Donation: The family's perspective

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Donation: The family’s perspective

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University of Nevada, Las Vegas, 1992

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DONATION:
THE FAMILY'S
PERSPECTIVE

by
Ann Marie Occhi

A thesis submitted in partial fulfillment of the requirements for the degree of
Master of Science
in
Nursing

Department of Nursing
University of Nevada, Las Vegas
November 23, 1992
The thesis of Ann Marie Occhi for the degree of Master of Science in Nursing is approved.

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November 23, 1992

ii
ABSTRACT

This study sought to describe the lived experience of families who had participated in donation. The research question is: Why do families participate in organ or tissue donation?

This is a descriptive qualitative study utilizing techniques of phenomenology for purposes of identifying areas of significance and importance to informants participating in donation. The conceptual framework is Neuman’s Systems Model.

Thematic discovery will be drawn from the data with the goal of identifying reoccurring themes. These themes will provide information useful to nursing in providing support to donor families.
## TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>CHAPTER</th>
<th>PAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>I. INTRODUCTION</td>
<td>1</td>
</tr>
<tr>
<td>II. PHILOSOPHICAL PERSPECTIVES</td>
<td>10</td>
</tr>
<tr>
<td>III. DESIGN</td>
<td>14</td>
</tr>
<tr>
<td>IV. RESULTS</td>
<td>24</td>
</tr>
<tr>
<td>V. IMPLICATIONS AND CONCLUSIONS</td>
<td>37</td>
</tr>
<tr>
<td>BIBLIOGRAPHY</td>
<td>47</td>
</tr>
</tbody>
</table>
APPENDIX

A. DONOR FAMILY LETTER ......................... 53
CONSENT FOR PARTICIPATION .................. 54
CHAPTER 1

INTRODUCTION

Transplantation has become the treatment of choice for many individuals with end-stage organ failure (Haag & Stuart, 1989). Recent advances in surgical techniques, organ preservation, tissue typing, and immunosuppressive therapies to reduce organ rejection have resulted in a restoration of quality of life for many people. In 1986, approximately 28,000 cornea transplants, 9,000 kidney transplants, 1,500 heart transplants, 700 liver transplants, 130 pancreas transplants, and 40 heart/lung transplants were performed in the United States (Bartucci, 1987).

The treatment of end stage renal disease has improved markedly in the past thirty years. Earlier, end stage renal disease was a condition that was uniformly fatal. However, with the advent of cyclosporine a one to two year graft survival of 77% to 95% is now possible for both cadaveric donor grafts and grafts from living relatives (Haag & Stuart, 1989).

The quality of life and degree of rehabilitation achieved in patients treated with transplantation are clearly superior when compared with patients maintained on dialysis. Rehabilitation and the return to work of the
transplant recipient not only provides savings in dialysis expenses and insurance payments, but also benefits the patient's families. For example, a patient undergoing chronic hemodialysis costs the federal government through Medicare approximately $40,000 per year. The cost for a kidney transplant is approximately $50,000 for the first year and $3,000 per year for follow up care thereafter. If the transplant functions for five years, the cost of the transplant is $62,000, compared with the cost of chronic dialysis for five years at $200,00. In addition, the potential earning power of the transplant recipient and the discontinuance of disability previously required are other areas of financial impact. (Bartucci, 1987,). Therefore, there is a medical consensus that kidney transplantation is the treatment of choice for most patients with end stage renal failure (Haag & Stuart, 1989).

As a result of these advances, a larger variety of organs can now be transplanted, allowing many people to live longer. These advances, however, result in an increasing demand for needed organs. Transplant centers suggest that the eventual need, each year, will reach 10,000 for heart transplants, 5,000 to 10,000 for liver transplants, 5,000 to 10,000 for pancreas transplants, and 16,000 for liver transplants. However, of the 12,500 to 27,000 potential organ donors and 50,000 potential tissue donors in the
United States every year, only 15% to 20% are recovered (Hawke, Kraft, & Smith, 1990).

The majority of organs is transplanted via cadaveric donation from people who have sustained an irreparable brain injury. Although public awareness of organ donation has increased, there still remains a large discrepancy between the amount of organs that could be donated and the amount actually donated. The Centers for Disease Control (CDC) estimates that no more than 15% of the 20,000 persons who could be organ donors actually become organ donors (Bartucci, 1987).

Several reasons for this discrepancy are implied by the literature. First, the diagnosis of brain death is often confusing for the patients’ families. Brain death is defined as irreversible cessation of all functions of the entire brain, including the brain stem (Haag & Stuart, 1989). With the absence of brain stem functioning, respiration and circulation are not possible without artificial support. Since many patients with head injuries require some degree of ventilatory support, they are often placed on ventilators upon admission to the hospital. The appearance of respiration and body functions often leaves families confused and unable to accept the reality of death. The family does not deny death, but rather simply cannot understand the loss. Therefore, it is important that the
family must understand that brain death is not synonymous with comatose. It is final (Haag & Stuart, 1989).

Additionally, those individuals that suffer irreparable brain injury are primarily young healthy people. This population group is not one usually considered when thinking of death. It is a common assumption that children will outlive their parents. Therefore, the disparity in perception results in the difficulty of accepting the reality of death.

Finally, the loss of a loved one has been described as the most distressful and disruptive of life changes for many individuals (Martocchio, 1985). An individual's most immediate response following death, regardless of whether the loss was anticipated, is shock, numbness and disbelief (Martocchio, 1985).

Factors such as sudden death, grief, and the concept of brain death, either singly or in combination will influence the degree of stress and the particular response of survivors to a death. These factors affect the intensity and duration of grief responses, as well as the way the grief is expressed and the adjustments or accommodations made to the changing environment after a death.

When a sudden death occurs, families are faced with the task of dealing with the loss of a significant relationship without prior preparation or warning. A sudden death complicates nearly all grief. Unlike a prolonged illness or
invalidism, there is no opportunity for a long good-bye (Martocchio, 1985).

According to Martocchio (1985), although unexpected and sudden bereavement is usually no more painful than the reaction to anticipated losses, the recovery can be more disabling and difficult. In a study by Lundin (1985) it was found that individuals who experience a sudden and unexpected loss have a significantly higher rate of morbidity during the first two years than those who expected the loss. Individuals who have had experiences with sudden, violent deaths appear to have difficulty, which Parkes (1972) described as including working through feelings related to the deceased, painfully reviewing the loss, that is, fitting it into one’s assumptions about the world and one’s self. Cowles (1988) reported that the grief work of murder victims appears to be inhibited due to the survivor’s involvement in many new and different experiences, such as extended contact with the legal and judicial system.

Martocchio commented that grieving is the total response (thoughts, feelings, behaviors) to the emotional suffering caused by loss. Grieving is a process of moving through the pain of loss, involving a series of complex, often bewildering, emotions and thoughts. The nature, quality, and type of relationship lost will influence the reactions of the survivor as each type of relationship (spouse, parent, child, sibling) has its own personal and
social meaning. Families may develop psychological immobility and withdraw as a result of their intense grief and pain.

Sudden death in a young person immobilizes many families. Death of a grown child is the most difficult and longest lasting grief to bear (Gorer, 1965). The death of a child is certainly viewed by most people as life's greatest tragedy. This view derives from the fact that a child’s death appears so out of place in the life cycle (Brown, 1989).

Grieving prohibits the decision making process, resulting in decreased timeliness in determination of organ/tissue donation due to the need for procurement within a specific time period following death. Therefore, the impact of sudden loss, concept of brain death, and grief may result in indecision to donate.

Area of Interest

Since the question of organ donation is not usually raised until pronouncement of brain death, it might be surmised that the concept of organ donation would be an extremely difficult decision for the majority of families. However, many families have the ability to look beyond their present grief and the issues being faced, and extend the gift of organ donation so that others may live. What influences the family’s ability to donate? Is there a sense
of altruism or are there other extenuating factors that influence the decision to donate?

The purpose of this study was to determine the process and the reasons for donation. In this study, families’ attitudes towards donation were investigated to assess what variables might influence the decision to donate.

**Research Question**

The research question was "Why do families donate organs or tissues?" There is little current published research that covers the area adequately. Researchers have explored how organ donation may affect survivors of the donor. Data has been gathered primarily by use of questionnaires (Bartucci, 1987). While such modes of inquiry do yield data that reflect survivors’ experiences in some areas of their lives, these structured methods may also inhibit reporting of unique perceptual experiences. Questionnaires primarily elicit objective data utilizing quantitative research methods, and does not have the capability to capture subjective data. As a result of this, the individual’s experience is seldom collected or examined. Swanson-Kauffman (1988) recommends qualitative methodology to understand the full experience of the individual.

**Significance to Nursing**

Nursing practice utilizes a holistic approach in treating human responses to potential and actual health
problems. Since humans respond as whole persons, knowledge of the lived experiences of health and healing are legitimate topics of nursing inquiry (Swanson-Kauffman & Schonwald, 1988).

Nurses, by the very nature of their training and experience, are skilled observers and interviewers, making them ideal candidates to conduct qualitative research. Donaldson and Crowley (1990) identified major concerns of nursing to be concerns regarding principles and laws governing life processes, concern with the patterning of human behavior, and concern with the process by which positive changes in health status are affected. Concepts that relate to these concerns need to be discovered utilizing qualitative methods. In addition, Donaldson and Crowley (1990) recommend that an effort be made to demonstrate the activities of discovery, identification, developing an understanding and explanation, and identifying the potential within the scope of identified themes.

It is now state law in Nevada for families to be approached about organ and tissue donation at the time of death. Within many hospitals in Southern Nevada, it is the responsibility of the nursing staff to discuss the issue of donation. Many nurses, however, still remain hesitant in discussion of donation. This hesitancy may be a result of inadequate training/counseling techniques in approaching families, and/or personal discomfort with donation.
Information about the process of donation from the donor family perspective will result in a better understanding of those thoughts, feelings, and concerns that occur during this process. With a better understanding of the donor family experience, nurses will be better prepared to approach families comfortably, sensitively, and effectively, assess their needs, and provide support throughout the donation process.

Conclusion

Although donation does occur, there is a discrepancy between those that potentially and actually donate. Factors which may prevent donation from occurring include the impact of sudden death, grief, the concept of brain death, and a hesitancy among nurses to discuss donation with families. Through review of the donation process with families who have participated in donation, nursing will become more attuned to the needs and concerns of these families in relation to death and donation.
CHAPTER 2

PHILOSOPHICAL PERSPECTIVES

The present approach to organ donation has been primarily grounded in the quantitative perspective of scientific inquiry. Though this method of data collection provides a vast amount of information, it does not address the subjective aspects of donation.

A richer, fuller meaning of the lived experience of organ donation can be achieved through qualitative research methods. Qualitative approaches in science are distinct modes of inquiry oriented toward understanding the unique nature of human thoughts, behaviors, negotiations and institutions under different sets of historical and environmental circumstances (Munhall & Oiler, 1986).

The phenomenological approach stands in contrast to the positivist tradition (Comte, 1877; Durkheim, 1938, 1951) that forms the foundation for quantitative research. Positivists seek the facts or causes of social phenomena separate from the subjective experience of the individual(s). Taylor and Bogdan (1984) summarize the
difference between the positivist and phenomenological approaches:

Adopting a natural science model of research, the positivist searches for causes through methods such as questionnaires, inventories, and demography that produce data amenable to statistical analysts. The phenomenologist seeks understanding through qualitative methods, such as participant observation, in-depth interviewing, and others that yield descriptive data. In contrast to a natural science approach, the phenomenologist strives for what Max Weber called *verstehen*, understanding on a personal level the motives and beliefs behind people’s actions.

Qualitative approaches in data collection range in a continuum from firm adherence to phenomenism, as in the phenomenology approach, to a type of phenomenism that leans toward the philosophical basis utilized in quantitative research known as positivism. For positivists, interviews are essentially about ascertaining facts or beliefs out there in the world (Silverman, 1985). During the interview process, the researcher interacts with the informant, however, the interaction is strictly defined by the research protocol. The researcher’s goal is to generate data which hold independently of both the research setting and the researcher or interviewer (Silverman, 1985). This is accomplished through use of a standardized interview.

Phenomenology is both a philosophical movement and a research methodology (Cohen, 1987). Phenomenology seeks to uncover the full experience of the informant using information from the person’s interaction with environment,
other people, and themselves. Swanson-Kauffman and
Schonwald (1988) state:

As a philosophy, phenomenology deals in the realm
of the ideal, pure, and perfect. As a methodology, it
deals in the practical world of concession, compromise,
and approximation. The reason for this seeming
contradiction is that phenomenological philosophers
strive to articulate a coherent and cohesive
description of existence, of "being-in-the-world."
Phenomenological researchers strive to understand and
describe lived experiences.

As a philosophical movement of the nineteenth century,
phenomenology has had a profound impact on how nurses
and other scientists view the nature of being in the
world. Such influence is obvious in the proliferation
of qualitative methodologies now employed by scientists
in the late twentieth century.

The cornerstone of qualitative research is its
descriptive nature. Taylor and Bogdan (1984) comment that
qualitative methodology refers in the broadest sense to
research that produces descriptive data: people’s own
written or spoken words and observable behavior (Leninger,
1985). Qualitative data has been described as "rich" in
its portrait of people, places, customs, habits, and events.

Qualitative methodology has its roots in what some
philosophers and sociologists call phenomenology (Deutscher,
1973, Husserl, 1931). The phenomenologist attempts to
understand social phenomena from the
subject’s personal perspective (Bogdan & Biklen, 1982;
Taylor & Bogdan, 1984). This perspective is identified as
the lived experience of the individual (Heidegger, 1982).

According to Oiler (1982), the goal of phenomenology is
to describe experience as it is lived by people. It is a
means of clarifying the subjective findings of human experience and to determine how these events appeared to those who experienced a certain situation. These situations often result in phenomena which cannot be dealt with adequately by means of quantitative methods.

Conclusion

Within the field of nursing, qualitative methodologies for the study of nursing phenomena is increasing. Since nursing practice involves diagnosing and treating human responses to actual and potential health problems, and since humans respond as whole persons, knowledge of the lived experience of health and healing are legitimate topics of nursing inquiry (Swanson-Kauffman and Schonwald, 1988).
CHAPTER 3

DESIGN

This study examined the phenomenon of organ donation from the donor family’s lived experience. This is a descriptive qualitative study using the techniques of phenomenology, designed for the purpose of identifying areas of significance and importance to informants participating in organ donation.

Selection of Informants

Informants were selected by purposive techniques. Purposive sampling is appropriate for qualitative research. It is defined as purposeful selection of informants to provide breadth of experience regarding the phenomenon of interest (Morse, 1989). Purposive sampling allows the researcher to study the phenomenon across many types of people, including within a sample a variety of age, ethnicity, culture, sexual orientation, and disease process. It is a nonrandom selection with a specific purpose in mind. Results are not affected by this broad diversity, as the goal in qualitative research is to identify the lived experience. Rather than selecting a sample using criteria based on characteristics such as age, economic status,
educational background, or sex, the sample is selected according to the informants' knowledge of the research topic (Morse, 1989).

Random sampling is a process where subjects are chosen from a given population to obtain a representative sample. This process examines data from specific groups; however, due to constraints as a result of sampling technique, these results are limited representation of a specific group.

Convenience sampling takes advantage of a group of subjects that fall within the population of interest and are conveniently located or readily accessible to the research team (Roberts & Burke, 1989). Although purposeful sampling was the intent in this research process, convenience sampling occurred within this study as a result of the group which emerged. However, it was felt by the researcher that this group was representative of the population of donor families.

Selected families who have participated in donation during 1991 through a southwestern organ procurement organization were contacted by the researcher through a letter and asked to participate in the study. These families were selected only by their participation in donation, with no regard to family structure or previous experience with donation. This letter provided information regarding the study and a phone number was listed to contact the researcher for further information. A copy of this
letter used is in the Appendix. If the family was interested in participating in the study, an interview was arranged at a time and place mutually agreed upon by the respondent and the researcher.

Informed consent was obtained from all families who participated in the study. Written consent was obtained which addressed the study purpose, procedure, risks, benefits, costs, anonymity, and right to withdraw. Respondents were verbally guaranteed anonymity by erasure of the taped interview following transcription of the tape to text. Informants were also asked verbally if direct quotes may be used for report purposes. Informants were offered a copy of the final report.

Anonymity was guaranteed by no written identification or markings on transcribed text. Numbering of informants was done at the time of the interview. There was no association with recorded demographics and names of informants. Further notification requiring informant participation was noted in the research log. A copy of the consent used is in the Appendix.

There were four families who responded and agreed to participate. The relationship between the donor and the individual interviewed, as well as the age of the donor is presented in Table 1.
Table 1

Relationship Between Donor and Informant and Age of Donor

<table>
<thead>
<tr>
<th>Informant 1</th>
<th>Informant 2</th>
<th>Informant 3</th>
<th>Informant 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relation to donor</td>
<td>Age of donor</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Daughter</td>
<td>52</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Son</td>
<td>47</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wife</td>
<td>52</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>18</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Reliability and validity

In qualitative research, reliability and validity must be addressed. According to Guba and Lincoln (1981), there are four areas that need to be present for rigor to occur: truth value, applicability, consistency, and neutrality.

Truth value is evaluated on the basis of the management of threats to internal validity and the validity of tests and instruments as measures of the phenomenon studied. Sandelowski (1986) states that

a research design is internally valid when there is confidence that the findings of a study are characteristic of the variables being studied and not of the investigative procedure itself.

Guba and Lincoln (1981) suggest that credibility, rather than internal validity by the criteria in which truth value be evaluated. They also further state:

A qualitative study is credible when it presents such faithful descriptions or interpretations of a human experience that the people having the experience would immediately recognize from those descriptions or interpretations as their own.

Within this study, truth value was established through record keeping which identified the informant with their interview, transcription of the interview into text, and
review of the text by the informant to ascertain that, in fact it was what they had said.

The applicability of qualitative research is evaluated by how well threats to external validity have been handled (Sandelowski, 1986). Fewer threats occur to external validity in qualitative research due to the emphasis on the study of phenomena with limited controlling conditions. The findings which occur as a result of phenomena are based on life experiences and is reflective of those influences. Findings are considered valid when there is assurance that selection biases, effects of pre-testing, effects of being in a study, and multi-treatment effects have not produced conditions that are unparalleled to conditions in the real world.

In developing this study, informants were selected through purposeful sampling as a result of their experience with donation, and there was no pre-testing which occurred. Minimization of study effects was attempted through rewording of questions throughout the interview to identify inconsistencies, and since this study involved a limited amount of time with the informants, there was no effect from multi-treatment.

Consistency in qualitative research refers to the reliability, stability, and dependability of a test or testing procedures (Sandelowski, 1986). When key informants are interviewed over time, content validity is attained.
Their responses to the same questions on the same topic should be answered with essentially the same information (Brink, 1989). Verification sessions clarifies the content as well as verbatim terminology, expand on the information by clarifying unclear or incomplete materials, and validate that the material is correct. Brink & Wood (cited in Brink) stated that over time, this procedure is repeated with a number of informants, until by the end of the field work period, the material is considered both valid and reliable.

Upon completion of each interview, the interview was transcribed into text. A second meeting was scheduled with each informant to review the content of the interview, validate material present in the interview, and to clarify and areas which needed further clarification. This second meeting was also recorded, with transcription into text. Upon completion of all interviews, the text was then analyzed for commonalities and reoccurring themes.

Neutrality refers to the freedom from bias in the research process and product (Sandelowski, 1986). It is suggested by Guba and Lincoln (1981) that:

confirmability be the criterion of neutrality in qualitative research. Confirmability is achieved when auditability, truth value, and applicability are established.

Sandelowski (1986) states:

The emphasis in qualitative research is to emphasize the meaningfulness of findings achieved by reducing the distance between investigator and subject and by eliminating artificial lines between subjective and objective reality...Confirmability, as the criterion of
neutrality in qualitative research, refers to the findings themselves, not to the subjective or objective stance of the researcher.

Within this study, the findings were verified by the informants for consistency, truth value established through identification of informants and their interview, and applicability through purposeful sampling.

Auditability occurs when the research decision trail is clear and concise. Guba and Lincoln (1981) propose that auditability be the criterion of rigor or merit relating to the consistency of qualitative findings. A study and its findings are auditable when another researcher can clearly follow the "decision trail" used by the investigator in the study. In addition, another researcher could arrive at the same or comparable but not contradictory conclusions given the researcher's data, perspective, and situation.

A research log was kept throughout the research project with entries made regarding informant response to the initial letter sent out, the interviews, and follow-up meetings with informants. Upon completion of the interviews, notes were also kept regarding utilization of the Ethnograph and development of emic and etic themes.

Data Collection Techniques

In depth interviews were conducted with each informant. The interview content developed following the use of broad,
open-ended questioning. Initially, a grand tour question was used. Examples of this question include:

1. I would like to talk with you today about your feelings concerning donation; or
2. Let's start out with your impressions and experience of donation; or
3. Tell me what it's like to experience donation.

The techniques of active listening and reflection were used to develop the content of the interview. Active listening is defined as allowing the informant to express their thoughts and feelings without prompting. Doyle (1980) states that by active listening the researcher is on the alert to indicate to the client what is heard and to understand what is said. Understanding can be expressed by briefly restating what the informant has said. Repetition of previous comments may be necessary for additional clarification. Use of open ended questioning also allows for the informant to reveal their ideas rather than those of the researcher. An example of a reflective question is "Can you recall some of your thoughts when you were approached about donation?"

Techniques of talk turning and snowball questions were used throughout the interview. Talk turning is an interviewing process whereby specific questions emerge as a result of information obtained. Spradley (1979) comments that the interviewer has to teach the informants to be good
informants by continually encouraging them to provide detailed descriptions of their experiences. Snowballing is a way to build a pool of information by utilizing probing questions in response to previous information to encourage the informant into providing additional information (Taylor & Bogdan, 1984). Utilization of these techniques will also provide consistency and truth value.

The interview was conducted by the use of tape recording with field notes written during the process. Bracketing was done by the researcher to identify phenomena already known to the researcher as a result of prior experience. Ray (1985) defines bracketing as holding in abeyance those elements that are irrelevant to nursing. Bracketing is important particularly when the nurse is uncovering a phenomenon of which he or she knows a great deal (Leninger, 1985). Through the use of bracketing, informants' responses were identified excluding comments or questions made by the researcher, resulting in information solely from the informant. Through this process, neutrality was maintained with threats to neutrality reduced.

Following the interview, the tapes were transcribed verbatim by a transcriptionist. Tapes were then transcribed to text using Word Perfect 5.1. The text and themes were managed using the Ethnograph (Seidel, 1986). The Ethnograph is a menu driven software program designed to assist the
researcher with the mechanical aspects of data analysis, coding, and sorting of data files.

Data analysis in phenomenology is performed by the systematic process of describing, analyzing, and intuiting reflectively the information received from the interviews. This information, the lived experience, will be reviewed to determine common themes which emerge. Hypothesis are not generated, but rather, thematic discovery will be drawn from the data with the goal of identifying reoccurring themes.

An interview with the Director of Procurement at a Southwestern organ procurement organization was conducted by the researcher to obtain his perspectives on why families donate. This director is viewed as an expert in the donation process, and could provide additional insight into the reasons for donation. Review of this interview, in context with the informants interviews, will assist in providing reliability and validity to the study.

Conclusion

Phenomenology is the cornerstone of qualitative research. Through this process, the researcher can obtain information from the informant as a result of their lived experience. Emerging themes will provide descriptive information regarding the donation experience.
CHAPTER 4

RESULTS

Thematic discovery is the identification of themes, within the interview text. Bergum (1989) states:

it is important not to make too much of moments or themes... the theme of an experience is the principle, or essence, that makes the experience what it is.

Berg (1989) defines theme as a useful unit to count. A theme is a simple sentence or string of words used to identify the experience (Berg, 1989). As Bergum stated, it is important not to make too much of theme; each individual's life experience will be experienced differently or realized in different ways and at different times. Thus, themes are not magically appearing essences but are useful focal points or commonalities of experience around which phenomenological interpretation occurs (Bergum, 1989).

Themes were first recorded in the emic perspective. Emic is defined by Leninger (1985) as the local or native view derived directly from the people's language, beliefs, and experiences. Emic themes are a result of the informants' perspective, using their own words. By using emic themes, it was hoped that it would decrease the possibility of researcher bias as a result of previous knowledge. Emic themes assure truth value, consistency, and
applicability. As previously mentioned, truth value is established through the discovery of phenomena experienced by the informants; therefore, if emic themes are the result of the informant’s perspective, truth value is confirmed.

Emic themes were derived in the following manner:

1. Text (transcribed interview) was entered into the Ethnograph, which assigned a number to each line.

2. Numbered lines were bracketed into units. These units were then named by using actual words used by the informant.

3. Numbered units were then re-entered into the Ethnograph to group into larger units. For instance, Informant 1 had addressed in lines 193-210 and 502-505 issues of family discussion regarding donation; using the Ethnograph, these units were then grouped together.

4. After all interviews were individually coded and grouped, they were then re-grouped together into similar areas. Development of emic themes was difficult, as some of the themes had different key words but carried the same central idea. Examples included "donation good" and "helping others"; "previous discussion" and "family support"; and "decisions" and "control"; and "loss" and "grief".

Emic themes were then merged from all interviews into etic themes which combined all informants together. Etic
themes are cluster commonalities between emic themes (in other words, between informants) allowing the emergence of commonalities. Leninger (1985) describes etic themes as:

the external, more universal, and generalized view. The emic view is grounded in language use and expressions, whereas the etic view may be the researcher’s or an outsider’s views and interpretations of some phenomenon under investigation.

This encourages understanding of a common experience to be used in practice (Munhall & Oiler, 1986).

In developing etic themes, the researcher examined emic themes which had similarities. For instance, themes relating to donation, such as approach, consent, tissue donation, decisions and control, and would do again were grouped into the etic theme of decision to donate, as it was felt that all of these themes related to the actual donation decision. Auditability was maintained throughout this process by field notes.

In addition to the major themes which emerged, there were several other themes which were identified as minor themes; however, these themes seemed to add pertinent background information to those major themes.

Findings

Themes emerged from the data, showing both central themes and subcategories of each theme. The results were verified through return second interviews. These themes are depicted in Table 2.
Table 2

Etic and Emic Themes

<table>
<thead>
<tr>
<th>Emic</th>
<th>Etic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disappointment regarding unused organs/tissues.</td>
<td>Frustration regarding inability to donate more.</td>
</tr>
<tr>
<td>More could have donated if things were done better.</td>
<td></td>
</tr>
<tr>
<td>Follow-up letter was discouraging regarding unused organs/tissues.</td>
<td></td>
</tr>
<tr>
<td>Holidays</td>
<td>Loss/Grief relating to death</td>
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<td>Consent to donate</td>
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<td>Tissue donation</td>
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<td>Decisions and control</td>
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<td>Would donate again</td>
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<td>Materialism</td>
<td>Re-prioritization</td>
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<td>Letting go</td>
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The first category of Frustration emerged as a result of this quote made by Informant #1: "... After we made this decision and thought something good was going to come out of this, they weren't able to use anything. ... So, we were kind of bummed about that, as, like I said, we thought it was something good that was going to be able to come out of something tragic in our lives." Informant #4 shared similar concerns regarding inability to donate: "We wanted to donate more than that but because it was a trauma case and murder case that hadn't seen the coroner and it took him too long to get there so it was too late to donate any organs." Other included categories were the need to do a better job to prevent interference with donation and thoughts pertaining to the follow-up letters received after the donation.

Initially, Loss and Grief were set apart as separate themes, however, information within both themes were overlapping and it seemed that the two concepts evolved into a central categories for identifying other related concepts. Loss was identified as the physical loss of the deceased, whereas grief was the outcome that related from the loss. Informant #4 stated:

"Christmas is the hardest. So is Thanksgiving; Halloween because he always liked Halloween. But Thanksgiving and Christmas are hard and they tell me that it is going to ease one day. ... I have isolated 99.9% of my friends. My phone used to ring all the time, it hardly rings at all anymore. My husband was almost destroyed over this. Not over the donation, over the murder. Just because neither him
nor I could work through the grief. I lost a lot of work because of this. I haven’t been able to sleep. I haven’t been able to enjoy life. I haven’t been able to enjoy my grandchild. I don’t know. That’s the way it is. It is real hard, you know, one minute you’re a mother and the next minute you have no children."

Informant # 3 also shared her feelings regarding loss:

"My husband died November 23, a month before Christmas and they sent me a real nice book and letter about other people’s situations with donating and how to get through the holidays. It was really helpful, because when you lose someone, a lot of times you feel guilty crying and it’s okay."

One category which strongly emerged was Pro-social vs. Self service relating to the importance of donation, both to themselves and for the general public. Donation was perceived as a means of helping others, and that it is good to donate.

"... it is just something that has always been important to me personally, that, if and when I go I would like as much useful, whatever, can be taken from me to make someone else’s life better is fine. ... it has always been something that has held importance to me. ... I think organ donation itself is important. It is a very big necessity in the world, if you will. New reports tell us about how people are waiting on these long lines and lists. Getting that message out, it has gotten a lot better over the years and maybe that message needs to be brought more."

The above quote by Informant # 2 summarized his feelings on the importance of donation. Informant # 4 had similar views: "I just knew that donation was a really good thing and that when someone dies young like that and they’re
considerably healthy, with all the children that are dying because they need transplants, that it should be done."

Another strong theme which emerged was Socializing Decisions. Many of the families had previously discussed donation. "It was just something that my husband and I had always agreed to" was a statement made by Informant # 3. Several of the individuals interviewed carried donor cards, and felt supported by their families in the decision for donation. Informant # 2 stated:

"My wife and I have discussed it though I don’t think she shares my feelings on the matter and I don’t think it is something she is comfortable with. . . she knows my feelings on the matter and if anything good comes of it, I’m sure that when I do die I’m sure that what I feel is important will be carried out even though it is not something she agrees with. That may be the one thing that has been gained out of this. . . I’m sure the rest of us will now make sure we respect our spouses feelings on the matter".

The third strong area which emerged was the Decision to Donate. "It was really a very easy decision to make" was a statement made by Informant # 4 that seems overall to describe her general feelings on decision making. "I told them whatever they could use" was a statement made by Informant # 3 that summed up the informants’ feelings towards donation, as all the informants had agreed to tissue donation, including corneas, bone, and other tissues.

In the discussion regarding who approached them for donation, many of the families were not able to remember who specifically (nurse or other staff) approached them for
donation. In one situation, the family brought up donation to the physician after they were told their father had died.

Informant # 1 stated:

"The doctors were in there explaining what had happened about his heart... and we were in shock to begin with and then all of a sudden out of the blue, she said "what about being a donor?" I didn’t think about it at the time but then later on I said whatever in the world made you think of that and she had just had her driver’s license out that day and had noticed her donor card and so it was fresh in her mind at the time and triggered or something. I don’t know that we would have thought about it, I wouldn’t have thought about it."

Informant # 2 was approached for donation, but was unsure of who it was, stating "they asked us if we would be interested in organ donation or if we had thought about it all...it was a receptionist in the emergency room, well, I don’t know."

Another common comment made was that the decision for donation was easy. It was felt that since these families had discussions about donation and many carried donor cards, that this was a decision that was easily made. Control and the ability to make decisions was an important aspect, probably as a result of the inability to control the circumstances which were occurring in relation to the death.

Informant # 4 stated:

"... donation, whether to donate or not to was the easy part. The cremation, whether to cremate or have a funeral, was an easy part. Whether to have a memorial service or a full-fledged funeral or not to have anything but a quiet observance by all the friends was an easy part. All those things were easy because we were in control of them. It’s the things that we are not in control of, the death itself, the fact that it
was murder, the court systems treatment of the whole trial, treatment of the newspapers and the news media... The easy part is deciding whether to donate or not, to give another person a chance at life or being able to walk again or being able to see again, that was easy."

Informant # 2 stated, "We had the decision made before he walked in the door", again strengthening the thought that the decision was easily made.

The central theme relating to Re-prioritization was the concept within spirituality that the person ceases to exist upon death, leaving a body that is void the person that once was. "I believe when you die your spirit has gone to a better place and your body is just a shell" was a comment made by Informant # 4. Informant # 1 also stated "Our beliefs were that it was just the body that was left over, the person does not exist." Also tied to this was the concept that the spirit moves on after death, although not necessarily as another physical being.

Materialism and the review of one's own belongings in terms of importance emerged as a reflection on death. Informant # 3 stated "...People that were helping me would say "what are you keeping this for?" or "why are you moving this?" Informant # 1, whose father died, described her experience in dealing with his possessions:

"...we had to go through all these boxes and when you go through people's stuff when they die, things that were important to them may not have any meaning to you and you hate to throw them away but you don't want to keep them...You start thinking that, well, of all the stuff that I have, what happens when I die. someone is going to have to go through all of your stuff and most
of it is really pretty meaningless. It may have some importance or sentimental value, but gosh, it probably just is to you or maybe one other person."

The themes of Family member death, Funeral, Transplant coordinator, and Death information had some influence on issues of control, decision making, and the donation experiences. Previous death of a family member occurred in two of the families interviewed. These individuals had had chronic, terminal illnesses, and those donor families that had experienced these deaths felt that prior experience had made some of the death related issues (i.e., funeral arrangements) somewhat easier having been involved in these events.

"My only concern was that none of the scars be visible" was a common feeling in those families who had viewings after donation. All families who had viewings stated they were not able to tell that donation had occurred, as there was no external appearance of removal of tissue.

As previously mentioned, all of the families interviewed had been involved in a sudden death event of another family member. Two of the individuals had heart attacks, one died during emergency cardiac surgery, and the fourth was murdered. "Having to wait at the hospital was not fun, and it was like this wild nightmare dream". seemed to sum up the overall experience of the sudden death experience for these families.
Transplant Coordinator issues varied from each family interviewed. Most of the families found them to be helpful, although one donor family felt that the transplant coordinator was too cold and businesslike.

"I guess in that job it is hard to be compassionate but, like I said, if anything, he made the decision harder in the way he phrased his answers...in the end, what I thought was, you know, we went into in pretty much that I kind of made the decision before the man walked into the room...if it had been something we didn’t know about or weren’t sure about, when he walked in the door, in the manner he did, I don’t think we would have made the same decision."

I interviewed the Director of Procurement in a southwestern organ procurement organization to determine from an expert’s point of view, why families donate. He felt that "they donate because they hope that it is going to help someone else and that it is the proper thing to do, that it is a good thing".

He also felt that perhaps the finality of death in tissue donation is why these families rather than organ donor families participated in this study. His opinion was that tissue donation in sudden death may be somewhat easier due to the actual appearance of death rather than in organ donation, where although the individual is brain dead, they still have bodily functions that are often related to life (heartbeat, blood pressure). "I think that seeing a person dead contributes to your ability to resolve the fact that the person is dead".
In relation to loss and grief, he stated:

"I don’t think it ever goes away. I mean, it would be more tolerable as time passes, but that type of a loss, I think, is so acute, that it would never, ever go away. I would imagine that you could talk with these people 20 years later and they would still have that real severe sense of loss when you brought up the situation".

He also felt that the reason people are comfortable with tissue donation is that these families were not so bound into the physical body, making it easy to donate.

"People who are absolutely appalled by the idea of donation tend to, well they don’t accept death first of all and I think their sense of loss is much greater because they don’t have a sense of a spiritual being in that individual, or if they do it is a very rudimentary perception of it...if a person doesn’t have that sense of continuation, it intensifies their sense of loss. If they are so bound into the physical being, your lost must be, I mean, immense because that physical being is now gone and if there is nothing else...I can’t imagine a loss worse that. At least, if you can have some sense that there is something else, you can accept that the person is transcended".

Conclusion

The experience of donation was identified and created review of interviews, and the expert’s view of donation. As a result of this data, emerging themes were identified.
CHAPTER 5

IMPLICATIONS AND CONCLUSIONS

A review of the literature suggests that bereavement and grief are responses to emotional pain. They are part of a human process, in response to the loss or separation of a significant other or thing. Switzer (1976) suggests that grief is a response of emotional pain; it is a sequence of subjective states that follow loss and accompany mourning.

In a study done by Sanders (1982) comparing sudden death versus chronic illness deaths, participants were interviewed shortly after the death of a spouse and 18 months later. Respondents were grouped according to the mode of death: sudden, short-term chronic, and long-term chronic. Though there were no statistically significant differences among the groups, some important trends were identified. The short-term chronic illness death groups maintained higher intensities of bereavement at 18 months, there appeared to be both quantitative and qualitative differences between their reactions. The sudden death group indicated an internalized emotional response described as an "anger-in" response, resulting in sustained, prolonged physical stress. The long-term chronic illness group expressed an "anger-out" response, which, while creating a
picture of frustration, dejection, and loneliness, did not cause those in this group to sustain the prolonged physiological components.

It has been well documented that bereaved families have special needs both immediately and over a period of time. Bereavement is a process of adapting to the loss of a close and significant relationship (Mian, 1989).

The initial response to death is often one of shock and disbelief. Families and friends desperately want their loved one to be alive. Initially there may be an intense denial of the reality of death. Denial can last for varying amounts of time, sometimes indefinitely, if the person is left unassisted (Fanslow, 1983). This is not usually the case, however, and the grieving process is set into motion and follows those stages identified by Kubler-Ross: anger, bargaining, despair, and acceptance. Gray (1977) defines this as the stage of restitution and recovery. Working the stages of grief usually requires 6-12 months, but can last longer with the individual vacillating back and forth between the states until complete resolution is achieved. Complete resolution is described as the ability to remember comfortably and realistically both the pleasure and the disappointments of the lost relationship (Fanslow, 1989).

The adaption to grief can be viewed as a gradual restoration of balance in all spheres of functioning. This
is compatible with the "tasks" of grief as described by Worden (1982):

1. To accept the reality of the loss;
2. To experience the pain of grief;
3. To adjust to an environment without the deceased;
4. To reinvest emotional energy into other relationships.

Collectively, these tasks point to the many cognitive, emotional, and behavioral changes that must occur in the course for recovery to occur.

The effort to examine the loss, give it some meaning, and validate perceptions of the changing relations to the dead is called grief work (Cutter, 1974). This process of reconciliation with the deceased will result in the resolution of grief. Davidson (1975 and Lindemann (1944) have both identified that grief is never completely resolved, but remains without the individual throughout their lifetime, and that one never "gets over" a death but with time will learn to live with it.

In relating these concepts to the emic and etic themes identified in this study, there are many similarities which support the literature. Although all informants had been involved in a sudden death situation, it did not appear as though there was an overwhelming difficulty in dealing with the reality of the death. This may have been an easier transition for these individuals as a result of the previous
experiences of death, and also perhaps also due to the spiritual beliefs expressed. Many of the informants were in the process of moving on with their lives, and although they expressed missing the individual, they were able to express fond memories about the deceased. Decision making in donation also facilitated an easier transition, as these families were able to maintain some control in a situation that otherwise was uncontrollable.

Expressions of loss and grief were consistent with those findings cited in the literature, especially in the writings of Worden. Although the informants were moving on with their lives, there was an underlying component of loss, particularly tied in with the holidays.

Conceptual Framework

In reviewing conceptual models for this paper, Orem’s Self-Care Model and Neuman’s System Model were chosen. Both of these models require the individual to maintain and assume responsibilities in health maintenance, with specific interventions from nursing should a situation occur where the individual becomes unable to return to the original state. Both of these models also offer requisites for maintenance of health, such as self-care in Orem and lines of defense and resistance in Neuman.

Orem’s conceptual framework utilizes the concept of self-care, which places responsibility for health on the individual. (Orem 1971) describes nursing as the giving of
direct assistance to a person, as required, because of a person's specific inabilities in self-care, resulting from a situation of personal health.

When an individual can no longer meet their self-care needs, a self-care deficit occurs. The goal of nursing is to identify the deficit present and provide appropriate intervention to assist the individual in the return to self-care.

The degree of interaction is based on individual need. Orem (1971) has develop three systems for interaction:

1. The wholly compensatory nursing system is represented by a situation in which the patient has no active role in the performance of care. The nurse "helps" by acting or doing for the patient.

2. The partly compensatory system is represented by a situation in which the nurse and the patient perform care measures or other actions involving manipulation or ambulation.

3. The supportive-educative system is a system where the person is able, or can and should learn, to perform the required self-care measure but cannot do without assistance. The methods of helping or assisting in this system would include: support, guidance, the provision of a developmental environment, and teaching.

Those individuals who have the ability to care for themselves are identified as self-care agents, whereas those who cannot care for themselves are dependent-care agents. Under ideal situations, these individuals are in full control and are able to participate in the decision making process which occurs in developing a plan of care. However, in individuals who have died, the decision making process
shifts to those who have been designated to make those decisions (i.e., next of kin, durable power of attorney). Nurses must work closely with these dependent-care agents to identify self-care needs and provide appropriate intervention. For many of these families, self-care needs will involve information and education. Some of this information will include the option of organ/tissue donation, identification of a mortuary, and other information needs the family may express.

In correlating the emic and etic themes which emerged with Orem’s theory, the death of the individual created a self-care deficit in the family. This deficit was one of lack of information and education relating to death issues. Since these families had prior knowledge, a high interest in donation, strong beliefs in spirituality, and previous discussion regarding donation, when approached about this information, the families were able to give consent. Though the donation was not as ideal as the families had hoped, the fact that others were helped was comforting to the families.

Although Orem’s model does not directly address spiritual issues, it would seem that this area is one in which nursing would want to address when working with families involved in sudden death.

The conceptual model of Neuman is an approach to maintain wellness in the individual. The model is based on the concepts of stress and the reaction to stress (Neuman,
1989). In this model, nursing’s goal is to assist in the stabilization of the client to maintain optimal wellness.

Neuman (1989) states:

The point of entry into the health care system for both the client and caregiver is either predominantly at the primary prevention level (before a reaction to stressors has occurred), at the secondary prevention level (after a stressor reaction has occurred), or at the tertiary prevention level (following treatment of a stressor reaction).

Neuman also identifies lines of resistance and defense. The lines of resistance provide protection to the basic structure, which is composed of strengths, weaknesses, and genetic composition. Flexible lines of defense are buffer zones which provide protection to the individual. These lines expand and contract in response to various stressors. When stressors penetrate these lines, they become weakened, allowing for illness to occur.

Neuman also identifies variables that are contained within each individual’s system. These variables include physiological, psychological, sociocultural, developmental, and spiritual. Within each individual, these variables are at different stages of development. These variables assist in how the individual reacts to a stressor as well and also facilitates a return to wellness.

When a stressor is identified, intervention begins and is based the degree of reaction, resources, goals, and anticipated outcome (Neuman, 1989). Reconstitution is a
term Neuman uses to describe the stabilization which occurs as a result of intervention and treatment.

Reconstitution can lead to client system stability and a level of wellness that is the same as it was prior to the stress reaction, to a level of wellness that is higher than usual, or to a level that is lower than usual. Health of the client/client system, therefore, is seen as being at various and changing levels - within normal range, higher, or lower - throughout the life span, because of basic structure factors and adjustment, whether satisfactory or unsatisfactory, to environmental stressors (Neuman, 1989).

Neuman's model could also be applied to families involved in death situations. In utilizing this model, the nurse would determine present stressors and the ability of the individual to manage these stressors in relation to the present developmental level of variables and flexible lines of defense. Intervention would be based on findings, with organ/tissue donation information provided.

In reviewing emic and etic themes within Neuman's model, stressors may be present as a result of the death itself or of the lack of information relating to death issues. With the families prior knowledge of donation, the high value of importance in donating, strong spiritual beliefs and previous discussion, approaching families and offering the option of donation would assist in returning these families to a state of wellness. In addition, since many felt that donation was important to themselves and others, the act of donation would also assist in reconstitution.
Relation to Practice

As a result of research on grief and loss and the impact of sudden death, many hospitals throughout the country have now developed bereavement support within their facility, though I am unaware of any programs present in the Southern Nevada area.

As part of these programs, nurses work directly with these families in addressing their needs and concerns, as well as provide information regarding organ and tissue donation. Many of these hospitals have also developed "after care" programs, where the families will receive additional information throughout the year to help with the grief process. Utilization of the nursing process for families experiencing sudden death involves close interaction and anticipation of needs, as specific interventions may facilitate the bereavement process.

Fanslow (1983) states:

grieving spouses in sudden death situations reported that being with the patient, being to verbalize their anxieties and concerns, and knowing their spouse was given all available emergency treatments were important needs...In cases of sudden death, the viewing of the body has also been found to be important in facilitating the expression of grief and making this unexpected loss more real.

In addition, providing an area of privacy for family members to express emotions is important. Grief work can begin much quicker if the griever is allowed to express emotions freely (Schultz, 1980). Other interventions, such as touch, being available to answer questions, and giving
permission to express feelings are interventions that will allow the family to begin the grief process. According to Schultz (1980):

*If grievers are to heal from grief, they must be able to cry for help, they must be able to elicit responses from others, they must have the inner resources to heal. The sooner after a death this can be done, the better. A person cannot heal from grief without outside help and this is much harder to elicit a month after a death than in the hours immediately following the death.*

Within the themes which emerged in this study, many families have a strong belief in donation, and are interested in donation. Although a small percentage of nurses do approach families regarding donation, many nurses, however, still are hesitant. It is still a common feeling among many nurses that families are already too stressed and that donation would be an additional stressor. However, this study has demonstrated the opposite, as many families support and are interested in donation when asked.

**Changes in Theory**

In order for nursing to be responsive to all needs of families regarding death, a broader understanding of the nature and meaning of donation was essential. The purpose of the study was to discover the meaning of donation from the family’s perspective.

Both Orem and Neuman could be easily utilized when interacting with families dealing with death. Within Orem’s model, the death itself would cause a self-care deficit, if
the family is unfamiliar with issues surrounding death, such as mortuary arrangements and donation. Sudden death would result in a self-care deficit, as the family may not have adequate coping skills due to grief and loss.

In Neuman’s model, the death itself would result in a disequilibrium as a result of stressors. Reconstitution would involve bereavement support as well as provision of information to facilitate the decision making process.

Of the two models, the Neuman Systems Model could be best utilized as a means of assisting donor families. Within this model, health promotion is viewed as a means of reconciling the individual self with the whole self in order to return to an optimal state of wellness. Implementation of Neuman’s Model, including donation of organs and tissues would provide a framework to nursing in which to provide care to bereaved families.

The major theme which emerged from this study was that the opportunity to donate was more important than the outcome of the donation process. The unifying theme throughout this study was that regardless of the outcome, the donor families would do it again. Therefore, utilization of Neuman’s Model would identify that the process of reconciliation, or a return of the individual to this optimal wellness state, is the underlying rationale for donation.
Future Studies

Since this study involved families who had participated in tissue donation, it would be useful to study families who participated in organ donation to compare results. It would also be helpful to study families who decided not to participate in donation to determine reasons or factors which led to this decision. There was an abundant amount of information obtained from families who had been involved in this experience; however, it did not include families of color (i.e., African-American, Hispanic, etc.). Future studies should include qualitative research with these families to examine cultural influences on donation.

Although current research shows a high level of support among nurses towards organ donation, little to no literature is currently available regarding attitudes towards tissue donation.
Bibliography


Interview with Procurement Director, October 6, 1992.


Appendix A

Dear ___________________,

I am a graduate student at the University of Nevada Las Vegas and am conducting a research study. I would appreciate your assistance in providing essential information about why families participate in organ donation.

If you agree to participate, you will be interviewed and the interview will be tape recorded. It is anticipated the interview will take approximately one to two hours to complete. Approximately three weeks after the first interview, a follow up interview will also take place to validate information obtained.

There is no cost to participants. Anonymity will be ensured. You may refuse or withdraw at any time.

Should you have any questions, I will be happy to answer them. I can be reached at __________________.

Thank you for your consideration in participating in this study.
CONSENT FOR PARTICIPATION

Purpose: The purpose of this study is to provide essential information about families' experience in organ donation.

Procedure: If you agree to participate, the interview will take approximately one to two hours to complete. A subsequent interview will occur three weeks later to validate information obtained at the initial interview.

Risks: No risks have been identified for persons participating in this study.

Benefits: The information obtained from this study will assist health care providers in obtaining a better understanding regarding issues surrounding donation.

Costs: There are no costs to participants.

Anonymity: All information obtained will be kept confidential.

Right to withdraw: You may refuse to participate or withdraw at any time.

Your verbal consent indicates that you have decided to participate in this study and that you have received the above information.