had of been there....and could have just reassured me...what are we supposed to do now?...I guess because you're in a pretty bad state and you kind of need someone to [explain the organ donation process]. (06)

The organ procurement coordinator normally was instrumental in facilitating the participant's attempts at making sense of their loss. They provided follow-up letters to participants within 4 to 8 weeks following the organ donation. This follow-up letter addressed several pertinent issues that facilitated the grieving and healing processes. Contained in this letter was information concerning which organs were procured and information about the health and well-being of the recipients. This information provided a great source of comfort. All participants agreed that the information conveyed by the organ procurement coordinator bolstered their confidence in their decision in favor of organ donation. The letter provided tangible proof that something good came from their tragedy, as well as affirmed their belief that others would not experience the death of a loved one, as they had.

> We said right from the beginning [when] we were sort of entertaining organ donation. Now the healing could begin for someone else. It's quite mind-boggling when you think of all these things that are happening at that time. As one group of you are giving up hope, there's all these others who are experiencing hope...[There's a sense of joy knowing that someone will live]. It was one of the things we'd said from the beginning. At least there can be a positive outcome, some good so some other people won't have to go through this horrible experience that we're having....A lot of wondering about who, where [the recipient was], naturally....[We received the letter] 6 weeks to 2 months afterwards, I think....We knew that there was AGE woman in CITY who had his liver. Two men, one in CITY and one in CITY [received the kidneys]....It's a pretty difficult letter to go through at the time, but [it was a source of comfort months later]. (01)

Another important component in making sense of one's loss are letters from the organ recipients. These letters, directed to the organ procurement program, reinforced the significance and importance of the donation. Participants were very happy to hear that the recipient's life and health had improved as a result of their loved one's organ donation. A participant shared these thoughts:

> We got a couple of letters from the [organ procurement] program, one stating the sex and ages of the children who received NAME's organs. And then one time we got a card with all identifying information taken off of it from the [organ procurement] program from the mother of one of the children that received some of NAME's organs. It was beautiful. It just said from someone very grateful to someone very kind. It was really nice....We only received one update on what [happened to the recipients]. I understand the reasons why because say one of the children that received an organ was to die or something, then I guess it brings up all that

> other stuff again [pain of loss, grief], but it would be nice to know [how they're doing]. I know there were five [recipients] at one time. I don't know how [they are] right now but that would be nice to know. (08)

Several participants expressed an interest in forwarding letters back to the recipients. The information the participant wanted to share included their happiness that the recipient was doing well after their transplant and information about who the donor was. They appreciated the need to keep the donor's identity anonymous, but they felt it was important for the recipient to know something about the life of the donor.

> [It] is a very nice letter but why does she think, like with everything being so anonymous like why does she think that I would care who she is and what kind of good life she's having when she showed, the letter seems to show no interest on who the donor was? Like why couldn't I write her back and say this was my AGE year-old son. He liked to play soccer. He had [siblings], a grandma who he was very close, he followed the baseball stats and the games, you know. Why doesn't she show some interest in who he is? She thinks we should know who she is, anonymously, like no names but she wants us to know who she is. Why isn't she showing any interest who the donor is?....I didn't think NAME [organ procurement coordinator] had told me that I was free to write a letter back. Like NAME said that they take the letters in and forward them to us but they make sure it's anonymous...I don't know what they tell the recipients about who this person was that died, who the donors are. I think well, if she thinks I should know who she is and that she likes gardening...then why doesn't she care who the donor is? Doesn't she know that the donor meant something to somebody, that he was special to somebody? Like to me I would be very curious as to who was the donor. Like what kind of person was this? (07)

Other participants wanted not only to hear from the recipients, but also to meet them. They felt that if both parties were willing and equally in favor of meeting each other that there should be no reason that this not be allowed. This idea stemmed from a television special on organ donation.

> Well, when we signed the organ donation [consent form], I said to the lady [organ procurement coordinator], I would really like to know how the recipients are doing, and if they ever wanted to meet me, I would really like to do that. Now whether or not that will ever happen or not, I don't know. Because you're always seeing cases, you know, people that, I think one time on NAME OF PROGRAM they had a show on organ donation....I think the accident happened just shortly after or just before our car accident, the people that were on holiday somewhere in Europe and there was a drive-by shooting and the little boy [was killed]. And the family went back and how the town [met the family]. [The family of the donor] met the [recipients], all of them except for one...I think right now that would be really meaningful for me, to meet them and see [them healthy]....That kind of gives you more satisfaction....I think if both parties would be willing, I can't see what the harm would be. (05)

Another task that facilitated making sense of the loss and facilitated the participant's grieving was collecting keepsakes of their family member. Keepsakes included sympathy cards, clippings of hair, footprint and handprints, and photographs. These were very important to the participants because it gave them something to leave the hospital with, as well as provided the family with a very personal and meaningful reminder of their experience.

> You don't think about a [sympathy] card as making that much difference but it does. It does. A card, all the cards, they make a lot of difference. I filed everything in these albums because I knew I wouldn't remember it [keepsakes] and now I can look back and I can remember and appreciate a little bit more than I did at the time because I was just too much in a fog. (04)
>
> The nurses had taken a picture and they showed me. I'm glad they did [that]. (09)
>
> Our lady [organ procurement coordinator] was very good. She took her handprints and her footprints. And gave each, myself and her dad each one...[That's a lovely keepsake]. It is. We got it done up [framed] and it's up on a wall. But it's the last thing. It was the only thing [we left the hospital with] and yet it was something. It was worth its weight in gold. Because she knew what it was going to be like for us to leave there with nothing. She was really wonderful. She said, you know, how did she put that? Something to the effect that I know what you're leaving behind but let me give you something to take with you. And I often look at it and it makes me sad but I thank God I have it. I mean it was the last thing and she was right. I mean she knew we would be leaving with nothing and wanted us to be able to carry something, I guess. (03)
>
> The lady [organ procurement coordinator] phoned me quite soon after and had told me that she had cut a lock of hair [for us]...I think that her phoning [helped] and that helped because we'd left, and just let them do what they needed to do. (02)

Another participant shared his experience of making sense of his loss. His experience involved the friends and teachers at his son's school. This exemplar shows that it was not only important for him to make sense of his loss, it was important for all his son's friends and teachers to also make sense of their loss. Concern about the family's reaction if the tree died was of significant concern. However, the participant shared that it was not important whether the tree lived or died, what was important was that everyone would remember his son. He stated:

> NAME'S [son's name] school decided that they were going to plant a crabapple tree in this beautiful garden courtyard out in the CITY....They had a special ceremony. A lot of NAME's friends were there and they planted this tree and dedicated it to NAME and the minister said a prayer.... And people think how could they stand it if this [tree] dies is really not the issue. What is the issue is that there was a remembrance there...I wouldn't be happy to hear that the

> little boy who got NAME's heart died but I would be happy that he got an extra year of life that he didn't have. (08)

In general, all participants felt that it would be sad to know if the recipients died following the organ transplant. However, the participants still wanted to hear the outcome of the transplantation. Participants who believed a part of the child lived on in the recipient felt that if they were told about the recipient's death, they would feel sadness over the death of the child. However, what was more important to them was the fact that the child had additional time with their family than they otherwise would not have had.

Regardless of the success of the transplant, participants needed to hear from the recipients in the months following the death of their loved one. This follow up with the recipient provided comfort that facilitated grieving and healing. A delay or not hearing at all from the recipients inhibited the ability to make sense of the loss in a timely fashion, thereby delaying the work of grieving.

> I wouldn't have minded to get some direct response from the recipients. Like especially when I heard that a little boy was receiving NAME's [son's] heart, like before we knew that it hadn't taken [rejected] we knew that a little boy had received his heart and it would have been sort of nice to know from the parents that he was doing better. In that case, of course, he never did; but I think if that little boy had lived, it would have really made you feel better to know some other little boy was living because your boy couldn't live. (04)

Making sense of the loss also involved the participants working through their emotions and feelings concerning their organ donation experience and the death of their loved one. Unresolved feelings of guilt and anger, or any regrets about their donation experience, inhibited the work of grieving and healing. Many of the participants utilized community support groups or family therapists to assist them in dealing with their grieving process. It was through these efforts that participants began to understand the work of grieving and healing. With support, they were able to effectively resolve any outstanding or unresolved feelings that prevented effective grief work. Participants shared the following experiences:

> Because my husband had died [by suicide], we were very fortunate that we were quickly contacted by the suicide bereavement group and we all went and participated in that....It was just the most beneficial program...It was through the coroner's office. We got a letter and it [mentioned] the suicide network, the something network and part of that is the suicide bereavement group and I know we all just felt like we needed someone to help us, you know, we had to talk to somebody about this...Which we're a little different than my other relatives. They didn't want to talk about it. They don't want to deal with. Grief is a process. I just thought you were sad. I did not realize that grief is a process [and you needed to work through stages]. (06)

> No one actually approached us and said you should [get counseling]...We did it on our own because a very good friend of mine said to me just shortly after, "Are you guys going to counseling?" and I said no; and he made it a point to share the statistics of family breakups after losing a child, more than 80%. And it's interesting. We had a lot of dissension in the family and there are some things I can remember saying. I said I didn't only lose my son, I lost a wife because she's different and, of course, she lost a husband that she had because I'm different. The children are different. Everybody's different. I mean, everybody thinks O.K., you've lost a child and everything's going to go on the same. It's not the same. (08)

Making sense of the loss also involved acknowledgement and resolution of any outstanding feelings of guilt or regret that occurred as a result of the death of their family member or their decision to agree in favor of organ donation. No participant in this study regretted his or her decision to consent to organ donation. Several participants experienced guilt because they felt they could not do anything to help their loved one survive. Others believed that they should have been able to prevent the accident that caused the death of their family member. The participant's guilt, if not resolved, inhibited effective movement through the grieving process. Identifying and exploring one's guilt often assisted the participant to effectively resolve these feelings. One participant shared:

> I would suspect that very few people [regret their decision to donate organs]...It would be awful because I mean, you're already going through a ton of guilt....I mean that's part of the grieving process. You're guilty and so if you start, if you tack that one [regret decision] onto yourself, well then not only did he die, then I had him all cut up. I mean that's a load of guilt that you just can't possible deal with....Everyone feels guilty. I felt I was driving. It was my fault. NAME felt I'm the mother. I should have been able to protect him. NAME felt that because she didn't [come], she backed out at the last minute that day, if she had been in the car she would have been able to stop him from hitting the window and so we all went through this stuff [short pause] so the therapy [counseling] helped. (08)

Seeking Public Acknowledgement of Organ Donation

The second task of Work of Grieving and Healing was seeking public acknowledgement of the organ donation. This task involved making others aware of the deceased's organ donation. This acknowledgement came in the form of conversations with others, the eulogy at the funeral, and the organ procurement program's memorial service for both the donor family members and the recipients and family.

The participants felt that it was very important to acknowledge their loved one's organ donation. Many felt comfort from sharing their experience and receiving feedback from friends and family about the donor's generous gift to others. Discussions with friends, family, and members of their support network provided an opportunity to heal, as this form of acknowledgment reinforced the significance of their loved one's life and their death. The funeral was the perfect avenue to share this information. Many of the participants shared their reasons for raising the topic of the organ donation at the funeral:

> [For both my sons' funerals, we announced that they were organ donors]. I wanted other people to have the comfort of knowing that some other people's lives would be made easier on account of our sons passing away. I wanted them to know that our sons weren't lost forever, that there were parts of them that were helping somebody else live. I wanted them to know that. (04)

> My friends or our other friends we certainly told about the organ donation, we felt very good about it and actually I was quite annoyed because at the funeral service I'd asked the pastor to mention something about [organ donation] and he didn't. You know, that there was this tragic event but there was some good coming out of it because [of the organ donation] and he didn't. He chose not to. I don't know why and we'd asked him to. It was important to me but this other person for some reason chose to ignore that, you know. (01)

Other participants chose to share the letter from the organ procurement coordinator with friends and family members. This often prompted feedback as to their feelings about the organ donation process. The participant may not share the family member's feelings but sharing the letter and receiving the feedback was important to the participants.

> I'm glad we made the decision. Later when we received the letter from the [organ procurement] organization stating that there were five children that had benefited and one child

> had been on a dialysis machine all her life and another boy received his heart. That added significance....I sent them [my family] a copy of this letter...It went to COUNTRY and COUNTRY and all over the place and my sister got really upset and said, if you believe that God took NAME's life so five other kids could have better lives, you're crazy, so she didn't see it as positive but then I think a lot of that was just straight out of pain...You know, I don't care about how many kids [it helped] it shouldn't have been NAME. I see it as positive [that others were helped]. (08)

Participants who attended the organ procurement program's memorial service felt that it was a wonderful tribute to the donors and a celebration of life for the transplant recipients. Everyone shared that it was helpful to see and hear the recipient's story about his or her transplant. As well, the recipients shared a sincere thank you to the participants and their loved one for their generous act of donation. Many felt that this was a fitting tribute and remembrance of the donors. This is an excellent strategy to facilitate the work of grieving and complete the task of making sense of the loss. Participants were actually able to see the results of the donation in the good health of the transplant recipient.

> I thought it [memorial service] was very good. It brought up a lot of tears. It was good because there were so many other people that you realize you're not the only one...I liked how eclectic it was. I belong to a church but I belong to a church that doesn't believe it's the only true religion or the only [faith] and I like the way the [organ procurement] program handled it. I could see little bits of NAME OF RELIGION with OBJECT, some of the Universalists with he/she for God and all that stuff and I thought that they were very sensitive as to people's beliefs....I loved the part that they did with the flowers and everything. They called out the child's name and then they gave everybody a flower. That was so nice. Then they lit a bunch of candles. It was good. It was very helpful [because] NAME was still remembered. He wasn't just another number here, another file, he was remembered. In the first one [memorial service], because we've gone to a couple of them, but the first one they allowed everyone to go up and say something about their children if they wanted to and there weren't very many people that did that. I did it for NAME because I just couldn't sit there and be quiet. I thought that was quite good. (08)

Reflections of the Donation Experience

The third task in Work of Healing and Grieving is for participants to reflect on the donation experience. Many reflected on the effect organ donation had on their lives, while others reflected on ways the donation process could be improved to make it better for future donor families. One participant felt that organ donation was an intrusion on her grief, yet a helpful intrusion, as organ donation provided a great deal of comfort to her in the months following her experience. She shared:

> Like it [organ donation] is an intrusion. There's no doubt about it that when you're in grief like that, you don't want to think of anything. Like I wanted to go home, stick my head under the pillow and never come out. That's what I wanted to do. I didn't want to think about anything. I wanted to go into a black void and stay there because I couldn't bear it. I just couldn't bear it. And so it is an intrusion on your grief but the motive is such a high motive that you have to, like I felt like you have to excuse the intrusion because it can't be done another time. It couldn't be done another time and it is a comfort afterwards. The thing is, is that it would be good if somehow it could all be set up to be done before the person actually died, because I think it's after death [has been declared that your grief is so intense], I don't know if they have to wait till after death to do it or not. I know for sure in NAME's case that we signed the papers [consent form] after he was pronounced dead. So I don't know if it [consent] has to wait for the [declaration of brain death] or not; but if it could be done before the person actually died, I think it might be a help because up until they die you sort of have like a waiting or holding pattern...you aren't in the same grief-stricken spot as you are after you know they're truly gone and that's it. They're not coming back. They're truly gone, and I think that like they did their best in both our boys' cases to set it up for us so it was just about all done before they died and I think that in as many cases as they could [they should do this]....The sooner you can set it up the better so that the family doesn't have to work with it when they're actually going through the grief, the real pain of knowing that their loved one's gone forever. (04)

This same participant had additional reflections on her donation experience that are important to share with others. She felt that organ donation helped her realize the reality of her sons' conditions, that her sons were in fact brain dead. As well, she strongly believed that if recipients were helped by her sons' death, then this positive outcome to her tragedy gave her sons' death greater meaning. Other participants shared similar thoughts:

> Well, it comforted me to know that other people were proceeding with their life, or having an easier time in their life on account of my sons were able to contribute to them and it comforted me to know some good came out of it for somebody....It helped us to realize that it was indeed true, that our sons were gone and being asked about organ donation was a practical thing ...because our sons were gone and it helped us realize the reality of it and it's so horrifying and shocking when you're losing someone like that [accidents] that I think that probably it was a beneficial thing in that it helped reinforce to us the reality of the situation and in some small way it said well as bad as this is, we can have a little good thing happen out of it. (04)

> Of course the fact that you have lost someone but there has been a benefit to someone else [has been very positive]. Absolutely. You can't ever take that away. You feel like we've lost him but he was able, in the last [moments] to help somebody else so certainly [it's positive]. [Pause] Well, I'm very glad we did it and I would do it again in a moment. (06)

One participant felt that organ donation was the right decision at the worst moment of his life. He shared these thoughts:

> I see it as positive that [others were helped]. It takes away the fifteen seconds on a highway, you know, like how futile life is and all that stuff. I mean because when you think about it you feel like curling up and rotting. You feel like dying and by saying yes, or even if you don't even really care at the time but you do it anyways at some point down the road you're going to feel well, I did the right thing at the worst a moment in my life. I still helped somebody. (08)

Another shared that organ donation offered hope for others, at the exact moment when she lost all hope. She stated:

> We said right from the beginning that we were sort of entertaining organ donation. Now the healing could begin for someone else. It's quite mind-boggling when you think of all these things that are happening at that time. As one group of you are giving up hope, there's all these others who are experiencing hope. (01)

Several participants shared that the surgical procurement of the organs was something that they thought about, but felt that it would in no way mar the appearance of their loved ones. They felt that it was a necessary requirement of the organ donation procedure and did not associate any negative thoughts or feelings with it. They all concurred that their loved one's body would be treated with the utmost respect and dignity.

> I understand that if they do remove things and they do want an open casket that they will be careful about how they do the surgery so that the body is not mutilated. Like they don't take big hunks out that would leave gaps or gouges or huge holes or obvious signs to someone who would be looking in a casket....I had no doubt that my sons' bodies would be treated properly and with respect. (04)

> I thought about the [surgical removal] of my son's organs. But any considerations in that regard were outweighed by the possible good that could come. I certainly [had no religious] belief about the necessity of the body being left intact. It's just that, I don't know, I guess for esthetics reasons more than anything else, [I thought about it]. I think one of the disturbing things for me about it [surgical removal of organs] was it's a custom in my husband's religion, even though he's not a religious person, that the family wash the body [same-sex ritual]. And I was worried that it might be very, very, upsetting for him....But my husband said not particularly so. (01)

Other participants, however, shared that they did have concerns about the surgical retrieval of the organs. Two participants stated that they intentionally did not think about the surgery when they made their decision to donate organs. They felt that if they did consider this aspect of organ donation, they would not have agreed in favor of organ donation. Some of the concern stemmed from the belief that their loved one's physical appearance would be drastically altered or marred. Having an open casket at the funeral was the main reason for this concern. One participant shared his reflections on the surgical retrieval of organs and are as follows:

> I had a dream about [the surgical removal of organs]....We were in COUNTRY of all things and he was in the hotel room and I was mad at him because I wanted to go somewhere and he didn't want to come with me and I got mad at him in the dream and he said, "Well, dad there's nothing inside of me. I'm too tired to go". I woke up. It was a horrible dream. And so I didn't consciously think about stuff like that but I remember that dream very strongly....[I was concerned about surgery] only when it had to do with his eyes. I guess I said and it's probably silly but I still think he didn't look the same because of the trauma of just removing his organs... Like I remember at the funeral we eventually closed the casket because there was too many little kids, little friends of NAME's coming around and one in particular was just ashen and I didn't want the casket open anyways but my daughter had requested that....I mean he was just different....I mean, that's quite a shock to your body, dead or alive, to have basically that many organs taken from it. He didn't look like himself at all. He was a total stranger. (08)

One participant viewed the incisions at the funeral home and found that to be a very difficult thing to do. Her thoughts:

> My daughters and I were at the funeral home when his body came back from the NAME OF HOSPITAL and my one daughter insisted on seeing him as soon as he got there and the funeral director had said that it probably was a good idea to wait till they had him kind of fixed up and she insisted no, she had to see him...He looked awful. His [incision] wasn't very nice. It's hard enough seeing them like sort of alive, you know, just being kept on the machine, and then to see him like that...It's something we both regret now, but it happened nonetheless. (06)

Concern about the donor heart not being used was particularly difficult for most of the participants. Many believed that because their loved one was strong and previously healthy that the heart would give the same strength to the recipient. In several cases, the heart could not be used because of chest trauma, or because of the severe strain the heart sustained as a result of the medical intervention used prior to being declared brain death. Many of the participants regret that the heart was not or could not be used.

> I guess I was a little disappointed in a way [that the heart could not be used]. Does that sound silly? I think because when we did find out about the other organ donations it felt good to know that there's someone in CITY who is living with his liver, and a young woman [with his liver], and it would have felt good to know that there was someone who was able to [use his]

> heart....But the heart valves are better than no heart at all so....It was just a bit of disappointment I felt. It'd be nice, I felt it would have been nice from our point of view. (01)

> I remember feeling bad that they couldn't use NAME's heart because he was so strong and healthy and I felt bad that they couldn't use his heart because I thought somebody could have gone a long way on that big strong heart of his. (04)

Often, the participant was not able to dissociate their thoughts and feelings about organ donation from their feelings about the death of their loved one. However, participants shared very insightful personal thoughts about how their lives have changed as a result of the death of their loved one.

> You feel like you've been cheated because we're not prepared. We had him for NUMBER of years. Suddenly, you know, [he's gone]...You don't have any other little kids, suddenly you've [just not prepared to live life without him]...You know, I've got another NUMBER of years here with NAME, eighteen, nineteen, and suddenly in an instant you just don't need to take care of a child any more and what do you do now? It's really tough to adjust your life. (08)

> I think the whole aspect of his passing has made us very aware of how precious life is in general....I think I've had to really walk down that path of medical ethics and sort of think about what is acceptable and what isn't acceptable. If one [intervention] is [acceptable], why isn't the other [intervention]? The whole sort of intervention process in sickness. I've certainly looked at that whole euthanasia debate as well. I think I've become sensitized to a lot of these issues around death and dying, but I don't know that that was the organ donation as much as just the whole loss. [long pause]. I guess maybe I'm more for the organ donation now that I've faced the whole issue so head on really. I guess before that I thought it was nice in a vague sort of way [half chuckles] but it was very vague because it wasn't personal to me. That was something that happened to other people, you know, that [type of thing]. (01)

Consequences of Cadaveric Organ Donation Experience

Throughout this chapter it is clear that most participants experienced a positive organ donation experience. The result of this positive experience is effective completion of the Work of Grieving and Healing. In addition, the participants all remain very strong advocates for organ donation, have no regrets about their decision, and remain concerned about the well-being of the transplant recipients. These positive consequences of organ donation have been clearly identified in the data and shared in this thesis.

It is noteworthy, however, to share several negative consequences of the organ donation process. Negative consequences include: possible regrets about their decision to agree to organ donation, viewing the overall outcome of the experience as negative, and being left with ambiguous feelings concerning their experience. By identifying these negative consequences, participants have shared their insights in how to improve the process so future donor families do not have similar experiences.

> I'm still glad we did it because I feel of a very tragic situation something [good came of it]. I didn't feel the overwhelming like isn't this wonderful, somebody else benefits because of the negative feelings I had. It's still in my head as a terrible experience....It would be helpful to have someone say...these are the [organs and tissues] you can decide [to donate]. Take your time. If you have any qualms about any of them, please feel free to [ask questions]....It's supportive just to have someone say do you understand what's [involved with organ retrieval]....Are you comfortable with this? (06)

One participant shared several negative aspects of her experience that influenced her overall negative feelings about her donation experience. She still felt that donating her husband's organs was a wonderful gift for others, and that sharing that gift made something good come from his death. However, these negative experiences overshadowed the positive nature of organ donation. Several key negative experiences include: no follow-up thank you letter from any recipients, not convinced of conclusiveness of brain death tests, and no organ procurement coordinator to facilitate the organ donation process.

> I guess the reason I'm here is because I felt like there were some things that could be better and I believe in it [organ donation] enough that I wouldn't want to see someone else not do it; or, if I had to make the decision again, I would want it to be made easier for me or for somebody to make that decision for the use of my body if that be the case. I still, even though I feel it was a negative experience more so than even a positive one, I guess, if I had to say positive or negative I would say it was a negative experience in this particular case....It's the feelings that come back that I feel and it was awful and I find that very interesting even though I'm very supportive of the program and that's what worries me because I'm a strong advocate of the program and because my feelings were so awful....I didn't feel real comfortable with what was happening and that's why it was negative, even though I guess the concept I agreed with but my feelings were bad because I didn't feel in control, maybe that's a better way to describe it. I supported it but I felt, I had all these questions. Was he really dead? When should I be with him? What happened to him after? Did they ever really use the organs? So all my negative experience was due to lack of information. When I got right down to it, to make it better, if someone had been there answering all those questions, that would have helped and then to

know more immediately the organs or some of the organs were used. That would have maybe helped instead of all these negative feelings being built up. I guess maybe there was resentment there that I didn't realize and then almost feeling let down when I finally did get that letter saying that they used them like I should have known this before. Damn it! Why didn't I know this before? So those were the negative things that could have been made more into a positive experience. (06)

Chapter 8: Seeking Direction

The phases of cadaveric organ donation are not static; they are dynamic, cyclical processes. Participants work through these phases at their own pace and may revisit a phase at any time. Often the participants revisit the work of decision-making phase, not to question their consent in favor of organ donation, rather to review the successfully completed tasks subsumed within this phase, namely seeking and gathering information, exploring the influencing factors and weighing the pros and cons of their decision.

The final phase of the cadaveric organ donation process is Seeking Direction. Seeking direction occurs throughout the donation process and is subsumed within the other three phases. There is no time limit as to when this phase is complete, as many participants continuously seek direction in the months following their donation experience.

This dynamic process requires the participant to utilize key behaviors that facilitate one's quest for knowledge and understanding of their donation experience. These behaviors include: the need to constantly identify knowledge needs; review information gleaned from healthcare providers; validate known information, while simultaneously identifying knowledge gaps; and continuously seeking affirmation from the healthcare providers as to the validity of their understanding of the donation process in its entirety (see Table 4 for a synopsis of behaviors that facilitate or inhibit seeking direction). Participants who demonstrated these behaviors progressed smoothly through the phases of the donation process. Participants who did not seek direction experienced difficulty negotiating and successfully completing the phases of the donation process. As a result, the participant experiences a delay in effectively completing the work of grieving and healing.

Another task subsumed in this phase includes identifying and exploring their own and healthcare professionals' roles and responsibilities. Role identification and clarification is necessary to facilitate understanding of the key players in the donation process, namely themselves, the physician, intensive care nurses, and the organ procurement coordinator; and to ensure that the healthcare providers are utilized as expert resources to facilitate progression through the donation process.

Table 4. Behaviors that Facilitate and Inhibit Seeking Direction

Behaviors that Facilitate Seeking Direction	**Behaviors that Inhibit Seeking Direction**
Ask frequent questions of all healthcare professionals	Does not ask questions during the donation process
Consult family members and other support network people for guidance throughout all phases of the donation process	Lack of support network, especially family members, to discuss donation process with No organ procurement coordinator to discuss donation process with
Understand the role and responsibilities of each healthcare professional and use his or her expertise to facilitate learning about the donation process	Does not identify and explore roles of healthcare professionals
Seek guidance from intensive care nurses as to what is normal behavior for donor family members (crying, difficulty attending to information, need for reassurance) Role clarity	Does not question intensive care nurses concerning usual behaviors of donor family members. Role ambiguity
Obtain business card of organ procurement coordinator for future reference and counsel	Does not obtain business card, therefore does not access organ procurement coordinator for future queries and concerns
Understand intensive care unit visitation policy	No understanding of intensive care unit visitation policy, results in long periods of waiting

Seeking Directions – Insights and Suggestions

Seeking direction throughout the donation process facilitated ease of movement between phases. Eight of the participants in this study successfully completed all four phases of the donation process. Actively seeking information and assimilating knowledge about the donation process, assembling a strong support network, identifying and exploring all significant influencing factors, and beginning the work of grieving and healing characterize the participant's successful completion of the donation process.

Conversely, if seeking direction behaviors are interrupted at any point in the donation process, the participant will experience a delay in progressing to the next phase, thereby jeopardizing his or her successful completion of the donation process. One participant felt that she did not have a strong support network, as the organ procurement coordinator was not directly involved with the family. In this situation, the participant's husband was admitted to a hospital other than a qualified organ retrieval facility. The body was transferred to the organ retrieval facility hours after the brain death tests were completed. Thus, no organ procurement coordinator was available as a resource person to assist in answering questions and addressing concerns about the donation process. This lack of direction was detrimental.

> I don't think I'd ever really dealt with it [organ donation] and how much it really had upset me. I just pushed it out of my mind and I think it was because there was no one there to help us through it and that was a flaw in the system and I recognize that. I think I was waiting for someone to come and tell me everything that was going to happen. I needed to know that this is the [organ donation] process and we will take care of [husband]...[very emotional]. That's what I needed. I needed someone that I had confidence in that they could tell me exactly what was going to happen and make me feel confident that the things that were happening were supposed to be happening and that if I felt I had a question or anything, she [organ procurement coordinator] was there for that...I guess it felt like I was abandoning him because I didn't know what was going to happen next or where his body was going, [emotional] and I wanted to be with him and I didn't know if I should be. Those were the questions....(06)

As a result of not understanding the donation process, this participant was unable to effectively grieve the loss of her husband; she perceived her donation experience as very negative; she experienced regrets about consenting to organ donation; and she experienced many unpleasant feelings and emotions that undermined the positive nature of the experience, namely helping three transplant recipients.

> The feelings are difficult. It's sort of like the difference in grief where you have, where you have your feelings and your thoughts are like two separate things. They don't always match; even though my intellect tells me that this is something I'm in favor of, my feelings are telling me I don't want this to happen. [Emotional]....And it's just not knowing what happens next; it's like when you have a child, you need to know what's going to happen so you can feel like you're making the right decision. I know he has to go in to surgery and have this done, or when you know you feel like you're doing the right thing but I wasn't sure what was happening next. Should I be phoning? Should I be going over with him when he goes to the NAME OF HOSPITAL or what happens? I didn't know what I should be doing either. I felt negligent....And you're in a state of shock anyway and then I guess what happened to me after because I was having these terrible feelings. All I knew is that it (organ donation) didn't feel very good at all which confused me because you're supposed to feel good when you donate a loved one's organs and I didn't feel good. I didn't feel good at all and it was because I didn't know what was happening. (06)

Many participants were instrumental in identifying specific incidences where the need for information was not met. The participants all shared that, at the time of their experience, many questions remained unanswered. They felt that this information was pertinent, yet the opportunity to obtain this information was not taken, or did not present itself. As well, many participants felt that they could only attend to finite amounts of information because of the emotional shock they were experiencing.

> I think I was waiting for someone to come and tell me everything that was going to happen. I needed to know that. I needed to know that this is the process....I guess I was just in shock ....and I was having all these terrible feelings....I felt very confused....You're trying to cope with the fact that they're dead and then having to make these other decisions...It's was very overwhelming. (06)

The following excerpts are a synopsis of the participant's informational needs that, if explored with the healthcare professionals, would have made their experience easier. Several participants were uncertain about the correct procedure to follow when visiting their family member in the intensive care unit. This environment was very disconcerting to the participants and many expressed that it was very stressful to remain there for long periods. However, no direction was given to the participants as to what other options were available to them during the long periods of waiting.

> I think the problem we had was no one really identified for us what we should do and like how long is it appropriate to stay in the ICU? [Because when] they were doing the tests they tell you to clear off. Not in those word but...[Chuckles]. But, you know, the wanting to be there. The feeling that you're out of place in the ICU. It's very emotionally draining to be there. What should you be doing in this time besides just waiting? Like was it a nuisance when we would buzz and say can we come in for a few minutes....You don't want to be in somebody's way. It's very difficult. (01)

> We knew that it was supposed to take half an hour but when it turned into an hour, an hour and a half, we hadn't seen nobody again, like are we free to go ahead and ring that buzzer and find out what was going on or will be interrupting something that they're doing. If they hadn't already told us that we shouldn't be having any hope, you'd have to look at it differently. Like if they're actually giving him medical attention where there's some hope that he could recover, then you don't want to be interrupting in the middle of a procedure that might cause some damage. Well, to me, I was thinking they've already said it's done. It's just a matter of these dang tests [brain death tests]. Like I should be able to come and go as I want but am I free to do it? We didn't see the nurse for an hour or anybody for an hour sitting in the waiting area. Am I free to go downstairs and make another phone call or do I have to be here? (07)

Several participants felt that the healthcare professional should have provided a private quiet environment when they were approached about organ donation. The commotion of hospital waiting areas was not conducive to, nor sensitive of, the participant's feelings at this difficult time. Several participants said that they needed to find a quiet private area, when they did not have the physical or emotional energy for such a task. One participant stated:

> I think when we were approached [by the physician], I think it may not have been the appropriate time or place because to me there were a lot of people around when he asked us. There were doctors, nurses and other family members there...There was just so many people and I know like time is critical but I look back and think [why was there no privacy]....I think we were then prepared for the worst, as prepared as you can be and that should have been the time to approach us. (02)

Participants identified the need for certain services or conveniences that would provide comfort during their ordeal. Suggestions include: accessible courtesy phones, quiet lounge or private room to wait in, a volunteer to assist with simple tasks, and on-site sleeping accommodations would have been very helpful, had they been available.

> Nobody was really telling us what was going on other than when NAME [organ procurement coordinator] started saying they're going to have to run these other tests and we couldn't find access to a phone, and people at home were waiting to find out what was happening so we ended up leaving the ICU and going down to the main area of the hospital to find a telephone.... But why didn't they have a phone there accessible? Why didn't they have somebody, a counselor [available]. Like if NAME [organ procurement coordinator] had come and spent time with us and said is there a phone call that has to be made? Is there something I can do for you? Like I'm downstairs fumbling with a pay phone, can't remember numbers, can't find my calling card, you know. If there had been somebody there for that, a volunteer [perhaps]. (07)

Another important facet of Seeking Direction is that the participant must know that the organ procurement coordinator is available to them in the months following their donation experience. This phase of the organ donation process is not complete when the organs are retrieved. Rather, this phase can go on for months, as the participant continually revisits the experience and identifies questions and/or concerns he or she may have. The organ procurement coordinator is instrumental in assisting the participant to effectively resolve any outstanding queries of their experience.

> Well, through the whole thing, [it's important] that there's somebody there that you can, if you've got some questions, some concerns, you can talk to them right from the time that you first start talking about organ donation until way beyond. Like it really helped me when, oh, about 5 or 6 months afterwards, NAME [organ procurement coordinator] contacted me. Because it's very limited the number of people that you can talk to. So someone you can talk to honestly about what has happened. If there's somebody who you [could] have contact with. I think it would help tremendously. If there's one person that if you're having a really tough day, [you could] give them a call...Someone who's there with you at the hospital when you're going through it. To answer any questions that you have. Because it is such an incredibly lonely experience. You feel like you're walking where no one's walked before. And you don't know where to go, which way to turn. And any one who could even point you in a direction would be welcome. (01)

Several participants specifically identified the lack of direction they experienced during the organ donation process. The participants requested that the intensive care nurses and the organ procurement coordinators identify step-by-step directions that would facilitate their understanding of, and progression through, the donation process. Participants felt that this support would be helpful in assisting them to cope with this stressful environment. One participate shared information and support she would like to see donor families receive from the intensive care nurses.

> I think it's important for [nurses] to give the families who are waiting some indication of what their choices are in that waiting period, you know, things to do...Some families like to stay here all the time. If you want to stay here all the time, this is how we can arrange it. This is what we can do. If you feel more comfortable with going home, which is what some people do, this is how it might be a useful sort of schedule. If you don't feel comfortable staying in the ICU for more than a few minutes, that's perfectly normal. I recognize how busy everybody is but this is I hope a novel experience every time someone has to go through it, and you have no idea what to do. You feel so out of place no matter what you do. You go down to the cafeteria in [hospital] and all you want to do is bawl. You don't really feel like eating but you feel you need something to drink. I felt awful in front of all these people. Is there some way I can eat and drink without being in front of all these people? Here I am. All these people going about their normal everyday [life] and something catastrophic has happened [to me]. I want the world to stop. Could someone give me some pointers as to how I should behave in this situation? What I might do to make the waiting more tolerable. Because you don't want to inconvenience the nursing staff and put them out. It's so difficult, the whole thing....It's what to do in between [visits] that's really difficult. They do provide a quiet room but I thought that was where the doctor [slept] so then [we weren't] able to sleep [there]. I think that's where the interns stop most of the time by the look of it. And sometimes they ask you to wait in the waiting room. Well, there's someone else there with a television on. You know, television seems so totally irrelevant [during this time]. (01)

Another participant wanted specific information concerning the care of the deceased's body during surgery, how long the surgery would take, and what arrangements were required to ensure the body would be transferred to their hometown. It was very unsettling for the participant not to have a clear understanding of where and when her son's body would be transferred to the town's funeral facility. She stated:

> I think it would have been nice to have somebody there to say O.K., now he's been declared. He's waiting for [organ retrieval]. It's going to take this long. Like we never dealt with anything like it [organ donation]. We didn't know where his body was ending up. How do we end up getting the body out of the CITY? Say if they'd had somebody there saying O.K., once he's declared [brain dead], he'll go into surgery. It will be an hour and then the transplants will take place and then the body's free to be removed at such and such a time from such and such a place. I mean we didn't know it at the time and it was kind of unnerving. Like so now we have to come home and we have to contact the funeral director...(07)

Understanding Role Expectations

The second task of this phase is for the participant to understand the different roles and responsibilities of the key players in this experience, namely the participant themselves, and the healthcare professionals. Role ambiguity and lack of clarity concerning the responsibilities of the healthcare professionals resulted in the participants experiencing confusion and a perceived lack of support by caregivers. In addition, role ambiguity resulted in participants not accessing the organ procurement coordinator as an expert resource of the donation process. Therefore, many participants did not seek the necessary information to facilitate their understanding of their donation experience. The result: participants experienced questions and queries that remained unanswered months and sometimes years later.

One participant specifically identified the need to understand the various roles of each of the healthcare providers involved in her son's care. She wanted to know who was involved at what point in the donation process. Because she raised the issue of organ donation with the physicians, she felt that she could have benefited from earlier contact with the organ procurement coordinator, rather than having to wait until brain death had been confirmed. By identifying these individuals and their roles in the donation process, the participant felt she could then access the appropriate resource person to answer her questions.

> I think the different roles of the people would be very, very useful. For instance, we were approaching the doctors and the nurses in the unit [about organ donation] and of course they're really not involved with the donation aspect of it. That was my understanding, that is, until brain death has been established, they're not going to talk about organ donation. In my own situation it would have been nice if there had been information about that whole process of who was involved at what stage of the game. Or could we have been referred to somebody who could talk to us about it sooner [before brain death declared]. (01)

The role of the intensive care nurse in the organ donation process was at times very ambiguous to the participants. Of interest is that one participant felt that if the intensive care nurses caring for their loved one raised the issue of organ donation, she would have felt that that was an inappropriate suggestion. She felt that it should be the organ procurement coordinator who addressed the issues concerning the organ donation process, and the intensive care nurses should be concerned with the care and potential recovery of the family member. One participant shared:

> At the time we didn't know that there was this sort of complete hands-off sort of attitude between the two camps really, isn't it? Between the people caring for the individual and the organ donation program....And the only information I got was when I actually met with NAME [organ procurement coordinator]. I didn't get any additional information from the staff on the unit. (01)

Conversely, one participant felt that the request for organs should come from the intensive care nurse. She felt that the nurse was the perfect person to suggest organ donation because of the trust and rapport they shared. Her thoughts:

> I think the staff were as considerate as they could possibly have been. It was brought to us like in about a one sentence way sort of early on by a nurse and then it was brought to us again by a doctor...When we had said we were interested, the organ donation lady went into it with us in detail several hours later...I think that that was a good way of bringing it to us because we had a chance to kind of get used to the idea as we were kind of getting used to the idea that we had lost our sons....I felt she [intensive care nurse] really demonstrated her caring for my son, me and my family....I felt that she [intensive care nurse] was my friend and she's somebody who really had empathy for us and I think I had an opener mind to something she would have said than to other staff that hadn't been doing direct care for my sons. (04)

Another important issue for the participants was when they felt the healthcare provider should approach them about organ donation. As previously shared, some participants appreciated being told to consider organ donation before brain death was confirmed. This allowed them time to consider the idea of organ donation, confirm the reality of their loved one's death, and discuss organ donation with their support network, be that family, friends or other healthcare professional, before they needed to sign the consent form. In addition, one participant felt that it was adventitious to sign the consent form immediately, and then be able to decide to stay until the organ retrieval was completed or to go home. It was helpful to have that choice in determining when her hospital ordeal was over.

> The nurses and doctors at the bedside didn't attach their own expectations or any expectations to the request. The request was put forward in a very straightforward way with no expectation should you decide to do it or not to do it. Simply did you want to do it and no sort of emotional issues around it at all. I think that was helpful and bringing it up before my son was pronounced dead I think was a big help because we had a little bit of time to think about that and get used to the idea and they had the lady [organ procurement coordinator] there. I think my son was pronounced dead at 2222h and the lady was there and we saw her at 2230h and so like right away when he was pronounced dead, then we were able to sign the forms....It [signing the consent form] was very quick after they pronounced him dead and I think that that's an advantage. If people want to stay [at the hospital], they can; but they don't have to stay and wait if they don't want to. To me, that was a big bonus. (04)

However, one participant felt that it would be grossly inappropriate to consider organ donation prior to brain death confirmation. One participant shared:

> My honest thinking is that you've got to let people hope to the very last second, to a nanosecond and then when it's done [brain death confirmed], then that's the time. I don't know why right after, I don't know if right after is good but then you people do get really involved, it has to be done right after. I mean the organs have to be kept [viable]. But personally speaking I would not have wanted to have been asked before. I would have probably been very annoyed. (08)

Most participants characterized the organ procurement coordinator, intensive care nurses and the physicians as: helpful, informative, friendly, personal, caring, sensitive and empathetic [see Table 5]. These qualities were instrumental in facilitating their progression through the phases of work of decision-making and the work of grieving and healing.

Table 5: Characteristics of Healthcare Professionals: Supportive versus Non-Supportive

Supportive Characteristics and Qualities of Healthcare Professionals	**Non-Supportive Characteristics and Qualities of Healthcare Professionals**
Friendly, Personal	Distant, Impersonal
Active Listener	Passive Listener
Available, Attentive	Unavailable
Caring, Empathetic	Cold, Casual
Informative, Knowledgeable	Non-informative, Lack of knowledge

Many of the participants felt that the healthcare professionals were extremely supportive during their ordeal, and these instances have been alluded to throughout this thesis. One participant felt that the organ procurement coordinator was especially supportive and extremely beneficial in assisting her to cope with the organ donation process. She shared these thoughts:

> The procurement person, she was as gentle about the whole thing as anybody could possibly be and she respected very much our feelings and she tried very hard to keep it as simple and as concise and yet still gave us as much information as we needed. Like I think making it as quick as a procedure and as sort of hitch free is better so you don't have to go through a whole bunch of jumping hoops, you know....Like it was straightforward and she made it as simple as possible. That was very helpful. (04)

Qualities and characteristics of healthcare professionals that inhibited the participants' progression through the organ donation experience include: distant, unavailable, disinterested, and impersonal [see Table 5]. These qualities were perceived by participants as unhelpful and inhibited them from seeking direction from healthcare professionals throughout their donation experience. In addition, the participants felt that healthcare professionals who demonstrated these negative qualities did not fulfill their role as a member of the participants' support network. This lack of support inhibited the participants' successful completion of the four phases of the cadaveric organ donation process.

For some participants, the role and responsibilities of the organ procurement coordinator were unclear and ambiguous. Many participants correctly understood the coordinator's role was to organize all organ procurement activities. However, several participants did not appreciate the coordinator's skills as an organ donation expert. In these instances, the coordinator's knowledge was not used to facilitate their understanding of the donation process. This resulted in the participants experiencing uncertainty and confusion about their donation experience. This confusion and uncertainty inhibited participants from successfully completing the tasks subsumed in the work of decision-making and the work of grieving and healing phases of the donation process.

> I can't remember if somebody actually came and talked to us from the [organ procurement program - NAME] Foundation. I think they [staff] would be contacting us later, after we had gone home, that type of thing. Like we gave our name and address and phone number so that somebody from the [organ procurement program - NAME] Foundation could contact us. I didn't even realize that it was in connection to this [organ donation]. I actually assumed that it was a support group for everybody who had lost someone here at the hospital....That was my understanding of it. It was not until the recent phone call from NAME [organ procurement coordinator] that she had said no, it was more people who had donated loved ones' organs...I didn't realize that it was connected. (02)

Chapter 9: Discussion, Implications and Reflections

The focus of this chapter is to compare the findings of this research study to those in the literature and identify implications for nursing research and practice. As well, I will share personal reflections on the quest to complete this research project and explore insights into my experience with qualitative research.

Discussion of Findings

The purpose of this study was to explore a family member's experience of cadaveric organ donation. The findings demonstrated that cadaveric organ donation is a dynamic, multifaceted process, composed of four distinct phases: Work of Waiting and Wigilance, Work of Decision-Making, Work of Grieving and Healing, and Seeking Direction. Subsumed within these four phases are specific tasks that must be completed before successfully moving to the next phase. There is no set time frame for completion of the tasks, nor the length of stay in each phase. The completion of tasks is dependent upon the amount of 'work' each task requires. Considerable physical, psychological, and spiritual energy is expended in the completion of these tasks. As well, the ease of task completion is dependent upon one's past experiences, values, beliefs and the presence of a strong support network. Failure to successfully complete the tasks results in ineffective and incomplete grief work. Incomplete grief work results in ambiguous feelings about the donation experience, possible regrets about the decision to donate, and perception of the overall experience as negative.

Upon completion of the data analysis and documentation of the study findings, a secondary literature review was conducted to explore empirical and theoretical literature on the experience of cadaveric organ donation in relation to the processes that were uncovered, particularly the coping and grieving processes. Given the paucity of research of family members' experiences with cadaveric organ donation, it was not surprising that scant new literature was found in this area. Results of the secondary literature review on coping styles and grieving processes used by donor family members was somewhat more fruitful. This empirical and theoretical literature supplemented that found during the initial literature review. In this chapter, I compare the findings of this study with findings of other cadaveric organ donation research, donor family member coping strategies and grief work.

Work of waiting and vigilance. An exploration of the family member's experience of the four phases of cadaveric organ donation has not previously been reported in the literature. Therefore, these findings present a unique contribution to the body of knowledge about cadaveric organ donation and the significance of grief work subsumed within these phases. Although unique, aspects of these findings are comparable to the results from several other studies. Pelletier (1992) identified different types of stressful situations experienced by donor family members during three phases of the organ donation process, namely Anticipation, Confrontation, and Post-Confrontation. Although the central premise of Pelletier's study was the stressful nature of the donation process, stress was not readily acknowledged as a significant concern or issue by the participants in this study. However, that is not to say that stress was not experienced; rather stress was not specifically identified by the participants. Nonetheless, there are similarities between participants' experiences in both studies. For example, participants expressed long periods of waiting to be 'difficult', 'unbearable' and 'lasting forever'. Regardless of whether this experience is subsumed in the work of Waiting and Vigilance, as it is in this study, or in the Pelletier's Anticipation stage, the findings themselves are significant. These periods of waiting are significant in that time is required for the participant to assemble their support network, enact religious rituals, understand the seriousness of their loved one's injuries and the reality of the ensuing brain death.

Coolican (1994) stated that time is an essential component of the donation process. It is important to provide the donor family members with an opportunity to acknowledge the death of their loved one and spend time saying good-bye before the finality of death is observed by the act of organ retrieval and removal of mechanical support. This was particularly evident in this study when several participants felt that they were not given sufficient time with their loved one or were not given a private moment without healthcare professionals in attendance of the donor. This lack of privacy was also addressed by Douglass and Daly (1995) who reported comments from participants such as "I wish I could have had a few moments alone" (p. 97). Willis and Skelley (1992) concur that adequate time must be given to the family to accept the severity of the injury and the imminent death of a loved one. Without this time, family members may not be able to acknowledge the loss of their loved one and as a consequence, true acceptance of the loss may take months or years.

Another significant finding in the Work of Waiting and Vigilance phase is the participant's need to understand the concept of brain death. The participant's understanding of brain death is essential before being approached by healthcare professionals to consider organ donation (Peele, 1989). The majority of participants in this study lacked a clear understanding of brain death, were not able to define brain death, nor were they able to explain the tests used to confirm brain death by healthcare professionals. Similarly, Batten and Prottas (1987) found family members often lacked a clear understanding of brain death even though they agreed to organ donation. They cited two reasons for this lack of understanding: (1) the donor was supported by mechanical ventilation, therefore did not appear dead and (2) the implications of brain death were not clearly explained. These findings were also noted by Pelletier (1992) where the appearance of 'being alive' and insufficient explanation of, and preparation for, the death of a loved one was considered extremely stressful. Pelletier's findings were also substantiated by the findings of this study as four participants commented that their loved one did not appear dead because of the mechanical support of the ventilators and cardiac monitors.

Franz et al. (1997) examined how family members' understanding of brain death affects their decision to donate. Their study suggests a strong association between whether a family agrees to donate organs and their understanding of concept of brain death One participant in this study clearly felt that brain death was not explained to her satisfaction. This participant experienced a great deal of confusion and uncertainty about her donation experience and experienced a delay in her grieving and healing as a result.

Findings of this study concerning the best time to approach family members about organ donation were of interest. Three participants stated that they wished they were approached before completion of the brain death tests, thereby allowing them more time to recognize the reality of their loss and to spend more time considering organ donation. All three participants recognized that their loved one was dead, before confirmation by the healthcare professionals. Comments such as "I held my son's hand and said he's not here, he's gone", or "when his eyes were so vacant, I knew, to me he was gone already" indicated that the participant recognized the death of the loved one, and at that time were prepared to consider organ donation. Six of the participants felt that they were approached at an appropriate time, that being at the conclusion of brain death tests. In this instance, participants were aware of the severity of the brain injury and the poor prognosis for their loved one. However, they did not perceive that their loved one had died. They recognized that there was no hope, that the staff was conducting the brain death tests to confirm brain death, yet thought it was appropriate to wait for confirmation of brain death before being approached.

In the literature, there exists a great deal of variation in regards to when the donor family members should be approached by the healthcare professionals about organ donation. Albert (1994) and Bartucci (1987) both stated that the family should not be approached about organ donation until the family understands that brain death is a terminal condition with no hope of recovery. Only when this is clearly understood, should the family be given the opportunity to consider organ donation. Savaria, Rovelli, and Schweizer (1990) conducted a mail survey of donor family members 6 months post-donation. Information was sought concerning previous discussions of donation, brain death, stressors surrounding the consent request, why they chose to donate, need for support groups and the option of receiving more frequent follow-up information. In regards to when to be approached about organ donation, 85% reported that they felt that the time they were approached was appropriate, that being 6 to 24 hours after being informed of brain death. Others shared that they were approached within 6 hours of being informed of brain death, three of the participants felt that "it should have happened sooner" and three others felt they "needed more time". Thus, there remains a lack of clarity about the best time to approach family members. This has significance because, without knowing the best time to approach families about organ donation, prematurely approaching families may be perceived negatively by the family and result in their refusal to donate organs (Franz et al, 1997).

Raper and Fisher (1995) suggest that the relationship with the family members and the progress of the patient should be the determinants of when to approach the family about organ donation, rather than some pre-determined rule or guideline. As well, they suggest that discussions with the family should always be frank and considerate. The pace at which family members are able to understand information, especially under great duress, is highly variable and should be determined by the individuals themselves, rather than by the physician.

Work of decision-making. Within the Work of Decision-Making several influencing factors were well substantiated in the literature. Specifically, the altruistic belief in helping others during one's own tragedy and that organ donation was viewed as a positive outcome to a tragic loss were supported by Pearson et al. (1995); Soukup (1991); Pelletier (1992 & 1993); Bartucci (1987). Douglass and Daly (1995) did a retrospective study to survey families who had consented to cadaveric organ donation and evaluate their experience of the organ donation process. Factors that motivated or influenced the family members' decision in favor of donation included: awareness of the deceased's wishes concerning organ donation, signed driver's license or donor cards, to have something positive come of their loss, having parts live on in others, and wanting to have someone else live a better life. All Douglass and Daly's (1995) findings were substantiated by the findings of this study.

Participants' need for information has been clearly identified in this thesis. Of particular significance is the need to understand brain death, as well as which organs and tissues can be donated and how the donation is to occur. This information facilitates the participants' understanding of which organs and tissues they want to donate. In cases where this information was not clearly identified, the participant experienced extreme duress as their lack of knowledge inhibited informed consent. Participants felt compelled to agree to certain organs and tissues rather than be perceived as "ignorant" or "selfish" by healthcare professionals. At no time did the healthcare professionals intentionally make them feel this way; rather lack of availability, perceived indifference, and insensitive communication style encourage this belief. Pelletier (1992) reported similar findings in her study. She found that hurried, busy, and matter-of-fact behaviors of healthcare professionals while interacting with family members conveyed an attitude of insensitivity. Conversely, healthcare professionals who displayed behaviors such as competency and efficiency conveyed a very positive environment, thus facilitating the participant's decision-making process.

Work of grieving and healing. The Work of Grieving and Healing had particular relevance to the participants' overall perception of their donation experience. When the four phases of the donation process were successfully navigated and the tasks subsumed within the phases completed, the participants viewed the overall donation experience in a very positive manner, had successfully initiated their grief work, and had become very strong advocates for organ donation. Participants who experience difficulty completing the tasks and progressing through the phases of the donation process experience ambiguous feelings and possible regrets about their donation experience, and view the overall donation experience as negative.

Several factors affect the work of grieving and healing significantly, namely follow-up letters from the transplant recipients, collecting keepsakes, and public acknowledgement of the organ donation. Follow-up letters from the transplant recipients were found to be extremely important to all participants in the study. Participants expressed an interest in knowing who the recipient was and how he or she was doing following their transplant. In the follow-up letter from the organ procurement coordinator, participants learned how many recipients benefited from the organ transplant, which organs were donated, and the sex and age of the recipients. These findings suggest that, although this information was very important and was gratefully received, many participants felt that further follow-up would be helpful. Three participants stated that they would not want to know if the recipient did not do well or died following the organ transplant. However, the remaining participants felt strongly that further follow-up over time was very important, even if the transplant was unsuccessful. This finding was supported by Soukup's (1991) study whereby participants verbalized the need for frequent updates about the transplant recipients even if the transplant was rejected. As well, four of the participants received a telephone call from the organ procurement coordinator following the completion of the organ donation. This call was extremely important as it gave the participants a sense of closure to the organ donation process. Family members were then able to make definitive funeral arrangements, thereby facilitating an effective coping strategy and their grief work.

The significance of obtaining keepsakes of a loved one has not been clearly established in the literature. Participants shared that having a memento, such as a lock of hair, foot and hand prints, or a picture of their loved one, assisted in coping with leaving the hospital without their loved one. This was particularly important to participants when the donor was a child. The keepsakes served as poignant reminders of their loved one and were very helpful in facilitating the participant's grief work and healing.

Public acknowledgement of the organ donation was important. Participants felt that it was important to share with others the positive outcome to their tragedy. As well, many felt that friends and relatives would receive comfort and solace from the knowledge that a transplant recipient had a better quality of life than they would have had without the transplant. This acknowledgement came in the form of an announcement in the eulogy at the funeral, sharing in the memorial service by the organ procurement program and sharing in discussions with community groups, friends and co-workers. Although the significance of public acknowledgement is not substantiated in the literature, the significance of these findings to the participants cannot be overly stressed.

Grief work for donor family members is not well explored in the literature. However, several key facets of the grieving process have been addressed and have significance for the findings in this study. The central premise of grieving and healing post-donation is that the family members are helped through the bereavement process, knowing that their loved one was able to donate organs (Stark, Reiley, Osiecki and Cook, 1984; Shanteau, Harris, VandenBos, 1992). In addition, it is suggested by several authors that donor family members often look for a meaning in the death of a loved one, and that many view organ donation as an act of consolation which diminishes the family members' feelings of loss (Coolican, 1987; Peele, 1989). Farrell (1989) suggests that nurses should be aware of the various stages of the grieving process and their manifestations so the needs of the donor family members can be understood and anticipated. This has relevance for this study, as four participants were aware of the stages of grieving which include: denial, anger, bargaining, depression, and acceptance. Participants were able to recognize these emotions as being a normal response to their bereavement. These emotions were especially apparent when one participant experienced difficulty understanding the significance of brain death when her husband appeared to be "alive", as evidenced by the ventilator and cardiac monitor. Johnson (1992) suggests that feelings of shock, disbelief, and denial are common at this point and result in the donor family member experiencing feelings of confusion that result in being unable to accept or comprehend their loss. This finding supports the findings in this study.

Petrin and Koutsogiannopoulos (1991) suggest using a holistic approach in family assessments in order to recognize that no two family members grieve alike. They state, "there is no stereotype of grief" (p. 97). Each member of the family will grieve differently, depending on personality type, age, relationship to the deceased, past experiences, and religious and culture influences. This finding substantiated what one participant clearly experienced:

> NAME and I, we've been married NUMBER of years and you think you'd pull together but because people grieve differently, you grieve alone. (09)

Seeking direction. The phase of seeking direction has numerous significant findings specific to the participant's need for information and understanding of the donation experience. As well, understanding the healthcare professionals' roles and responsibilities is essential to successfully progressing through the four phases of the donation process. Both these tasks are pertinent to the successful completion of the donation process, facilitate a positive outcome, and to assist in fostering an environment conducive to effective grieving and healing.

Health care professionals' knowledge and attitudes about organ donation and transplantation have a direct effect on influencing participants' perceptions, knowledge and attitudes about their experience (Stark et al., 1984; Sammons, 1988; Sophie et al., 1983; Matten et al., 1991; Kiberb & Kiberb, 1992). One participant perceived that the nurses were indifferent to her situation as she thought no one knew what was going on throughout the donation process. As a result, she experienced ambivalent feelings about her donation experience. As well, she was not convinced that the donation process was completed in a timely, efficient manner. Each time she questioned the time delay, she felt that the nurses did not know what was going on, nor did they convey any concern for the family's distress with the long periods of waiting. Three other participants wanted specific step-by-step information about the organ donation process and experienced tremendous anxiety when the healthcare professionals did not assist in providing this information. Clarification of role expectations for key players, including the donor family member, the critical care nurse, physician, pastoral care, social workers, and the organ procurement coordinator, is essential.

The family members need to be informed of their position in the decision-making process. Their role in the donation process requires that they actively seek and gather information, ask frequent questions, request healthcare professionals to clarify any misinformation or expand upon explanations given. Conversely, it is the healthcare professionals' responsibility to identify and facilitate the participants' role in this process. Because of the participant's emotional shock and intense grieving, the healthcare professional needs to facilitate the participant's quest for knowledge and ensure they understand the four phases of cadaveric organ donation. The Canadian Nurses Association (1988) recognized the following roles of nurses in the organ procurement process and include: one of assessment, support, counseling, teaching, coordination, referral, health maintenance, supervision, monitoring, and advocacy (p. 16).

Prottas and Batten (1989) state that it is the responsibility of all healthcare professionals to be familiar with the organ donation process, recognize that offering the choice to consider organ and tissue donation is a benefit to the grieving family, and that it is the right of every family member to be given the option of donation. Peele (1989) supports this finding in that donor families have repeatedly stated that the option of organ donation, offered to them at the most difficult time in their lives, has helped them make something positive come from a loved one's death. Peele and Denvey (1994) state that one of the major difficulties in obtaining consent for organ and tissue donation has been the attitudes of healthcare professionals themselves. Healthcare professionals' discomfort with donation is perceived by the family and may result in refusal to donate a loved one's organs (Stark et al., 1984). This finding was not substantiated in this study. However, the participants did share several instances when the healthcare professionals did not appear knowledgeable about the donation process, thereby causing the participant to experience feelings of uneasiness and confusion about their donation experience. These ambiguous feelings delayed the grieving process and inhibited the participants' personal coping strategies.

Nursing Implications

The findings of this study have several implications for all healthcare professionals' clinical practice. Because the scope of my clinical practice is within the realm of nursing, implications specific to nursing practice will be addressed.

Given that this study is the first to identify and document the four phases of the cadaveric organ donation process and there is a paucity of research on this phenomenon, the implication for nursing practice must be viewed as suggestions rather than specific guidelines for practice. Further research is required to substantiate, challenge or refute the findings of this study and to identify definitive recommendations for practice.

The most significant implication for nursing is to have substantial knowledge concerning organ donation in general (Coolican & Politoski, 1994), and a thorough understanding of the four phases of the cadaveric organ donation process. An overall understanding of the donation process is necessary to act as an expert resource person at the bedside. In this manner, the critical care nurse can facilitate the donor family members' understanding of the hopelessness of a catastrophic brain injury, determinants of brain death, procedures required to support organ viability, and the logistics of organizing the O.R. staff for organ retrieval. The critical care nurse must also be responsible for: understanding the four phases of cadaveric organ donation to facilitate the family members' progression through the phases, assist with task completion, and act as a grief counselor as soon as the severity and nature of the brain injury is determined.

Other implications for nursing practice are specific to each phase of the donation process. Nurses must assess the applicability of the following suggested nursing actions to ensure that they are individualized and tailored to the family members' cultural, ethnic and religious philosophies. Potentially facilitative nursing actions include:

Work of Waiting and Vigilance

- Encourage the expression of feelings associated with emotional shock.

- Assist the family member in assembling their support network.
- Actively listen to family members.
- Identify that periods of waiting are a normal component of the donation process and that they are necessary for healthcare professionals to complete patient assessments and initiate brain death testing.
- Facilitate the family members' grief work by recognizing the loss of their loved one as soon as the brain death is considered.
- Establish trust and rapport with family members.
- Accurate assessments of the family members' need for guidance, support, comfort, and information.
- Answer questions in brief, simple explanations. Provide repeated explanations to reinforce the family member's understanding of the donation process.
- Communicate clearly, accurately and in a kind, sensitive, sincere manner.
- Approach the subject of organ donation in a positive manner, showing sensitivity and conveying the belief that organ donation is beneficial in facilitating one's grief work.
- Provide a private, quiet environment so family members can discuss organ donation without interruptions.
- Provide an opportunity to enact religious beliefs, as family members define them.
- Provide a supportive environment – be available, provide privacy, and provide conveniences that reduce the stressfulness of the intensive care environment – convenience telephones and a quiet waiting lounge.

Work of Decision-Making

- Ensure that brain death is understood and that the implications of brain death are that the condition is irreversible permanently and not compatible with life.

- Ensure that family members recognize that mechanical support is not to promote recovery; rather, it is to support organ viability for optimal organ retrieval.
- Ensure that family members are given every opportunity to seek and gather all information pertinent to organ donation, that they identify and review the significance of all influencing factors and that they weigh all pros and cons of organ donation in order to give informed consent.
- Answer all questions concerning the donation process, including brain death determination, which organs and tissues can be retrieved, implications of the surgery (incision), dispel any misconceptions of disfigurement, assist in understanding the role of the medical examiner or coroner, and when and what type of funeral arrangements can be made.
- Encourage family members to participate in simple nursing tasks. This allows the family members to spend more time at the bedside to facilitate their acceptance of finality of the situation.
- Ensure that the family members understand that the deceased will be treated with respect and dignity throughout the donation process.
- Ensure that the transition period between obtaining the consent and the act of donation is made as easy as possible for the family members. Be available to comfort them, facilitate their expression of their grief, and provide an opportunity to say good-bye to their family member in a quiet, private environment.
- If the family choose to leave the hospital after the consent is signed, call family members when their loved one goes in to surgery, and again when organ donation is complete to facilitate a sense of closure to their experience.

Work of Grieving and Healing

- Observe family member behaviors that are associated with the common stages of grief that include: denial, anger, bargaining, depression and acceptance. These behaviors should be confirmed as being normal and expected.
- Encourage family members to attend bereavement support groups such as Compassionate Friends or family counseling.
- Encourage family members to attend and participate in memorial services conducted by the organ procurement organization.
- Encourage family members to inquire about the transplant recipients through the organ procurement organization.
- Encourage family members to collect keepsakes, such as a lock of hair, hand and footprints.
- Provide the family members with an opportunity to visit the body of a loved one post-donation.

Seeking Direction

- Ensure family members understand their role and responsibilities in the four phases of the donation process.
- Ensure that family members understand each healthcare professional's role and responsibilities in the process of organ donation.
- Facilitate family members' understanding of who the key players are in the donation process and ensure that expert resources are used to assist family members in understanding all facets of the donation process.
- Provide family members with a step-by-step recipe of what they can expect and what they are required to do at each phase of the donation process.

Implications for Nursing Research

Implications for nursing research have arisen in several areas of the four phases of the cadaveric organ donation process. First, the four phases of the cadaveric organ donation process must be explored and validated with other populations, namely non-donor family members. Given that all participants in the study consented to organ donation, it is pertinent to determine if the process is valid for individuals who chose not to agree to organ donation and if so, determine which tasks were and were not completed and the influence that this has on their decision. As well, given that all participants in this study were middle-aged, married, either a parent (8) or wife (1) to the donor, and caucasian; differences in the experiences of individuals in different relationships with the donor, age groups, and other ethnic and cultural groups must be explored. Validation of this process with a heterogeneous sample and the influence of these other variables are worth exploring.

Secondly, further research is required to clarify and elaborate on the four phases of cadaveric organ donation. As well, the significance of the transition period between the consent for organ donation and the act of organ donation requires further exploration. Additional research is required to more clearly distinguish the importance of this transition phase, and identify strategies to facilitate the donor family member's progression through this period of prolonged waiting.

Thirdly, further research is required to explore ways to facilitate the individual's movement through the four phases of the cadaveric organ donation process. Specifically, what behaviors are indicative of the individual's readiness to progress to the next phase of the process? How can healthcare professionals facilitate movement between the four phases of the cadaveric organ donation process?

Lastly, further research is required to explore the grieving process with this population. For instance, at what point in the Work of Waiting and Vigilance is the grieving process begun? What strategies facilitate effective grief work throughout the cadaveric organ donation process?

Personal Reflections

I began this journey into qualitative research with great enthusiasm and excitement. I felt that I was finally able to pursue an area of interest that had consumed me throughout my 9 years of critical care nursing. I eagerly began discussions with the organ procurement coordinators to identify my role as novice researcher, and to determine their interest and commitment to the research study. However, at the onset of the study, I experienced a key setback that significantly delayed the research process. Because of the lack of organ donors within the specified time period of the study, coupled with the extensive chart review that was required by the organ procurement coordinators, an 8-month delay in identifying and recruiting the first participant occurred. This unfortunate delay severely restricted my ability to complete the study as per the established timeline.

I realize now that I was in no way prepared for the time commitment required to conduct a qualitative research study. The seemingly endless research activities proved at times to be exhausting. This work in a nutshell include: conducting nine participant interviews; transcribing 20 audiotapes; reviewing all transcripts; documenting extensive field notes and personal journal entries; analyzing data, revising the interview guide to reflect the emerging data themes and then conducting the second interviews. This cyclic process on average took approximately 6 to 8 weeks per participant. Thus, data collection took approximately 17 months. A rewarding yet overwhelming process.

Then began the process of writing this thesis. At times, I experienced such overwhelming fear and frustration I would intentionally pull away from the study. Although unproductive, by purposefully removing myself from the data, I was able to experience moments of great insight as I spent a great deal of time reflecting on the participant's experiences. This reflection allowed me to gain clarity of thought, energy to reinvest myself in the study, and restored my objectivity.

Were I to describe the emotions during this journey, I think the most common feelings were ones of excitement, frustration, bewilderment, joy, and a great sense of achievement. The journey was definitely long, but the effort and commitment were worth it as the final outcome resulted in the discovery of the family member's experience of cadaveric organ donation. I sincerely believe, however, that the greatest joy and sorrow of this project was sharing in the participants' stories of their donation experience. Their courage in the face of such great pain was astonishing. The opportunity to meet these remarkable individuals was an honor and privilege. They taught me to have courage in the face of adversity and intense grief.

Conclusion

The findings from this study are unique and contribute to the current body of knowledge about the cadaveric organ donation process. Further research is required to explore our understanding of this process and to identify and substantiate definitive nursing interventions to facilitate the family member's journey through this multifaceted process. Only with continued efforts at furthering our understanding of this phenomenon will we be able to ensure that nurses fulfill their responsibility in providing family members the opportunity to consider organ donation for a brain-dead family member.

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Appendix A

Letter of Introduction

Page 1 of 1

Brenda Kindlemen, R.N., BScN.
Master of Nursing Candidate
Graduate Student, Faculty of Nursing
3-134 Clinical Science Building
University of Alberta
Edmonton, Alberta T6G 2G3
Telephone # 437-9154

Date

Dear _________;

I would like to take this opportunity to introduce myself to you. I am a nurse and graduate student in the Faculty of Nursing at the University of Alberta. I have worked in a Neurosurgical Intensive Care unit for approximately nine years, and have a special interest in understanding the experiences of organ donor family members. I have cared for many organ donors, and have spent a great deal of time interacting with donor families during the acute phase of the donation process.

I am doing a research study of the experiences of family members who have donated organs of a significant other, following his or her death. I realize it would be difficult to discuss your experience, however I want you to know that I would appreciate anything you feel comfortable sharing. The decision is yours as to how much or what we discuss. I am interested in hearing about <u>your experience</u>.

If you would like to participate in this research study, please read the enclosed information letter to ensure that you understand the research process. If you have any questions, please do not hesitate to call. I can be reached at the telephone number listed above. If I am unable to take your call, please leave a message and I will get back to you as soon as possible.

Thank-you.

Sincerely,

Brenda Kindleman, R.N., BScN.
Master of Nursing Candidate

Appendix B

Information Letter

Page 1 of 2

Brenda Kindleman, R.N., BScN.
Master of Nursing Candidate
Graduate Student, Faculty of Nursing
3-134 Clinical Science Building
University of Alberta
Edmonton, Alberta T6G 2G3
Telephone # 437-9154

Date

Dear ________;

Thank-you for agreeing to receive this information letter. I would like to take this opportunity to describe my proposed research study. I am interested in describing and exploring your experience as a family member who has consented to organ donation, following the death of a significant other. Before deciding whether or not to participate in this study, there are a number of research procedures you must be informed about.

Should you agree to participate in this study, you will be interviewed two or three times. The first interview will last approximately one hour, the second interview may be shorter in duration. The interviews will be scheduled on a day, time, and location convenient for both of us. Possible locations may included your home, or an unoccupied office/classroom at the Clinical Science Building at the University of Alberta. If possible, the first interview should be conducted in person. The second interview can take place by telephone, as the intent of this interview is to clarify any questions I have following the review of the first interview. All interviews will be recorded, and the audio tapes will be typed word for word by a typist. The only people who will listen to the tape, or read the typed interview are the typist, myself, and the three members of my thesis committee. The audio tapes and the typed interview will be stored in a locked cabinet, and I am the only individual with access to this information.

The information obtained from the recorded and typed interviews will be store in a locked cabinet for seven years and then destroyed. It is possible that the data obtained from the interviews may be used for a future research study; however, ethical clearance will be obtained prior to its use. As well, the data and research findings may be presented at conferences or appear in published articles. However, no information that may identify you will be used. If information from your interview is recorded in the findings of the study, a false name will be used so that your identity will be protected.

Participation in this study is voluntary, and if you choose, you can leave the study, or stop an interview at any time, without penalty. As well, you do not have to answer any questions, or discuss any subject you do not want to. If at any time you have questions or concerns you would like to discuss, you can contact me at the above telephone number. Because of the nature of the study, and the sensitivity of the topic, you may experience feelings of sadness, pain and grief. This may be considered a possible risk of the study. However, no tangible harm will come to you as a result of participating in this study. Nor will you benefit from the study, other than if it helps you to share your experience with another person. If at any time you feel you would like to talk with someone about your feelings, I will make a referral to a professional or support agency that can assist you.

If you have any questions or concerns that have not be addressed in this letter, or if you would like to participate in this study, please contact me by telephone at the above listed number, or return the enclosed form in the self-addressed stamped envelope. If you are not interested in participating in the study, no contact with me is necessary, as it will be assumed that if you do not respond in three to four weeks, you are not interested in participating in the study. Thank you for your interest and time. I look forward to talking with you!

Sincerely,

Brenda Kindleman, R.N., BScN.
Master of Nursing Candidate

Reply Form

Date: ______________________________

I, ______________________________, (print name) would like to be a participant in the research study "A Family Member's Experience of Cadaveric Organ Donation". Please contact me by telephone at ____________________(telephone number) so that a convenient date, time, and location for the first interview can be arranged.

Thank-you

Appendix C

Consent Form

Page 1 of 2

Project Title: A Family Member's Experience of Cadaveric Organ Donation

Investigator: Brenda Kindleman, R.N., BScN. Master of Nursing Candidate Graduate Student, Faculty of Nursing 3-134 Clinical Sciences Building University of Alberta Edmonton, Alberta T6G 2G3 Telephone: 437-9154	Dr. Marion Allen, R.N., PhD. Professor Faculty of Nursing 4-112 C Clinical Sciences Building Edmonton, Alberta T6G 2G3 Telephone: 492-6411

Purpose: The purpose of this research study is to explore and describe the experience of organ donation from an immediate family member's perspective.

Procedure: Should you decide to participate in this research study, you will be interviewed two, possibly three times. The first interview will last approximately one hour, and will be in person, if possible. The second interview may be shorter in duration. The interviews will be schedule at a date, time, and place convenient for both you and me. All interviews will be recorded, and the audio tapes will be typed word for word by a typist. Any information recorded on the audio tapes that will identify you will be erased. The only people who will listen to the audio tapes, or read the typed interviews, are the researcher, typist, and the members of the researcher's thesis committee. The audio tapes and the typed interviews will be stored in a locked cabinet, and only the researcher will have access to the cabinet.

Upon completion of the research study, the audio tapes and typed interviews will be kept for seven years, after which time they will be destroyed. The typed interviews may be used for another future research study; however, ethical clearance will be obtained prior to their use. As well, the information and research findings may be presented at conferences or be published; however, no information that may identify you will be used. If information from your interview is recorded in the findings of the study, a false name will be used so that your identity will be protected. If you have any concerns about this research study, now or in the future, you can contact the researcher at the number listed above.

Participation: You do not have to be in this study if you do not wish to be. If you agree to be in the study, you may leave the study at any time without penalty, simply by informing the researcher that you no longer wish to participate. You do not have to answer any questions, or discuss any subject in the interview if you do not want to. As well, you can stop the interview at any time without penalty.

There will be no harm to you if you participate in this study, nor will you benefit directly from this study. You may experience feelings of sadness when you discuss your experience with the researcher. If at any time you feel you would like to talk to someone about these feelings, the researcher can refer you to the appropriate agency. The potential benefit of this study may be that the study results may be useful to other families who have consented to organ donation.

Consent Form

Page 2 of 2

Consent: I,__________________________, (print name) understand the above research guidelines, and any questions I have, have been answered to my satisfaction. If I, at any time, have questions or concerns about this study, I can contact the researcher at the number listed above. I understand that there are no direct benefits or risks to me for being a participant in this study. I understand that the recorded tapes and the typed interviews will be seen by the researcher, the typist and the three members of the thesis committee. I have been told that my name will not be linked with the information I share, and that if information from my interview is used, a false name will be used. I understand that I can stop the interview at any time, and that I do not have to answer any questions or discuss any subject during the interview that I do not want to. As well, I understand that I can leave the study at any time without penalty. I have been given a copy of this form to keep for my records.

__________________________ __________________________

(Signature of Participant) (Date)

__________________________ __________________________

(Signature of Researcher) (Date)

If you wish to have a summary of the findings of the study, please complete the following:

Name: ____________________________________

Address: __________________________________

____

____

Appendix D

Interview Guide: Examples of Guiding Questions

Concurrent data collection and analysis resulted in the continuous revisions of the interview guide. The intent of these revisions was to collect "rich" data on emerging themes and categories. Opening questions were broad in nature to encourage the participant to share their experience and unique perspectives in their entirety. If necessary, probe questions were asked to facilitate the participant's elaboration on specific aspects of their experience. With the exception of the opening questions, participants were asked only questions that were pertinent to their experience. As well, the order and form of the questions varied as did when the questions were asked – first or second interview.

Opening Questions:

- Tell me about your organ donation.
- Tell me how you feel about the organ donation process.
- Tell me about how this experience has influenced your life, if at all.

Probe Questions:

- What made you decide to consent to organ donation?
- What or who influenced your decision to consent to organ donation?

Support Questions:

- Who provided you with the most support during this difficult time?
- What type of support did he/she offer that was the most helpful?
- What support was offered that you found unhelpful?
- What community support, if any, was available to you to assist you with your loved one's death?

Health Professional Questions:

- Who approached you about considering organ donation?
- What role did each of the healthcare professionals play in assisting you with your decision to donate your loved one's organs?

Information Questions:

- What type of information was given to you in order to assist you with your decision to donate your loved one's organs? (Written and /or verbal information: brain death criteria, diagnostic tests, etc.)
- Would you have benefited from written information in the form of a pamphlet, to which you could refer to, as needed?

- How would this information pamphlet have assisted you, if at all?

- What type of information would you like to see included in the information pamphlet?

Terminology Questions:

- What type of terminology was used to inform you about organ donation?

- What are your feelings about the terminology used to talk about organ donation?

Mutilation Questions:

- Can you tell me how you felt about the surgical removal of your loved ones organs?

- Did you have any concerns about the appearance of your loved one following the surgical removal? If so, what concerned you most about your loved one's appearance post-donation?

Respect Questions?

- What type of care was provided that demonstrated to you that your loved one was treated with respect and dignity?

- Did you ever have any concerns about how your loved one was treated after your consent to organ donation? If so, what were your concerns?

Appendix E

Biographical Data Form

Code Number: ____________________ Code Name: ___________________________

Date and Time: ___________________

1. Gender: Male.____ Female.____

2. Age:____

3. Relationship to the organ donor:
   Wife: ______
   Husband: ___
   Son: _______
   Daughter: ___
   Brother: _____
   Sister: ______
   Mother: _____
   Father: ______
   Other: ________________(Grandparent, guardian, or other legal next-of-kin)

4. Date of organ donation:________________
   *approximate time: 0 to 3 months: ____
   6 to 6 months: ____
   6 to 12 months: ____
   other: ____________

- Donor information:
  age: _______
  relationship: ___________
  cause of death: ____________________________
  circumstances: ____
  ____

  organs donated: heart___
  lungs___
  liver____
  pancreas____
  small bowel____
  kidneys_____
  other____________________

  tissues: corneas_____
  heart valves____
  skin_____
  bone______
  other_______________________

1. Offer bereavement support services summary: ______ (yes)
2. Offer follow-up by organ procurement coordinators: ___________ (yes)
   accepted: _________ declined: ___________