Research Project:

The Experience of Consenting to Organ Donation

Marilou Sempio and Lisa Baldwin

Oregon Health Sciences University

May 28, 1991

Running head: ORGAN DONATION

Approved:

[redacted]

Christine A. Tanner, R.N., Ph.D., F.A.A.N., Professor of Nursing, Advisor

[redacted]

Virginia P. Tilden, R.N., D.N.sc., F.A.A.N., Professor of Nursing, Reader

[redacted]

Carol A. Lindeman, R.N., Ph.D., F.A.A.N, Dean and Professor, School of Nursing

ACKNOWLEDGMENTS

We would like to express our deepest appreciation to the following individuals who made the completion of this research project possible:

Christine Tanner, our committee chair, Professor of Nursing, for her support, encouragement and guidance in the preparation of our research project. Her expertise and critical review were invaluable.

Virginia Tilden, Professor of Nursing, for her encouragement, editorial expertise and valued suggestions.

Kristine Nelson, former Department Director of the Pacific Northwest Transplant Bank, for her encouragement, enthusiasm, and valuable suggestions. Her assistance in obtaining our study sample was vital to our study.

Joan Chan, R.N., Assistant Director of Nursing, Providence Medical Center, for her technical support.

The nursing and clerical staff of the Pacific Northwest Transplant Bank, for their role in obtaining our study sample.

Debra Anderson, for her valuable time and energy and our Ethnograph lessons.

Carol Holt, for her assistance with data transcription and editing our final Master's Research Project.

Audrey Maederer, for her computer instruction and technical assistance.

Mary Cornish, R.N., for providing scheduling flexibility and moral support.

Cathy and Steve Splonskowski, for their time, hospitality and use of their MacIntosh computer.

Finally, our families and friends, for their never-ending support and encouragement.

TABLE OF CONTENTS

APPENDICES

CHAPTER I

Introduction and Statement of the Problem

Every day there are families who face the task of deciding the fate of loved ones involved in catastrophic events which have rendered them brain dead. This study proposed to describe the experiences of the legal decision makers who are involved in such situations and who have consented to donate the organs of brain dead individuals for transplantation. Each year, of the 20,000 who die who would qualify as organ donors, only 15% actually become organ donors. This is largely because families were not presented with the opportunity to donate (National Kidney Foundation, 1987). More recent statistics indicate that as of February 1991, 22,512 people were waiting for organ transplantation, e.g. heart, liver, kidney, heart/lung, pancreas and lung (United Network Organ Sharing Update, 1991).

The legally prescribed task of asking families for a decision about organ donation (with each hospital death) recently became the task of individuals designated as trained requestors. In July 1985, Oregon passed its first Routine Inquiry Law which states that "when death occurs in a hospital to a person who has not made an anatomical gift, the hospital administrator or designated representative shall request the (legal next-of-kin)... to consent to the gift of all or any part of the decedent's body as an anatomical gift" (Oregon's Routine Inquiry Law, 1986). The necessary informed consent entails disclosure of information by the hospital's designated representative (e.g. nurses, doctors, clergy, social worker, etc.) to the family and the family's understanding of the presented information. Nurses, as a significant number of the trained requestor personnel, have an ethical responsibility to ascertain that the family clearly understands the brain dead patient's condition, recommendation for care, and the ramifications involved in this care plan.

In general, it is the responsibility of health care professionals, including nurses, to provide objective and complete information to families. Within the organ donation request realm, hospitals in Oregon are legally bound by the Routine Inquiry law to designate and train staff (e.g. nurses, doctors, clergy, social workers, etc.; operating as trained requestors) to make inquiry of families about their wishes for organ donation. More specifically, trained requesters are morally and legally obligated to approach families of brain dead patients, during an emotionally charged time and ask for a decision regarding organ donation.

Although Oregon's Routine Inquiry Law was passed in 1986, no information was located describing the outcomes of the required request law and/or an evaluation of the request process and it's impact on families or trained requesters.

In addition, few research studies were found exploring the recollections of families related to the organ donation decision making experiences.

The investigators' clinical experiences in critical care, transplantation, and organ donation have allowed them opportunities to view first-hand the process of grief and loss associated with brain death, as well as the decision making surrounding organ donation. Because of these experiences and the previously stated factors, it is reasonable to descriptively investigate the experiences of the persons who consented to cadaveric organ donation. The study results may enable a better understanding of this process and assist in educating trained requesters to better meet the needs of the family in the future.

CHAPTER II

Review of Literature

Limited research related to decision making surrounding organ donation was found. The literature believed relevant to decision making about organ donation falls into three areas: informed consent, public and health professional attitudes toward organ donation, and the Routine Inquiry law. Informed consent is relevant to this study because optimally it is an integral part of any health care decision a family member makes. Public and health professional attitudes toward organ donation is pertinent since these groups' exposure to, understanding and perception of the organ donation process may influence the number of donations that occur. The Routine Inquiry law mandates that each hospital in Oregon designate trained requesters to ask each deceased patient's next of kin to consent to donate all or any part of the deceased's body.

Informed Consent

The existence of true informed consent has been debated in the literature (Caplan, 1983; Davis, 1989; Parks, Barber, & Painvin, 1986; Peele, 1989; Rodgers, 1989; Rose, 1982). One must consider the psychologically traumatic circumstances in which families are approached regarding organ donation. These people may be in a state of shock, grief, and confusion. Because of these conditions, there is limited opportunity for families to make an informed or voluntary choice. Time for decision making and a suitable environment for thoughtful consideration of the donation question are often scarce. It is questionable whether the bereaved family is able to comprehend the information given them (Caplan, 1983). No research to support this opinion was located.

Attitudes toward Organ Donation

Public attitudes toward organ donation may affect the number of people who actually give consent to donate a loved one's organs. In 1990, the Gallup Organization conducted a telephone survey (sponsored by the Dow Chemical Company) of 1012 randomly selected adults, in an effort to better understand opinions and perceptions regarding organ donation. Seventy-three percent of the 1012 reported that they were likely to very likely to want their own organs donated after death. Eighty-nine percent of this group indicated they would likely donate the organs of a loved one if that loved one had indicated a desire to donate prior to death. Those who were most likely to donate had more formal education, higher incomes and were living in the western portion of the United States. Whites were twice as likely as blacks to donate their own organs after death, but no difference between the groups was found when asked if they would be willing to donate the organs of their loved ones. Since 1985, the number of Americans who have completed their own organ donor card has increased 75%. However, only 51% of the surveyed group were aware that, even with a signed donor card, family consent must be obtained before organs can be removed for transplantation.

Several factors may influence refusal to donate. According to a survey (Robinette, 1985), these include the following:

a. fear of hastiness in organ removal
b. fear of mutilation
c. fatalism
d. religious reasons
e. age -- too young or too old
f. never considered organ donation

The methodology and data collection techniques for this survey were not adequately described or referenced. The research drew from a few unnamed hospitals (patient charts), hospital death records and a Gallup poll. Unfortunately, this survey did not identify the demographics of the population studied. As a result, it is unknown whose opinions were surveyed. This survey was conducted in Canada and the results may not be generalizable to the United States considering the differing health care system that exists in Canada.

Robinette (1985) also described that professional attitudes may also play a role in whether or not consent for organ donation will be obtained. According to a survey of intensive care unit (ICU) staff, which included medical (interns/residents - 55; ICU physicians - 119; other physicians - 251) and nursing (1479) - from a transplant and dialysis center, chaplains (87), and neurosurgeons (33) from 102 of 118 hospitals in Ontario, Canada, some of the main reasons why permission for organ donation is not obtained are as follows:

a. a lack of hospital policy regarding organ donation and recovery causes confusion to physicians and nurses.

b. the whole process is time consuming and disruptive to the unit.

c. a lack of an in-hospital team or individual assigned to the donation process.

d. a lack of specific information regarding suitability for organ donation and optimal donor maintenance.

e. a need for further education regarding the process of donation.

f. a lack of monetary reimbursement for physicians.

g. personal feelings as barriers, e.g. they "don't want to bother the grieving family for consent".

One study was located exploring the family's decision making in organ donation conducted by Bartucci (1987). She qualitatively described donor families' feelings and experiences related to organ donation. She mailed a questionnaire to 41 families directed at determining their feelings about the donation process. Her research concluded that most donor families had positive feelings about organ donation as a result of their desire to help someone else and make something good come out of a tragedy. What her research did not address was potential differences related to what organ(s) were donated and the questionnaire she used asked closed-ended questions that did not facilitate detailed narrative from the study's subjects. Because our study incorporates open-ended questions, we should obtain a richer informant description that is more detailed, encompassing the range of organ donation possibilities.

Soukup (1989) conducted home interviews with 46 legal next of kin of totally brain dead (TBD) individuals. This study sought to measure the relationship of six situational variables on the stressful experience families perceived at the time of organ donation. The six variables included: 1) unknown (the family was not aware whether the TBD patient wanted to donate an organ(s) after death); 2) type of family decision making (isolated family member decision versus concensus among family members); 3) time between suspected and declared brain death; 4) family participation in immediate post death bedside customs; 5) heart as a donated organ; and 6) age of the TBD family member. The investigator designed tools used in this study were Organ Donation Family Stress (ODFS) scale, Family Participiption Visual Analogue (FPVA), and Demographic Data Form. Other tools were F-COPES and Family APGAR used to evaluate OPFS construct validity. The findings suggested that ODFS may be increased when preference of TBD is unknown or when the family participation is low in the immediate post death bedside customs. In addition, evidence existed that the ODFS and FPVA were useful self report instruments.

While the sample in this study and Soukup's (1989) study were similar, Soukup's quantitative study focused on the stress a donor family might experience, where this study qualitatively concentrated on the overall experience of organ donation as described by the next of kin of TBD individuals. The sample size in both studies was insufficient for generalization to other similar groups.

Routine Inquiry

Another factor influencing organ donation is whether the request is made. Not all states require routine inquiry. Of the states that do mandate request, there is a great deal of variability in: 1) legal requirements for routine inquiry, 2) training required for requesters, 3) evaluation of requesters, and 4) audits of reasons for consent or refusal to donate. Hence, very little research is found in this arena.

The specific gaps in the literature include the lack of audit describing the outcomes of the Required Request law, an absence of an apparent evaluation in the organ donation process and its impact on families or designated requesters, and the scarcity of research studies exploring the recollections of families related to the organ donation decision making experiences. Because of these gaps in literature, this study is both necessary and timely.

Research Questions

The research questions of this study were:

1) How do consenters describe the experience of giving consent for organ donation for transplantation?
2) What do consenters describe as helpful and not helpful actions on the part of the health care providers in making the decision?

CHAPTER III

Methods

Design

This study used a descriptive qualitative design. Family members who consented to donate brain-dead members' organs for transplantation and were present during the routine inquiry request were interviewed by telephone. These interviews were tape recorded and were an average of 30 to 45 minutes in length depending on the individual needs and situation. A total of twelve interviews were conducted, one of which was with a married couple who were interviewed simultaneously and counted as one respondent.

Sample

The initial sample was identified by the Pacific Northwest Transplant Bank (PNTB) as those who consented to cadaveric organ donation for transplantation from six weeks to six months prior to the time of the study's start through the time when data collection was completed.

Initially, 17 cover letters (explaining the purpose, risk and benefits) and consent forms were sent to the appropriate family members. Five out of 17 consent forms were returned. Of the original 17 participants contacted, one telephoned the Pacific Northwest Transplant Bank (see subsequent description) and angrily expressed how insulting it was to receive the cover letter and consent form.

This sample was originally planned to include those who had agreed to donate their loved one's organs for transplantation six weeks to six months prior to the time of this study. Because the response rate of the first mailing was less than 30% and yielded only five study participants, a second mailing was undertaken. In the second mailing, inclusion criteria were changed from those who donated six weeks to six months prior to the study to those who donated six weeks to 12 months prior to the study. The second mailing yielded a 43% response rate (with 9 out of 21 individuals consenting to be in the study).

The sample included five males (42% of the sample) and eight females. The consenter age range was 30 - 67 years, with a mean age of 46.4 years. Six of the study participants were parents of the donor, four were spouses, and two were children. Four of the organ donors were male and eight were females. The donor age range was 17 to 66 years of age, with a mean age of 36.5 years. In seven cases, the donor's cause of death was a ruptured brain aneurysm, two donors died in motor vehicle accidents, one was a bicycle accident victim, one was involved in a horseback riding accident and one suffered a gunshot wound to the head. The time interval between the donation date and the time of the telephone interview was six weeks to six months for four participants and greater than six months for the remaining eight study participants. Twelve of the participants described themselves as Caucasian and one reported being of Native American descent. When asked about religious preference, four said they were Catholic, three were Protestant, two had no religious preference, and there was one Baptist, one Lutheran, and one Methodist. Four of the participants in the study identified a nurse as the requester, two said the requester was a stranger, two reported a physician as the requester, one said a doctor and nurse both made the donation request, one was approached about donation by a transplant coordinator, one could only remember it was "a lady that worked at the hospital" and one consenter asked to donate his loved one's organs.

Based on the transcribed data, there was a question of whether or not the donor with the gunshot wound was a homicide or suicide victim. While either of these instances would have excluded him from the study, after consultation with the thesis advisor, a decision was made to include him in the study because the interview provided rich narrative description vital to this study.

The specific individuals who signed the consent form for organ donation were used as informants, rather than several family members, because of the potentially confusing interpersonal/family dynamics that may be present. This was a recognized limitation of this study.

Procedure

Initially, these individuals were contacted by the department director of the Pacific Northwest Transplant Bank (PNTB), maintaining informant confidentiality. PNTB is the organ procurement agency for the state of Oregon. This agency is affiliated with the OHSU and functions as the initial contact for all internal organ donations and as a liaison with other transplant centers in the United States and Canada.

Potential study participants were selected based on the following inclusion criteria:

1) The donor population were individuals 15 to 65 years of age who were diagnosed as brain dead as a result of primary brain tumor, motor vehicle accident, or cerebral hemorrhage.
2) The consenter population were the legal next-of-kin of the donors according to the legal hierarchial ladder -- spouse, adult offspring (18 years or older), parent, sibling (18 years or older), or legal guardian. The consenter was present when the request of a decision about organ donation was made.

Exclusion criteria included:

1) the families of pediatric donors less than 15 years of age,
2) living related donors,

3) suicides and homicides.

An introductory letter and consent form (Appendix B, pp. 63-64), prepared by the investigators, were sent by the PNTB, at least six weeks post donation to the families explaining the purposes and goals of the study. Also included with the letter were the study's consent form as approved by the Oregon Health Sciences University Committee on Human Research.

If the family member who signed the organ donation form agreed to participate in the study, they were asked to sign the consent form and return it to the investigators within one week. One of the investigators contacted the family member to arrange a mutually agreeable time to conduct the telephone interview.

The 12 study informants were interviewed six weeks to twelve months after donation. We anticipated this time period would allow the PNTB to inform families of organ disposition and burial issues would be completed. It was unknown what phase of grieving the family were in during this period since grieving is a subjective experience and varies individually.

A tape recorder was used to record the telephone interviews (after the consent form was signed). Interviews occurred at mutually agreeable times. Because the researcher and the informant agreed on these specifics, distractions for both during the conversation were minimal. Data were transcribed verbatim, coded, and categorized according to emerging themes. Coding was done independently by the investigators within one week of data transcription. This time period was also used for comparing data and determining the direction subsequent interview questions should take.

Instrument

The initial interview questions used for the first five interviews were broad and open ended, and thus allowed for rich narrative that was essential for the descriptive phenomenological method. The questions were designed to probe the memories of consenters pertaining to the organ donation experience and what actions consenters found helpful and not helpful on the part of requesters. The interview questions were further focused based on themes emerging from the transcribed and coded data. These questions were designed to further facilitate re-living the experience and to explore doubts they had related to the diagnosis of brain death and/or organ donation. Demographic information was also collected. Family members were asked if they could be contacted at a later time if the investigators had further questions.

Initial questions used in the first interviews (see Appendix A, pp. 61-62) facilitated the informants' narrative description of the organ donation process and probed the informants' memories and feelings regarding the trained requestor's role in the organ donation process. Even though the questions were standardized, the open-ended nature of the questions guided the direction of subsequent interview questions. After the first five interviews were transcribed and reviewed, subsequent interview questions were revised with the assistance of the thesis advisor. The revisions were designed to more effectively probe the participant's memory of the donation process. Additionally, the demographic questions (see Appendix C, pp. 67-68) were asked at the end of the interview, rather than at the beginning.

Analysis

The three major components of analysis were: 1) derivation of codes and coding of the transcribed data, 2) independent and collective examination of the data for patterns and, 3) an in-depth analysis of the identified patterns.

Derivation of Codes

When deriving the codes and coding the transcribed data, the codes were applied independently by the two investigators to the initial five interviews and subsequently reviewed by the thesis advisor. The codes were revised and refined as data collection and analysis continued. All of the study transcripts were coded with the final set of codes independently. Any discrepancies between the investigators about coding the data was resolved by consensus. The data were entered on an ethnograph data management system for later retrieval according to coding category.

Patterns of relationships between categories

The data were examined for patterns among the coded categories. Theoretical memos were kept throughout data collection and analysis to assist with this aspect.

Segments of coded data were retrieved for in depth analysis and were compared across individuals. The ethnograph computer program was used for data retrieval. The thesis advisor audited all aspects of analysis.

Trustworthiness of Data

The degree to which data are reliable, valid and bias free may be referred to as trustworthiness of the data (Guba, 1981). Trustworthiness of data in this study was enhanced by triangulation, peer debriefing, referential adequacy, applicability, dependability and consistency, and confirmability and neutrality. Two limitations in this study's design were lack of time and adequate finances for prolonged engagement and persistent observation. The approach to these means of enhancing trustworthiness of qualitative data are further described below.

Data were gathered using open ended style questions during tape recorded telephone interviews. After each telephone interview the investigator jotted notes about her impressions of the conversation. The investigators compared their impressions after each interview and proceeded with subsequent interviews according to the direction and flow of recurring themes. Investigators avoided overrapport, premature closure, and inconsistent triangulation methods. Chance of bias was minimized because of the ongoing analysis and critique by the thesis advisor and the study's two investigators. Additionally, no other method or tool appropriate to our purpose was found.

To reduce the possibility of bias and maintain investigator focus, the investigators met after each telephone interview, read the telephone transcripts and discussed emerging themes. The assistance of the thesis advisor was sought regularly to validate investigators' thought processes and interpretations. Written records were kept of each of these debriefings as part of the study's audit trail. Data analysis, process, study results, interpretations and conclusions were defended.

The investigator(s) shared their interpretations of each subject's description of the organ donation experience (during the telephone interview) to assure adequacy of interpretation. These interpretations were later validated by the thesis advisor when telephone transcripts were reviewed.

The study provided thick descriptions that may assist future research targeting the consenter's description of helpful and unhelpful characteristics of trained requesters and/or consenter description of the organ donation experience. Possible transfer situations for this study may include future families and/or the edification of trained requesters. Demographic information about the study subjects was complied (see Appendix E and F, pp. 74 & 75).

The audit trail of this study consisted of the interview transcripts, tape recordings, research log and theoretical notes. The primary auditor (e.g. thesis advisor) was an individual not involved in the data collection, but knowledgeable in qualitative methods and the study content area.

CHAPTER IV

Results and Discussion

After the first five interviews, five codes were identified from recurring themes seen in the data. Subsequently, additional themes emerged as data collection and analysis continued. Nine additional codes were generated for a total of 14. The codes appear in Appendix D, pp. 69-71 in order of development and are further described below. Study data revealed that the experience of consenting to organ donation was a three step process and was influenced by various contextual factors (see Figure 1, p. 23).

The way each study participant perceived the process and contextual factors contributed to their resolved or unresolved feelings about the organ donation experience. The study participants who felt resolved about the donation experience had overall positive feelings of satisfaction and contribution gained from the organ donation. The study participants who felt unresolved about the donation experience had overall negative feelings of dissatisfaction about the organ donation process, and aften expressed these feelings in anger. Each aspect of the experience is described in detail in the next section.

The Experience of Consenting to Organ Donation

<u>Process</u>

Data suggested that the experiences of consenters who

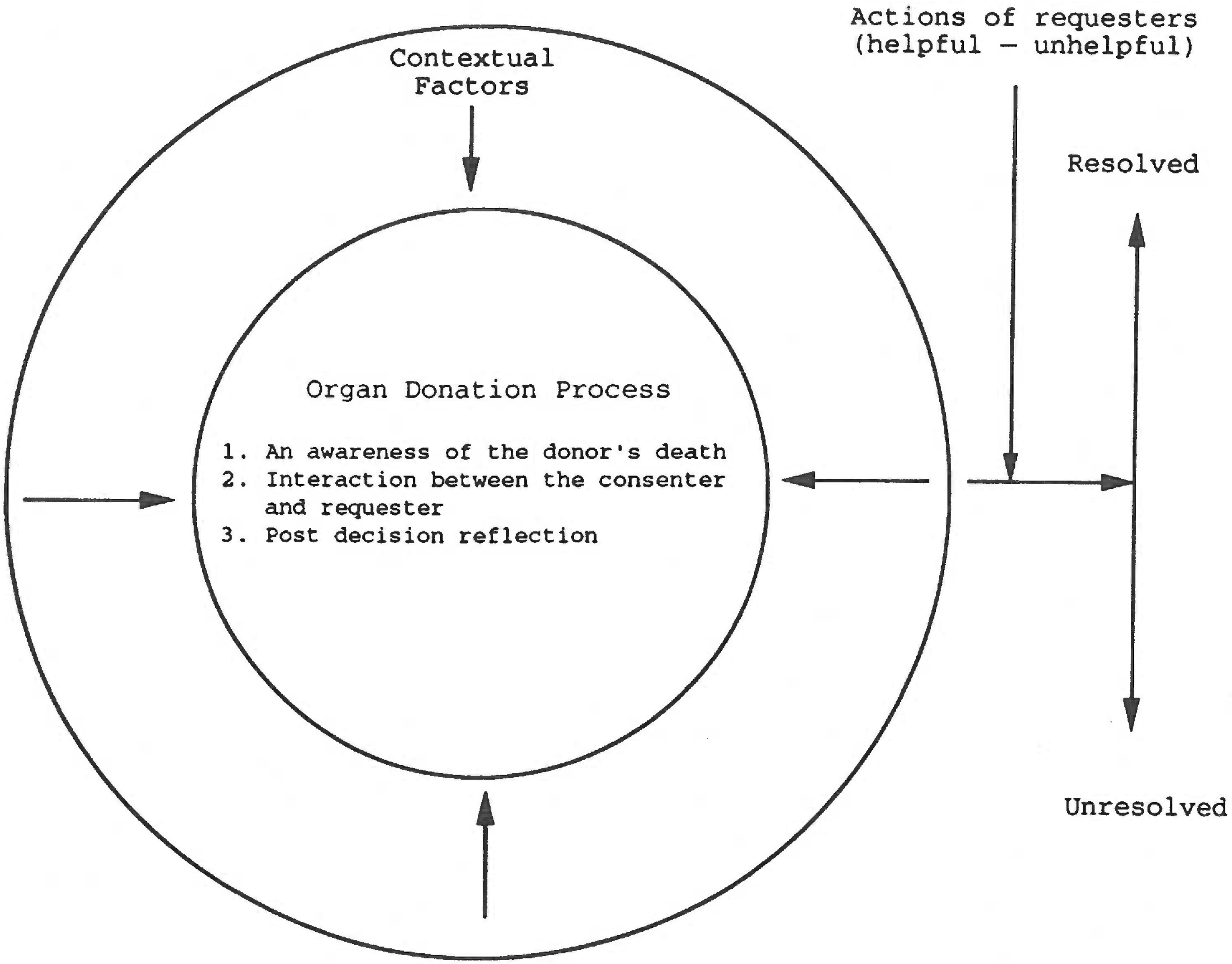

Figure 1.
Organ Donation Process. This process occurs in three phases, is mediated by contextual factors, is influenced by actions of requesters and results in the consenter feeling some degree of resolution with their decision.

agreed to organ donation could be described as a process. This process involved three main phases which included the following:

1) An awareness of the donor's death
2) Interaction between the consenter and requester
3) Post decision reflection.

This process, which led to consenting for organ donation, was influenced by several contextual factors: 1) consenter's awareness of the deceased's desire to donate his/her organs, 2) past discussion between the donor and consenter regarding organ donation, 3) requester characteristics, 4) previous relationship between the consenter and a health care provider and, 5) feelings of beneficence experienced after notification of organ disposition and/or letters of thanks receieve from the organ recipients. (Phases one and two above were experienced by some study participants in interchangable order.) Each of the above phases and contextual factors is discussed below.

Awareness of the Donor's Death The awareness of death was common among all participants. Awareness was experienced in predominantly two different ways: 1) immediate recognition when the consenter saw their loved one (4 respondents), typically confirmed verbally by the health care provider, and 2) by being directly informed that brain death occured (8 respondents). Of these eight, four participants did not agreed to organ donation could be described as a process. This process involved three main phases which included the following:

1) An awareness of the donor's death
2) Interaction between the consenter and requester
3) Post decision reflection.

This process, which led to consenting for organ donation, was influenced by several contextual factors: 1) consenter's awareness of the deceased's desire to donate his/her organs, 2) past discussion between the donor and consenter regarding organ donation, 3) requester characteristics, 4) previous relationship between the consenter and a health care provider and, 5) feelings of beneficence experienced after notification of organ disposition and/or letters of thanks receieve from the organ recipients. (Phases one and two above were experienced by some study participants in interchangable order.) Each of the above phases and contextual factors is discussed below.

<u>Awareness of the Donor's Death</u> The awareness of death was common among all participants. Awareness was experienced in predominantly two different ways: 1) immediate recognition when the consenter saw their loved one (4 respondents), typically confirmed verbally by the health care provider, and 2) by being directly informed that brain death occured (8 respondents). Of these eight, four participants did not

explicitly describe being informed of death but used language in the interview implying that they understood that brain death had occurred.

An example of immediate recognition that brain death had occurred was given by the father of a 22 year old student who suffered severe head injury after being hit by a car while riding her bicycle. He said, "The minute I saw her I knew, I just felt she was gone. I just felt that it wasn't her there ... I don't have any hope."

Another parent recounted her son's death and her immediate recognition that brain death had occured. Her 23 year old son was involved in a motor vehicle accident. " ... He was all but dead by the time I got here ... I've taken care of cancer patients and stuff. My ... step dad and things and I ... recognized the signs only too well."

A 33 year old gentleman described his 37 year old wife's appearance after a ruptured cerebral aneurysm. He had left the hospital "for a few hours" and when he returned " ... she was just changing, I could see that she was just going downhill quick." When asked what he saw, he replied, "well her, her, color, when I first seen her, that night and felt her, and held her hand and stuff, she was still warm. But then her, her eyes look kind of, they were, her eyes looked like they were sinking in a little bit and ... all her extremities were cold and they looked completely different".

The most common way the consenters learned about their loved ones' death was through verbal communication. Brain function assessment procedures were performed on the deceased in order to establish brain death. These test results also assisted in clarifying the brain death explanation to the consenter. The following are excerpts that epitomized the process for these participants.

A 43 year old gentleman relived the process of discovering that his 42 year wife was brain dead after a fall from a horse. "The whole time frame, I mean the moment that we got there I knew there was very little hope because of the brain damage from the accident. The doctor filled me in on that ... It was basically if there is at all, it would be a vegetable. ... he just filled me in. We took three tests (EEG's) ... One of them had a little bit and then the next day we took one and the next day and they had two back to back, ... there was none then (brain wave activity). And they basically all the machines were ... keeping her going. And Dopamine was keeping the heart in shape and the blood pressure up."

A husband and wife described the process of understanding that their 22 year old daughter was brain dead. "They (the physicians and nurses) talked about brain activity ... whether there was any ... she was on total life support for her breathing and that her heart strong ... They made it clear to us that they were looking for any sign of life in her brain. And my assumption was, whether they used brain death or not, if there was no sign of life, then she was brain dead ... They explained how they would take the respirator down ... slack off on that and see if there was any natural instinct ... as her CO2 built up ... she would start to try to fight for a breath. ... there was none. ... and the nurse explained to us about that test. What, and then to EEG's, those tests." When asked to recall at what point a decision about organ donation occurred, they replied, "I think ... it first began when the nurse came in and said that, and with the doctor and they said that there was no ... sign of life at all." In each of these situations the EEG seemed to provide the confirming evidence the loved one needed to feel certain that death had occurred.

Four study participants never succinctly said that their loved one was brain dead, but their language and tone implied that they recognized that brain death had occured. For example, a mother described how she was informed of her 23 year old son's death. " ... They were real good about it, explaining things. ... they said even if he lived, if his brain kept functioning, he'd of been only a vegetable".

One physician cogently illustrated the concept of brain death to a 40 year old woman whose 40 year old husband suffered a ruptured cerebral aneurysm. " ... He (her husband) just went to sleep and the next day he ... wouldn't wake up so we took him to the hospital. And they did tests and stuff and told me that they didn't think he'd make it. ... they came and asked me if I would consider them (her husband's organs)." When asked if the physicians explained what was wrong with her husband, she answered, " ... he had an aneurysm in his brain. And it had exploded. And so his brain was full of blood ... they didn't think surgery would help him at all. ... when they came and asked me ... I told them that we had discussed it, not in detail, but kind of discussed it and that we both felt ... that would be a good idea."

In addition to a thorough explanation of the situation, one 60 year old participant recounted the physician's attempt to clarify his explanations by showing the participant his daughter's CAT scan. "(The doctor) came immediately, and he came and talked to me and he told me that there ... wasn't no thinking about it. It was, you know, it was just a matter of a little bit of time. And uh, he explained to me that they could keep her on that respirator deal and whatever she was on, that machine. And keep her, probably alive for six hours or six days or six months or six or sixty years ... Under those conditions. But that half of her brain was totally dead. And the other half was sporadic. It wasn't a regular brain pattern and that they suspected a berry aneurysm in the

Willis circle. Which I've read a little bit about that and ... I'm familiar with it. ... I asked him ... what I could do and he said ... at this stage it would just be a vegetative state that she would lay in and never be any different than what she was right there. And I was in there, standing beside her (his daughter) at that time. My wife was out in another room out there because she wasn't in too good a shape. ... he came back, and I left there too, just kind of think for a second, went back into the room where my wife was at. And then I asked (the doctor) about the donor program." When asked what specifically facilitated his understanding of his daughter's condition, he replied, "The CAT scan. (The doctor) showing me the CAT scan. Showing me how a normal brain looks inside the human skull and how it looks when the vessels erupted and caused it to swell to such tremendous size. ... it was just the pressure of blood building up in the brain, that killed her ... When (the doctor) brought the CAT scan into the emergency room there and put it on the light and explained to me the sizes, he outlined it with is finger, how a normal brain would be in there, and then I seen how hers (his daughter's) was in there and he said that was caused by blood. ... that tremendous pressure was, was what was killing her. And that's why he said it would be just a matter of time and he said there was no way they could go in there, right to the center of the brain where the Willis circle is, and do any type of surgery. As a matter of fact, had she been laying right there in the hospital, at the time that happened, right at the very onset of it, and that would have happened right there in that emergency room, he said, we couldn't of saved her. It was too severe. That's what he said. It was just a massive thing. ... the showing me of the CAT scan was probably the ... turning point in deciding. Well, it was definitely the turning point."

The above participant was unique because he was the only one of the study participants that approached the health care professionals and asked to donate his daughter's organs. In addition, he was an unusually knowledgable layman with regard to the need for organ donors.

The similarity in the preceding four excerpts was that each of them implied (but did not state) that brain death had occurred. This is in contrast to the first four excerpts where the study participants specifically stated that brain death had occurred.

A recurring issue expressed was the participants' doubt that death had actually occured. Examples of this type of doubt follow. A 33 year old gentleman described his emotions as the physicians informed him that his 37 year old wife was brain dead from a ruptured cerebral aneurysm. " ... the most difficult part of having to make that decision to me would, it would be easier ... this would be selfish. But it would be easier for me to acknowledge that she's gone. When you see somebody straight line coded out and they're not resuscitation, and she's gone. She really is dead. But ... I got 100% confidence in ... the neurosurgeons and the doctors and everybody that was working on her. ... still, you have to take a person's word for it ... you think that there might be a miracle or something. Cause a person really is dead, but they're not, because they're kept alive so that ... organs will be of use later on. And that was one of the things that I had the most difficulty with. I think it would have been easier for me just to see her expire rather than just say good-by to her in that way."

A 39 year old woman described some other doubts about her mother's brain death when she said," So, I know in my heart that she wouldn't have woken up. But, once in a while ... when I think about it, I can't help but wonder. You know, with modern medicine, that way it is. Maybe ... the wishful thinking."

Another study participant described her doubt about her son's death when she said "I think that (doubt) happens naturally. I really do. I don't ... know if anybody could, ... because when you're in this grieving period and you're so devastated. I believed them when they told me ... But, there are ... times when you think, gee, maybe we reacted too soon or whatever. But ... that's a ... hard question to answer because when you're grieving, you're not thinking straight ... I mean there are so many situations where you're having a really bad day. And you may think, well, gee, all these people got a second life but it's only because my son died. That's a terrific bad, bad day ..."

A rare occurance was the perception of one consenter who felt she had never been told that her son died. As she described it " ... it was just such confusion and I couldn't get any place in that hospital. Finally they put us in a little room. ... I didn't get a police report, nothing. The doctor came out and he said, 'Well, often times when there is a shot to the head ...' The first indication as to what happened. 'We like to run a brain scan' I had no idea he was dead. I was never told that." During the interview she expressed a great deal of anger, resentment, and dissatisfaction, which may in part have been fueled by feeling that she had not been adequately told about what had happened to her son. The same unresolved consenter described her blurred thoughts when she was speaking of signing the donor consent form. She said " ... , they have little boxes on the top that says, 'signed by guardian, by mother, by father, sister, brother ... ' I could not remember, at this point, how to spell my name." This participant had prior negative experiences and perceptions (with the same health care facility) that may have contributed to her anger at the time of her son's death.

Interaction. The second phase in the experiences of the consenters involved the interaction between the consenter and requester, specifically on the topic of donation. The resolved consenters described their requesters as compassionate, well-informed, and direct. Those that were unresolved with the organ donation process described a lack of compassion and information.

One resolved father recounted his interaction with his daughter's nurse, "But, it was after that (the brain death criteria had been met), she (his daughter's nurse) asked us if ... we had ever discussed this and, and of course there was no question in our mind. You know, from the very beginning of this whole process that, that would be the ... eventuality .... I don't think there could have been anyone anymore professional or compassionate than she (the nurse requester) was".

Another participant described compassion when she said "they (the health care providers) really have the gift. They just have a soothing way of talking to you .... I considered her (the nurse requester) my nurse. My son had his nurses and she took care of me."

The unresolved 42 year old mother described the interaction with the physician (requester) managing the care of her 17 year old son when she said " a little compassion would have helped. A little sit-down and explain, people know a lot about the organ program, but until they are faced with it, they know nothing." This consenter also said "well I think that there needs to be more compassion, there needs to be more information." When the investigator asked if communication was a central issue, she responded "Yeh, a lot of it and just disinformation, my word."

One study participant recalled how her well informed requester assisted her decision making process to donate. "(The requester who was also her son's nurse) went through it (donation process) in detail as to what would happen ... from the moment (my son) was pronounced dead ... how it would be handled from the hospital aspect ... how they would go about contacting other people and how we would find out later ... what happened with his organs ... (the requester) was so informed of the program ... because he's (the requester) such a warm person ... it was just fine."

Thorough explanation of patient options in a direct manner was a positive factor for the resolved consenter group. One said, "they were very thorough in their explanation and you know, very accurate in the fact they did not try and paint any false hope for us." Another mentioned detailed explanation (by three physicians) of his daughter's injuries and prognosis and said when asking about organ donation the physician "looked at me and very softly, he told me ... we can use everything."

A mother described her requester's direct approach (which eventually assisted in her decision to donate her son's organs). "She (the nurse requester) came out of ICU ... she met us and took us outside and talked to us for awhile ... so she could prepare me ... she talked to me ahead of time to tell me what kind of condition my son was in and beings how he was thrown out of the car, he was ... road burned. With scrapes and stuff. She spent quite a long time with us. In fact, I considered her my nurse ... she explained ... 'he's hooked up to everything. He's scraped, he's bruised ... he's not a pretty sight. So I wanted to prepare you for that ...' I thought she had done such a wonderful job ... once she talked to me, I calmed down a lot."

Post decision reflection. The third phase experienced by the consenters involved reflection after the donation process. The majority of the consenters had recurring doubt about whether or not their loved one was really dead. One said, "Anyway, he (doctor) assured me that she was totally brain dead ... there was no hope. But, ... I still have, have questions about that ... I was kind of in a state of shock". when another study participant was asked if he had post-donation doubts about his daughter's death he said, "Yes, I did ..." Later he visited one of the physicians that had confirmed his daughter's diagnosis of brain death. During that visit he reported, "and so he went through the whole procedure with me, step-by-step and if I had a question, he was very nice about it. He answered every question I asked him. He never used no fancy words ... He never used any at all. He put it all to me in a layman's language like I can understand ... I think he probably he probably sensed that I was having problems ... He spent about an hour and a half with me, going over the CAT scan and explaining the, he had gotten a copy of the CAT scan from (the hospital) ... and he ... went over it with me and told me that it was his opinion too that there would have been no hope ... for survival under any conditions. And he was very helpful to me ... the talk afterwards relieved all thought (doubt) in my mind whatsoever."

When one study participant was asked if she had doubts that her son was really brain dead (after she had signed the organ donation consent form), she responded, " ... I think that happens naturally ... because when you're in this grieving period and you're so devastated. I believed them when they told me (that her son was brain dead) and I ... still believe it. But there are ... times when you think ... maybe we reacted too soon ... but that's ... a hard ... question to answer because when you're grieving, you're not thinking straight ... there are so many situations where you're having a really bad day ... because my son gave up his life ... these people (organ recipients) have a second chance on life. And that's what he wanted... that's what happened... you get that satisfaction out of it."

Another consenter conveyed a similar experience when the question of doubt regarding brain death after the donation process was asked, " ... Yeah ... I think everybody would. I think you don't get over it (feeling of doubt) ... Because the doctor told us and gave us all the proof ... the only thing he might have done differently ... is bring in that piece of paper that showed the flat line (EEG) ... that would have been proof on paper, but still in my mind ... I don't think they can prove a person's dead ... Because people like me don't understand ... medical science ... are still going to have doubt and still wonder ... it happens to people ... the doubts ... it's not unusual." The study participants who had discussed organ donation with the deceased prior to their death or possessed previous knowledge or experience with organ donation, generally had resolved feelings about the organ donation process. The minority of the study participants who were not well informed about brain death, patient prognosis and organ removal procedure exhibited unresolved feelings about the same process.

Positive requester characteristics (compassionate, well informed, and direct) seemed to contribute to resolved feelings about the donation process. The study participants who expressed unresolved feelings about the donation process recounted lack of communication, explanation, and compassion.

Contextual Factors

Contextual factors in the experiences of the consenters influenced resolution or nonresolution prior to the donor's death, during the donor's hospitalization and the request process, and the period after the consent for donation was given. Contextual factors included: consenter's prior knowledge and past discussion of the deceased's desire to donate organs, positive requester characteristics, previous relationship between the consenter and requester, and/or feelings of beneficence.

Prior knowledge and past discussion. One major factor that influenced the degree of resolution the consenters felt with the organ donation experience was prior knowledge and past discussion of the deceased's desire to donate their organs after their death. One father said, "When she first got her drivers license, when she was sixteen, almost seventeen... I mean, she put that on her drivers license and told us in no uncertain terms that that's what she wanted ... And I'm sure that when she first heard about the option, that there was no question in her mind that ... she wanted to do that ... she (requester) said that had we given any thought to the option of ... organ donation and ... we said, not only had we given thought to it ... it's something that (our daughter) wanted. And so, I said there's no question that ... if that is the eventuality, then that's ... what we will do. And so ... there was never a question. It was nothing that we had to sit and discuss, it was nothing that, where we said we'll get back to you, it was just an automatic yes. That, that was her wish and that's our wish."

One participant told of her prior knowledge and past discussion of her son's desire to donate his organs in the event of his death. " ... My son and I talked about this (organ donation). We used to watch ... Rescue 911 and seen how other people were traumatized ... and he said, 'Hey, anything ever happens to me like that. And ... I'm going to be on life supports or ... brain dead ... don't you dare keep me alive ... Whatever I've got that somebody else can use, they can have it."

One father remembered a discussion with his daughter concerning death and organ donation, " ... I read something in Reader's Digest and was talking to her about it and ... she let me know that she believed in it too ... I kind of took it from her tone of voice that ... she'd always help anybody ... at anytime. Do something for them or give whatever she had or anything and I thought maybe she felt that way just about life in general."

Requester characteristics. During the donor's hospitalization, another description of the experience of giving consent for organ donation was the commonality of positive requestor characteristics. These positive characteristics were described by one as "She was an incredible lady. And extremely caring and extremely professional. She was really outstanding. In fact I told her I was in awe at her ability to handle this situation which I know was real difficult for her ... she just did a tremendous job."

Another study participant described the requester/care-provider as "he's such a warm person that it was just fine" (referring to the organ donation process).

One unresolved study respondent characterized her requester's lack of support and compassion when she said, "After I signed it (donation form) they gave it to my pastor to witness, the doctor took his little clipboard, stood up, looked me in the eye and said 'You no longer have control of the machines' and that is the last thing I ever heard from that doctor".

The other unresolved study participant related the lack of support when she said, " ... If they would just sit there and explain everything to families and what they can use and all this stuff and like I said, I suppose the only other thing is just to really understand that piece of paper (donation request form), and to let you see it ... we need things really explained, you know, verbalized and then, then if we semi-understand what he was saying, then we can say, 'well, what does that mean?' or 'where in the body is that? that you are talking about' ... And there, the biggest thing that I suppose, regarding not treat you like you're stupid, you can say 'what's a cornea?' Maybe you don't know what cornea is ... "

Previous relationship. In one case, the previous relationship of the consenter and requester played a significant role in the study participant's decision. When asked if he knew the physicians involved in his daughter's care, he said, "Yeah, yes ... " When asked if he had rapport with them and if that helped in his decision making he said, "Certainly, absolutely. Yeah. "Later he added, "And I told them, when I left the hospital about five. I told Dr. C_____, ... when Dr. I_____'s gets here, if he concurs and agrees with you, you go ahead and do what's necessary."

Beneficence. Beneficence, or the feeling that others would benefit, was another contextual factor that affected the process of organ donation. Factors that contributed to resolution or nonresolution after consent for donation included a feeling of fulfillment or beneficence that others benefitted despite the loss of a loved one and peace of mind. One consenter described getting letters from the Lion's Eye

Bank and the Kidney Foundation like this "It just tickled me to death. ... getting that letter made things kind of fall into place ... I thought 'My God, something good came of this.' Someone still has their daddy even if I don't have my mom. And it just kind of put things into perspective for me. And I've really been able to deal with it alot better. Knowing that there are two little children out there that probably would have had a real hard time adjusting to losing their father, in comparison to me, an older person, losing their mother, you know? ... And, it gives me a feeling in my mind and in my heart that, there's still a piece of my mother out there. She's still fighting for someone's life. She can't fight for her own, but there's still a piece of her out there that, that's fighting for someone. ... it has made for me, the grieving process, alot easier."

Another consenter spoke of a letter he received from the woman who received one of his daughter's kidneys. He said, " ... She wrote me a letter of thanks and it's really quite a letter ... she named her kidney 'Dawn' because it was the dawning of a new life for her. And I thought that was quite nice ... that she wrote to me. That's the only one I've got, actually from a recipient". When asked if this letter was helpful, he responded, "That helped a lot. I think if ... you never know the name of the person. If you get some follow-up. That somebody has got some good out of it".

The husband and wife interviewed in this study conveyed a unique experience when they recounted, " ... we received a letter from one of the nurses who was in the operating room when they removed the organs. And it was probably one of the most touching things that I had ever read. And just explaining how she was touched, having read about (our daughter) in the newspaper and, and the atmosphere in the room when ... this took place ... the reverence that was there and that they did say a prayer and it just really was a tremendous contribution to us and our peace of mind."

One study participant reflected that receiving notification of her son's organ disposition helped to validate her decision to donate. "It makes you feel so good when you get that report back ... a man with two children can now enjoy his life because he has my son's heart. Another man with his liver and another man and woman with each kidney. And two blind people can see because each one got a cornea ... burn victims got his skin tissue, osteopathic people got his bone tissue ... it does help. It really does help ... it does (validate my decision to donate) ... when you get this letter ... you can identify with a person ... that they did have children and now their children can enjoy their father or their mother ... you appreciate having these things afterwards."

One unresolved consenter recalled receiving a letter about the disposition of her son's pancreas and kidney. She said, " ... these recipients need to be encouraged to get in touch with the family. ... I understand ... the privacy business, the ... anonymous business, but they need, nothing would be more comforting to me than to get a thank you from each of them. And I would think that after someone has given them life, that wouldn't be too much to ask. We received one card. From ... the one that got his pancreas and one kidney. It was very impersonal, but it was caring ... I wish the family (the donor's) could be a little more involved (with the recipients) ... "

The experience of organ donation appeared to occur in three phases: 1) an awareness of the donor's death, 2) interaction betweeen the consenter and requester and, 3) post decision reflection. These three phases were affected by four contextual factors: 1) consenter's prior knowledge and past discussion of the deceased's desire to donate organs, 2) positive requester characteristics, 3) previous relationship between the consenter and requester and, 4) feelings of beneficence. Once the consenter was made aware of the occurrence of brain death the decision to consent for organ donation was facilitated by the consenter's awareness of the deceased's desire to donate organs and past discussion about donation between the deceased and consenter.

Positive requester characteristics (compassionate, well informed, direct) were important contextual factors that contributed to resolution. In one instance, a prior relationship with the requester was a facilitating factor in a consenter's decision to donate his daughter's organs. The tone and language in his interview implied that this consenter had developed a rapport and respect for this physician before the donation request. Because of this prior relationship, the consenter expressed a level of trust and confidence in the physician caring for his daughter. This trusting relationship was instrumental in his consent to donate his daughter's organs.

Post decision reflection was the third phase in the process experienced by the consenters in donating their loved one's organs. In this phase, some consenters had recurring doubts about whether or not brain death had actually occurred. However, the contextual factor that seemed to alleviate this doubt was the feeling of beneficence after receiving letters from the organ recipients.

These findings concur with those of Soukup (1989). She investigated variables associated with family stress related to organ donation from a totally brain dead family member. In general, this study and Soukup's are similar since both are focused on the experiences of the legal next of kin consenter in the organ donation process. However, Soukup specifically investigated variables associated with family stress related to organ donation. This study explored the overall experience of the legal next of kin (consenter) from the time of the donor's injury/illness until the time this study's telephone interview was conducted. Although the concept of stress might be involved in the current study, it was not specifically addressed. Soukup found that Organ Donation Family Stress increased when preference (donor's organ donation preference) was unknown. This particular finding might be similar to the current study's findings that previous consenter knowledge of the deceased's desire to donate facilitated the consenter's decision to donate the deceased's organs.

Helpful and Unhelpful Actions of the Requesters

During the interviews, informants were asked their responses regarding helpful actions of the requesters. These fell into the following categories:

1) actions that reflected the requester's concern for the consenter (e.g. compassion, caring, kindness);
2) actions that provided information pertaining to the donation process (e.g. answering questions, explaining the process of organ donation);
3) actions that treated the consenter with respect.

Conversely, those actions believed to be unhelpful by the study participant's included:

1) actions that conveyed a lack of concern for the

consenter (e.g. not compassionate, uncaring);

2) actions that did not provide information regarding the donation process (e.g. requester not answering questions or providing information about organ donation);

3) actions that were discourteous to the consenter.

Helpful actions

Actions reflecting concern. Helpful actions on the part of the requesters were described by a majority of the participants as concern for the consenter (e.g. compassion, caring, kindness). The following excerpts were examples of this concept. A husband and wife described their requester as "... an incredible lady. And extremely professional ... she was really professional ... she was really outstanding. In fact, I told her I was in awe at her ability to handle this situation which I know was real difficult for her ... She just did a tremendous job ... I don't think there could have been anyone more professional or compassionate than she was."

Another study participant recounted her experiences with the requester who was her son's nurse, " ... (the nurse was) ... so well informed of the (donor) program ... I think that's the most important thing ... he (the nurse) is such a warm person that it was just fine ... it was helpful to have these people (health care providers) there ... (the nurse) has cared for (my son) the whole time and... it was just really obvious... it was really helpful to know that all these people (health care providers) were there."

A 46 year old mother described her experiences with her requester and the health care team involved in her son's organ donation process. The health care team was " ... very kind, considerate people ... they really have the gift ... (the nurse requester) met us, before I seen my son or anything, she come out of ICU and she met us and took us outside and talked to us for a while ... we went outside to smoke so she could prepare me for this. She talked to me ahead of time to tell me what kind of condition my son was in ... she spent quite a long time with us. In fact I considered her my nurse. My son had his nurses and she took care of me ... They (health care providers) were ... so kind and understanding ... (the nurse requester) let me take my whole family in the room after my son was gone ... She didn't push us out of there or anything. And then, after everybody left ... she said, '... would you like to go in there by yourself?' And I said I would because I just didn't get to spend that much time with him.

Another study participant described her requester in the following manner," ... the one nurse that was in the room with (my son) was very kind ... she just encouraged me to touch him."

Actions providing information. Requester actions that provided information about the donation process were viewed as helpful by a majority of the study participants. The 60 year old participant (who asked to donate his daughter's organs) described his daughter's physician in this process. "And so he (physician that confirmed brain death) went through the whole procedure with me, step by step and if I had a question, he was very nice about it. He answered every question I asked him. He never used no fancy words ... He never used any at all, he put it to me in layman's language like I can understand ... I was there for over an hour ... "

A 46 year old mother recounted the ways her daughter's nurse requester was instrumental in explaining organ donation procedure to her and her family, " ... They (the health care providers) were real good about it, explaining things ... (the nurse requester) said, ' ... there's never a good time, but time is involved here ... in order to transplant his organs into other people, time is (of the) essence ... they were still so kind and understanding ... they told me and I understood that time was of the essence ..."

Actions conveying respect for the consenter. The third group of actions that a few of the participants expressed as helpful involved treating the consenter in a polite and respectful manner. One such participant described the health care provider/requester in the following excerpt, "...I thought they were very ... helpful and ... very courteous and ... I appreciated that."

The interview data seemed to indicate that the helpful actions on the part of the requesters encompassed three main classifications. These were: 1) actions that reflected the requester's concern for the consenter (e.g. compassion, caring kindness), 2) actions that provided information pertaining to the donation process (e.g. explaining the process of organ donation, answering questions) and, 3) actions that treated the consenter with respect. All of these actions contributed to a positive, resolved organ donation experience.

Unhelpful actions

Actions reflecting a lack of concern. There were two consenters who had unresolved feelings regarding their organ donation experiences. These unresolved feelings involved dissatisfaction with the way the requester presented himself/herself or donation information during the request process. One of the consenters was a 42 year old mother who described her requesting experience in the following way. "A little compassion would have helped. A little sit down and explain, people know a lot about the organ program, but until they are faced with it, they know nothing ... They (the health care providers) didn't want me there at all, after I signed the papers. I no longer had control of the machines."

When this same participant was asked what could be done in the future when families are asked to donate their loved one's organs, she replied, "... number one is that they (consenters) need some compassion." A 30 year old daughter also expressed a similar dissatisfaction with her requester. "...basically, just the way the request was made could have been better."

In one instance, a 67 year old mother summarized her overall experience with organ donation as positive. However, she too commented on the requester's lack of compassion during the request process saying, it was "unhelpful". Further, she said, "They (health care provider/requester) didn't say ... what they wanted to use or what they could use ... it was ... not very compassionate."

Actions not providing information. The same two study participants (with unresolved feelings about the donation process) indicated that not providing information to family members was a detrimental component of their donation experience. They stated that the lack of explanation about the donation process was not helpful. One said the following, " ... A little sit down and explain, people know a lot about the organ program, but until they are faced with it, they know nothing ... I would never in this world again ... sign a blank donor (form) ... It would have been helpful had someone been there to explain what a blank donor (form) was. Even go through the whole process again. Because you're quite mixed up at that point."

The second study participant with unresolved feelings about the donation process expressed her frustrations when she said, "They didn't explain anything to us ... They didn't even tell us what they may or may not take. We ... were thinking of just the basics ... like corneas ... heart, lungs, liver ... never even thought in our wildest dreams that they would take other things ... if they (the requesters) could just say it out loud and ... mark these things with you watching, each one they're marking ... yes or no, take this part ... I didn't know what I was doing and then I felt responsible ... I kind of wished that someone would have explained ... it would be nice if the doctors would kind of explain these things ... I needed an explanation ... if the doctors verbally ... call out the things and then explain if you don't understand what it is, and mark those things right in front of your face ... and let you know that is exactly what is going to be taken out."

<u>Actions conveying lack of respect</u>. Actions which conveyed lack of respect for the consenter were described by one of unresolved participants when she said, " ... We were in the middle of a little waiting room, with no lights on, because it was the middle of the night. They didn't even bother to turn the lights on for us. After I signed it (the

donor consent form), they (requester) gave it to my pastor to witness, the doctor took his little clipboard, stood up, looked me in the eye and said, 'You no longer have control over the machines.' And that is the last thing I ever heard from that doctor ... I was treated like he (my son) was nothing but a piece of meat ... we didn't need the treatment we got ... there was no reason to treat us the way we were treated."

Data indicated that actions of requesters described as not helpful by the participants included actions that reflected a lack of concern for the consenter, actions not providing information to the consenter, and actions conveying lack of respect for the consenter. Two study participants experienced unresolved feelings related to their organ donation experiences. Both participants supported the above requester actions as unhelpful in their donation experience. Although these unhelpful actions transpired, donation still occurred.

One participant who had resolved feelings about her donation experience described her requester as lacking compassion when the donation request was made. Lack of compassion was categorized under actions reflecting a lack of concern for the consenter.

Other Findings

The interview data yielded numerous interesting incidental findings. A 43 year old gentleman donated his 42 year old wife's organs and later discovered that his sister's boyfriend assisted in surgery when his wife's liver was transplanted into a recipient.

A 67 year old mother received a telephone call from the surgical suite during the retrieval process. This phone call only served to confuse the consenter into thinking that her daughter was still alive.

In addition to the above findings, study participants offered suggestions that they felt would be helpful to others in a similar situation in the future. These are:

1. increasing public awareness of organ donation by using inexpensive means of advertisement (e.g. posters in a doctor's office) to stimulate dialogue among families about organ donation;
2. encouraging communication among loved ones (especially spouses) about individual preferences in relation to organ donation;
3. using more flexibility and leniency in the frequency and length of visiting times for donor families;
4. providing a private comfortable room for the donor family;
5. approaching the consenter one-on-one when asking about organ donation, in this way conflict among

family members can be avoided at the onset of the request;

6. providing consenter and donor family with the option of talking to a donor family (that has previously donated);
7. explaining the organ donation consent form thoroughly; perhaps, a checklist consent form on which the requester can check off each organ as the consenter agrees to donate;
8. providing a thorough and understandable explanation of the retrieval process and a description of how the deceased would physically appear after organ retrieval is completed;
9. increasing availability of a procurement coordinator or donor program representative to the consenter and their family members;
10. establishing a support and recovery group for consenters and their families;
11. creating a program that provides regular follow-up for the consenter and the donor family members; this follow up can be a phone call, with the first follow-up should be within a week of donation, and continue according to the needs of the consenter.

CHAPTER V

Summary

The purpose of this study was to describe the experiences of the legal decision makers who gave consent to donate the organs of their brain dead next-of-kin. Based of inclusion criteria, the PNTB identified potential subjects. Initially, 17 cover letters and consent forms were sent to these next-of-kin who had donated their loved one's organs six weeks to six months prior to the beginning of this study's data collection period. Five consent forms were returned, translating into a less than 30% response rate. To obtain the target number of study participants, the inclusion criteria were expanded to those PNTB identified six weeks to 12 months post donation. Twenty-one cover letters and consent forms were mailed based on the revised inclusion criteria. Nine of the twenty-one contacted in the second mailing agreed to participate in the study. This number equaled a number of 43% response rate. At the study's conclusion, the total number of study participants was 12. One of these twelve was a husband and wife who were interviewed simultaneously and were counted as one.

The consenters were contacted to schedule a tape-recorded telephone interview. Standardized open-ended questions were used in the first five interviews and were revised for the subsequent interviews based on the data's emerging themes.

Each interview was transcribed verbatim, coded and classified according to evolving themes. All aspects of coding and analysis were audited by the thesis advisor. Study data revealed that the experience of consenting to organ donation was a three-step process: 1) an awareness of the donor's death, 2) interaction between the requester and consenter, and 3) post decision reflection. This process was influenced by four contextual factors: 1) prior knowledge and past discussion of the deceased's desire to donate his/her organs, 2) requester characteristics, 3) previous relationship between consenter and requester, and 4) feelings of beneficence. The way in which each study participant perceived the process and contextual factors contributed to their resolved or unresolved feelings about the organ donation experience. When answering this study's second research question, the consenters identified helpful and unhelpful actions of the requesters during the organ donation process. Helpful actions were those that reflected compassion for the consenter, those that provided complete donation information to the consenter, and a direct approach that conveyed respect toward the consenter.

Participants identified the unhelpful actions as those conveying lack of compassion, information, and courtesy. Participants also offered suggestions that would benefit individuals faced with similar decisions in the future.

Limitations

There are several identified limitations of the study. Because of time constraints, saturation of data was not achieved. Additionally, the population was racially homogeneous (11 Caucasians and one Native American). While racial homogeneity may be typical of the geographic region where the sample was obtained, it can not be assumed to be representative on a national level. Moreover, the response rate was very low; it is possible that our results will not capture the experiences of the non-responders, who may have been less resolved with their decision. The intent of the study was to generate a theoretical description from a purposive sample. To determine if this description can be generalized to the experience of other consenters would require probability sampling. Educational and income demographic information were not assessed. Based on the Gallup Poll findings described earlier, the researchers wondered if a link may exist between the consenters resolved and unresolved feelings about organ donation and their income and educational levels (similar to the findings in the Gallop study). Additionally, one donor may have been a homicide or suicide victim. His consenter's experience was likely to be different. This may introduce systematic bias into the study.

Conclusions

Despite the study limitations, the researchers are confident that a three step process existed leading to the consent for organ donation. The three steps are: 1) death awareness, 2) interaction between the consenter and requester, and 3) post decision reflection. This process was influenced by contextual factors: 1) prior knowledge and past discussion of the deceased's desire to donate his/her organs after death, 2) requester characteristics, 3) previous relationship between consenter and requester, and 4) feelings of beneficence after notification of organ disposition. The consenters who perceived their trained requesters as compassionate, well informed and direct had resolved feelings about the organ donation experience. This result is tentative because saturation of data was not reached.

The two major strengths of the study are: 1) it is a beginning step in understanding the organ donation experience from the consenter's viewpoint and 2) it contributed to the recognition that the more time that had elapsed since organ donation, the more likely the subjects were to describe in detail the organ donation experience.

Recommendations for Future Research

Optimally, this study would be continued until saturation of data occurred. With saturation, the tentative concepts this research produced could be expanded or refined.

Furthermore, this topic lends itself to tool development and qualitative study in similar populations. One way to quantitatively study this topic would be to generate an instrument and to survey a probability sample of consenters.

The pressing questions for future research are: 1) How are the consenters of suicide and homicide victims different from consenters in this study? 2) How can the consenters who describe lingering doubt (about whether or not their next-of kin was brain dead) best be assisted by health care professionals?

Implications for Practice

This study is not generalizable because of the small size and qualitative design. However, the study results indicate that trained requesters who are compassionate, well informed, and direct will better assist consenters faced with organ donation decisions in the future. These characteristics could be emphasized in the educational preparation of the trained requesters so that the needs of grieving consenters/family members could better be met.

Additionally, many of the suggestions the participants made could be easily implemented and might also heighten the awareness of trained requesters and consenters about the issue surrounding organ donation.

Dissemination of this study's findings should increase the sensitivity and understanding of trained requesters and assist them in accommodating the consenter's individual needs (e.g. providing reading materials, verbal explanation, showing and explaining the results of CT scan and/or EEG, and reviewing the donation process and consent form format).

References

Bartucci, M.R. (1987). Organ donation: a study of the donor family perspective. Journal of Neuroscience Nursing, 19(6), 305-309.

Caplan, A.L. (1983). Organ transplants: the cost of success. The Hastings Center Report, December, 23-32.

Caplan, A.L. (1986). Requests, gifts, and obligations: the ethics of organ procurement. Transplantation Proceedings, 18(3), 49-56.

Davis, F.D. (1989). Organ procurement and transplantation. Nursing Clinics of North America, 24(4), 823-835.

Dow Chemical Company Gallup Poll (1990).

Erstling, S.S. (1985). The shared burden: when physicians and families decide to forgo life-sustaining treatment. The Journal of Family Practice, 20(4), 393-399.

Guba, E.G. (1981). Criteria for assessing the trustworthiness of naturalistic inquiry. Educational Communications and Technology Journal, 29(2), 75-91.

Manninen, D.L., & Evans, R.W. (1985). Public attitudes and behavior regarding organ donation. Journal of American Medical Association, 253(21), 3111-3115.

National Kidney Foundation, 1987.

Oregon's Routine Inquiry Law, November 1986.

Parks, W.E., Barber, R., & Painvin, G.A. (1986). Ethical issues in transplantation. Surgical Clinics of North America, 66(3), 633-639.

Peele, A.S. (1989). The nurse's role in promoting the rights of donor families. Nursing Clinics of North America, 24(4), 837-850.

Reinharz, S. (1979). On Becoming a Social Scientist. San Francisco: Jossey-Bass.

Robinette, M.A. (1985). Public attitudes toward human organ donation. Transplantation Proceedings, 17(6), 103-110.

Rodgers, S.B. (1989). Legal framework for organ donation and transplantation. Nursing Clinics of North America, 24(4), 837-850.

Rose, E.F. (1982). Medicolegal problems associated with organ and tissue transplantations. Legal Medicine 1982 (pp. 85-100). Philadelphia: W.B. Saunders Company.

Soukup, M. (1989). Variables associated with family stress related to organ donation from a totally brain dead family member. Dissertation Abstracts International, 48, (12-B), 3532.

Sterns, P.N. (1980). Grounded theory methodology: its uses and processes. Image, 12(1), 20-23.

Stuart, F.P., Veith, F.J., & Cranford, R.E. (1981). Brain death laws and patterns of consent to remove organs for transplantation from cadavers in the United States and 28 other countries. Transplantation, 31(4), 238-244.

United Network Organ Sharing Update: the national organ procurement and transplantation network. February 1991.

APPENDIX A

Initial Interview Questions

1. How old was your loved one at the time of donation?

   _____________years

2. How are you related to the person that donated organs?

   _______________ (e.g. wife, husband, mother, father, etc)

3. How long has it been since your loved one died?

   _____________weeks/ ____________months

4. Did you know anything about organ donation before you agreed to donate your loved one's organ(s) for transplantation?

5. Would you agree to donate your loved one's organs for transplantation again?

6. How old are you? _____________years

7. What is your sex? ____________

8. What is your religion? ___________________

9. What is your race? ______________ (e.g. Black, Mexican-American, White, Native American, etc.)

10. Tell me everything you can remember from the time you found out that ____________(the deceased's name) had died to the time you signed the form that gave permission to donate your loved one's organ(s) for transplantation?

11. What do you remember about the talk you had with the person who asked you about organ donation?
12. Could you share with me what the person who asked you about organ donation did or said that was helpful and not helpful?
13. Was there anything you and ________________ (the deceased's name) did or said before he/she passed away that helped you decide about organ donation?
14. Who asked you about organ donation? ________________ (e.g. the doctor, the nurse, the chaplain, the transplant coordinator)
15. Were you there when the request about organ donation was first asked?

APPENDIX B

Oregon Health Sciences University

Consent Form

Title: An investigation of family decision making process in organ donation.

Principal Investigators: Lisa Baldwin, RN (phone # 634-2613) and Marilou Sempio, RN (phone # 297-8809), under the supervision of Christine Tanner, RN, PhD.

Purpose: The main purpose of this study is to describe your decision making process that lead to your consent to donate your loved one's organs for transplantation. Also, we are interested in finding out ways that health care professionals can be helpful during this time.

Procedure: Whether or not you choose to join in this study, your relationship with Pacific Northwest Transplant Bank (PNTB) or Oregon Health Sciences University (OHSU) will not be affected. If you agree to enter the study you will be interviewed by one of the nurses named above. If you are interested in joining this study, please sign this consent form and return it in the provided envelope within one week.

One the nurses will call you to arrange a convenient time and date for a telephone interview. The telephone interview will take approximately two hours. Depending on your wishes, the interview will be conducted in one or two sessions. The interviews will be tape recorded to help the nurses discover the helpful and less than helpful things that happened to you around the time you agreed to donate your loved one's organs for transplantation. All information gathered from the interviews will be kept confidential. No information will be linked to your name.

Risks and Benefits: There is no risk to you. While you may not have any direct benefit from joining the study, the information gathered by the nurses may be helpful to families and/or people faced with the same situation in the future. Also, the study results may provide useful information for the people who ask for decisions about organ donation. Hopefully, these people can better meet the needs of future donor families.

I, ________________________, have read and understand the above information and the purpose and benefits of the study. I also understand that if I have further questions I may contact the above nurses and that if I wish to withdraw from the study at any time I may do so without affecting my relationship with the PNTB or OHSU. A copy of this document will be given to me.

Date:__________________

Your signature:_________________

Your phone number:__________________

APPENDIX B

Family Cover Letter

Dear _____________,

On behalf of the staff at the Pacific Northwest Transplant Bank, I would like to tell you that you have our sympathy and thank you for agreeing to organ donation. We appreciate the decision you made to help other people at this difficult time. Because of your decision, you have made an important and unselfish contribution to others in need and improved their chances for a better life.

I'm writing now to ask you to make another contribution. Two nurses, Lisa Baldwin and Marilou Sempio, who are graduate students at the Oregon Health Sciences University School of Nursing, are very interested in studying what was helpful and not helpful to you when you agreed to donate your loved one's organs for transplantation. They would like to interview you about your experiences in making the decision about organ donation. This information may help other families who are in a similar situation in the future.

If you agree to join this study, you will need to sign the enclosed consent form and return it in the provided envelope within one week. After your consent form is received, your name, address, and telephone number will be given to these nurses. They will call you and set up the best time to interview you by telephone.

Your relationship with Oregon Health Sciences University (OHSU) and Pacific Northwest Transplant Bank (PNTB) will not be affected whether you join this study or not. Also, you are free to leave the study at any time.

Your name, address and phone number will be kept secret. A consent form telling you more about the study is included with this letter.

If you have questions about the study, please call either of the nurses. Lisa Baldwin's number is (503) 634-2613 and Marilou Sempio's number is (503) 297-8809. Thank you for your help.

Sincerely,

Kristine Nelson, RN, MN
Department Director, PNTB

APPENDIX C

Revised Interview Questions

1. How are you related to the person who died?
2. Tell me what happened to _____________ from the time you found out he/she was hospitalized, to the time you signed the consent for organ donation?
3. How did you learn that _______________ had died?
4. What was said to help you understand that ______________ had died?
5. Who asked you about organ donation (e.g. doctor, nurse, chaplain, transplant coordinator)?
6. What do you remember about the talk you had with the person who asked you about organ donation?
   a. Could you share with me what the person who asked you about organ donation did or said that was helpful and not helpful?
   b. Were you there when the request about organ donation was first asked?
   c. Had you had previous contact with the requestor? If yes, describe.
7. Was there anything you and ______________ did or said before he/she passed away that helped you decide about organ donation?
8. Did you know anything about organ donation before you agreed to donate ________________ organs for

transplantation?

9. Do you have any doubts about your decision?
    a. Some people experience doubts about their loved ones being dead at the time they donated organs, have you had any of those doubts?
10. Would you agree to donate your loved ones organs for transplantation again?
11. How old was your loved one at the time of donation?

    _____________ years
12. How long has it been since your loved one died?

    _____________weeks/ ______________ months
13. How old are you? ______________ years
14. What is your sex? _______________ (optional)
15. Do you have a religious preference?
16. What is your race? ______________ (e.g. black, Mexican-American, white, Native American, etc.)
17. Can we call you again if we have further questions?

APPENDIX D

Code Definitions

RESOLVED: the overall positive feelings of satisfaction and contribution gained from the organ donation process.

UNRESOLVED: the overall negative feelings of dissatisfaction felt about the organ donation process.

DISCUSS: the participant's recollection of past communication with the donor about organ donation prior to the donor's death.

REFLECT: thoughtfully looking back at the experiences, feelings and responses to the organ donation process.

REQUESTER CHARACTERISTICS: the distinguishing traits and qualities of the trained requester.

SUPPORT: the encouragement/help felt by the study participant from the health care provider and/or family/significant other(s).

RELATIONSHIP IMPACT: the effect of the link between the --- 1) consenter/donor (e.g. parent-child, spouse-spouse, sibling-sibling), 2) consenter/requester.

ENVIRONMENTAL IMPACT: the totality of surrounding conditions and circumstances affecting the organ donation process.

RECOLLECTION: description of events leading to and during the donor's hospitalization.

PARTICIPANT'S SUGGESTIONS: suggestions offered by participants to better or change the organ donation request and/or education process.

FEELINGS ABOUT ORGAN DONATION: positive/negative feelings about the disposition of loved one's organs.

CONSENTER AWARENESS: consenter's previous knowledge of organ donation/transplantation prior to giving consent for donation.

DEATH AWARENESS: awareness of family member/consenter that death has occurred; any doubts of the consenter that the donor was really dead; any doubts of the consenter that he/she made the right choice to consent for organ donation.

COMMUNICATION REQUESTER: description of what was communicated about the donation process (between the consenter and requester).

APPENDIX E

Demographics

		#	%
Relationship to consenter			
	child	2	17
	parent	6	50
	spouse	4	33
Requesters			
	RN	4	33
	MD	2	17
	RN and MD	1	8
	transplant coordinator	1	8
	stranger	2	17
	consenter asked to donate	1	8
	"lady at the hospital"	1	8
Gender of consenter			
	male	5	42
	female	8	58
Race of consenter			
	Caucasian	11	92
	Native American	1	8

APPENDIX F

Demographics

Consenter	Sex	Age	CDR	Donor Age	TSD	Rel	Race	Req
1	M	59	H	59	5mo	B	Ca	RN
2	M	33	H	37	4mo	C	Ca	*
3	F	37	M	18	3mo	C	NA	RN
4	F	42	M	17	7mo	L	Ca	MD
5	F	40	W	40	3mo	NP	Ca	**
6	M	43	H	42	11mo	C	Ca	*
7	F	46	M	23	11mo	P	Ca	RN
8	F	30	D	52	13mo	P	Ca	MD
9	F	39	D	60	13mo	NP	Ca	***
10	F	67	M	38	13mo	P	Ca	RN/MD
11	M	60	F	34	14mo	C	Ca	*
12	F/M	53/55	P	22	11mo	M	Ca	RN

CRD - consenter's relation to donor
TSD - time since donation
Rel - religion
Req - requester

F - father
M - mother
P - parents

W - wife
H - husband
D - daughter

* - stranger
** - "lady at the hospital"
*** - transplant coordinator
\# - consenter asked to donate

C - Catholic
B - Baptist
M - Methodist

L - Lutheran
P - Protestant
NP - no preference

Ca - Caucasian
NA - Native American

ABSTRACT

TITLE: An Investigation of Family Decision Making in Organ Donation

AUTHORS: Marilou Sempio, R.N., B.S. &
[redacted]

APPROVED:
Christine A. Tanner, R.N., PhD., FAAN, Advisor

STATEMENT OF THE PROBLEM: The purpose of this study was to describe the experiences of legal decision makers who gave consent to donate the organs of brain dead family members.

SAMPLE: Based on inclusion criteria, the Pacific Northwest Transplant Bank, the organ procurement agency for the state of Oregon, identified potential subjects. The total number of study participants was 12.

METHODS: Standardized open-ended interview questions were used during the tape-recorded telephone interviews. These questions were revised based on emerging themes. Each interview was transcribed, coded and classified according to evolving themes.

MAJOR FINDINGS: Study data revealed that the experience of consenting to organ donation was a three-step process influenced by various contextual factors. Each study participant's perception of the process and contextual factors contributed to either resolved or unresolved feelings about the donation process. In addition, the consenters indicated helpful and unhelpful requester actions which seemed to correlate with resolved or unresolved feelings about organ donation. Furthermore, the consenters offered suggestions that may benefit future consenters in similar circumstances.

LIMITATIONS: Because of time limits, saturation of data was not achieved. Additionally, the population was racially homogeneous (11 Caucasian and 1 Native American).

IMPLICATIONS FOR PRACTICE: The study results indicated that requesters who are compassionate, well-informed and direct will better assist future consenters faced with similar decisions. These characteristics could be emphasized in the education of trained requesters, so that the needs of grieving consenter/family could be met.