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Nursing care of potential organ donors:

An articulation of ethics, etiquette and practice

by

Lisa J. Day

DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF PHILOSOPHY

in

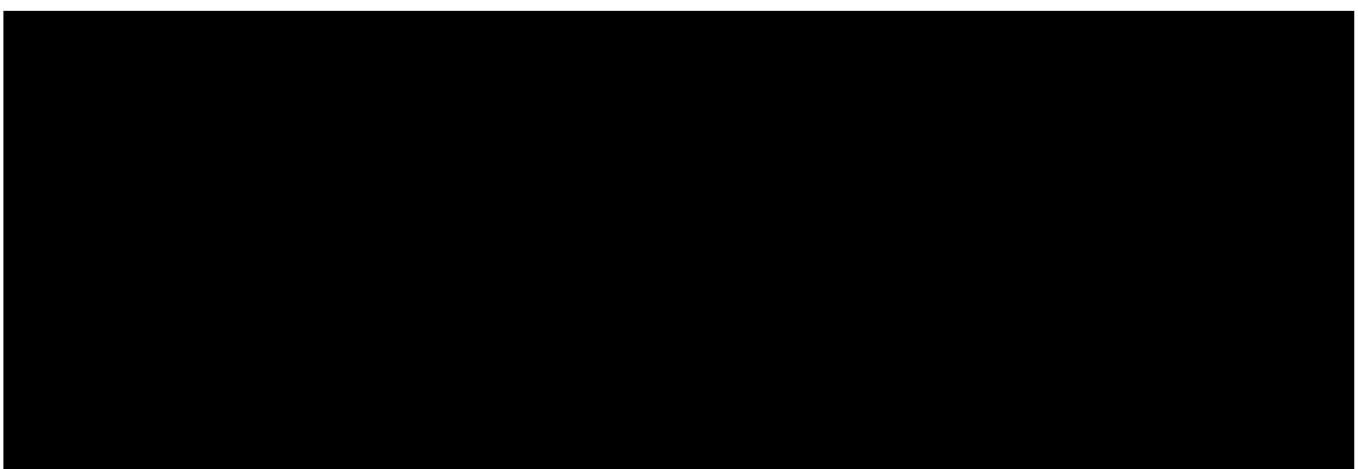
Nursing

in the

GRADUATE DIVISION

of the

UNIVERSITY OF CALIFORNIA SAN FRANCISCO



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Lisa J. Day

For Anne, my love.

Preface and acknowledgements

Many people contributed to the success of this modest project. I feel privileged to have worked with such an impressive dissertation committee. My research advisor and mentor, Patricia Benner, always knew just how to get me to write, and just how far to push and pull me to articulate the inside out perspective. I continue to marvel at Professor Benner's insight and ability to open up a whole new way of thinking in a single hour-long meeting. Kit Chesla has also been an inspiration to me and an important influence on my development as a qualitative researcher. Dr. Chesla's rigor and demand for interpretive precision combined with her sense of humor made the project joyful as well as scientifically sound. Thanks also are due to Professor Adele Clarke whose sociological perspective took the project in important directions, problemitizing areas for which I would otherwise have no language.

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Theresa Drought, Guy Micco, Wade Smith, Daryl Gress, and Professor Emeritus Anne Davis helped me to sort out the ethical issues involved in organ donation and procurement and challenged me to articulate more clearly my philosophical position. Anne Davis and Theresa Drought are directly responsible for my presence in the UCSF

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School of Nursing Doctoral program; I thank them for their faith in my ability to succeed. The staff of the neurologic intensive care unit at UCSF and UCSF-Stanford Healthcare's Moffit hospital, 1991-1999 further nurtured and supported the present work. Marylou Muwaswes first encouraged my interest in neuroscience nursing which directly led to this research. Also of particular help were my friends Caroline Morris without whose support and encouragement in times of doubt I would certainly never have finished, and Cindy Reed who introduced me to the wonders of mountain biking and kept me physically active and challenged during psychologically and academically difficult times. It has been an honor to be a part of such a thoughtful, bright and dedicated team of nurses.

Anne Pagliarulo loved and sustained me through all the trials of graduate school, in addition to transcribing the interview tapes with impeccable skill and patience. My love for her cannot be transcribed.

Finally, many thanks are due to my four sisters and three brothers, Carol, Teri, Sheila, Mike, Cindy, Tim and Steve, and to my parents, Martin and Loretta, for raising me to believe I could strive for something as odd and important as a PhD in nursing.

Abstract

Nursing care of potential organ donors: An articulation of ethics, etiquette and practice

Lisa J. Day

Organ procurement takes place in the intensive care unit (ICU) under the care and direction of nurses. This interpretive study uses a phenomenologic method to articulate nursing practices and concerns in the context of caring for a potential organ donor in the ICU. Data consisted of typed transcripts of open-ended interviews with 12 nurses, 9 from two ICUs and 3 from one organ procurement organization, and notes from observations of four nurses. The nurses' experiences of identification of patients as potential organ donors, making the transition from treating the patient to preserving the organs, and approaching the family with the possibility of organ donation provide evidence of the ethics and etiquette nurses are developing in this practice. The nurses' response to the particular when identifying a potential donor, predicting brain death, maintaining the brain dead body, coaching the family and opening the possibility of donation for the family provides evidence that the practice is primarily phronetic and relational rather than an application of pre-determined techniques. These findings provide the basis for further study of the nurses' and family's experiences and provide an argument against approaching organ procurement as a set of techniques intended only to increase the number of available organs.

Patricia Benner

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Chapter 1

Review of Current Literature on Nurses and Organ Procurement

Organ donation and procurement have been issues in the medical literature since the 1950s when the first successful kidney transplant was done. In the early days of transplant, donor organs were obtained from living relatives (since the kidney is a paired organ) who matched histocompatibility better than a stranger and whose organs were in better shape than the only other option, the cadaver donor. Before 1968, the cadaver donor was a non-heart-beating donor; that is, the heart beat stopped before any organs were removed. But in 1968, after Christiaan Barnard had some success with the first human heart transplant, an Ad Hoc committee of the Harvard Medical School published the paper, "A definition of irreversible coma," which outlined a method for declaring death based on brain criteria. This opened up the possibility of obtaining organs from heart-beating donors; patients who had lost all function of their entire brain but whose blood pressure and respirations were maintained by drugs and machines. These ventilator dependent, hemodynamically unstable patients/corpses, usually cared for by nurses in the intensive care unit (ICU) have become the main source for all transplantable organs.

Tissue donors first appeared as a heading in the Cumulative Index Medicus in 1967, and in the Cumulative Index to Nursing and Allied Health Literature (CINAHL) in 1974, but there is no literature specific to nursing care of the donor until 1978 in the CINAHL, and 1981 in Melvyl Medline. In 1974, Fox and Swazey published their sociologic study, The Courage to Fail, which chronicled nearly twenty years of field research in transplantation. In this work, the authors focused almost exclusively on the

transplant surgeons and organ recipients. Although they did offer some analysis of organ donation based on gift-exchange theory, these authors offered no reference to nursing care of donors or recipients. In 1983, Sophie, Salloway, Sorock, Volek and Merkel identified ICU nurses as an important link in the identification and maintenance of the potential donor, and by 1985, there was a dramatic increase in the number of published articles on nurses and organ procurement. By this time, the organ shortage, which had appeared in the medical literature since at least 1966 (Couch, 1966), was firmly entrenched thanks to the widespread use of cyclosporine, a highly successful immunosuppressant. Research on nurses and organ procurement has followed primarily two paths: exploring attitudes, beliefs, and knowledge using surveys; and exploring the procurement experience through qualitative methods. Other studies in the procurement field have attempted to identify specific factors related to consent rates, and to develop hospital programs that manipulate these identified factors in order to increase the rate of consent for donation.

Descriptive and Correlational Studies

Much research has been done in the field of organ procurement by way of descriptive and descriptive-correlational designs. Studies of health care professionals' attitudes toward, beliefs about, and knowledge of organ procurement, transplantation, and brain death have taken descriptive and/or correlational designs that all use structured, written questionnaires to collect data, share certain assumptions about the connections between attitudes, knowledge, and action, and have produced similar findings. They also share many problems in design and theoretical background that cast doubt on the

findings, and sometimes even question the conception of the entire project. The bulk of research related to nurses and organ procurement describes nurses' attitudes, beliefs, and knowledge of transplantation, organ donation and procurement, and tries to explain and find ways to correct the organ shortage by correlating certain variables to the number of requests made and consents obtained for donation. Looking at this literature helps to expose how this phenomenon continues to be problematized only in terms of an organ shortage.

Advances in transplantation techniques, including the development of powerful immunosuppressants and the increasing technical competence of surgeons, created the organ shortage. As more and more people began to be seen as potential organ recipients, the need for organs was not matched by donation. But this shortage of organs in the United States cannot be explained by technical or legal difficulties alone; the United Network for Organ Sharing forms the basis for a highly efficient, nationwide organ procurement system. The Uniform Anatomical Gift Act, written in the 1960s by the National Conference of Commissioners on Uniform State Laws, made it legally acceptable to donate and procure vital organs for transplantation and medical research, and has passed in every State. In addition, each State has adopted a brain death statute making it legally acceptable to take organs from heart-beating donors declared dead based on brain-related criteria. Neither can the shortage of organs be fully explained by an actual lack of supply as research has shown many brain-injured patients who seem to have the potential to donate organs die without donating.

The authors of the descriptive-correlational studies reviewed here took up the shortage as a problem and began to examine institutional factors that might account for it. Was it the nurses' attitudes? Did the nurses lack the knowledge to identify and properly refer a potential donor or lack a commitment to transplantation? Each author claims solving the organ shortage as an underlying purpose or background significance to their study. Gaber, Hall, Phillips, Tolley and Britt (1990) distributed a 50-item survey including both open-ended and forced choice questions to 766 health-care professionals from intensive care units (ICU), emergency rooms (ER), and operating rooms (OR). The survey asked questions intended to assess knowledge of the effectiveness of transplantation, awareness of existing laws and policies regulating procurement, understanding of brain death, moral, religious, and ethical views of transplantation, professional attitudes toward donation, and personal discomfort in approaching families about donation. In what the authors described as overwhelming approval of organ donation and transplantation, 90% of respondents indicated they had no moral objections to it. Yet less than half the sample indicated they would be willing to donate their own or their relatives' organs, and fewer had signed donor cards. Despite fears that requesting organ donation might be offensive to, or cause strain on the bereaved family, 77% of the sample indicated a willingness to approach families about organ donation. The authors found employees who attended an educational program given by the organ procurement agency were more knowledgeable about required request laws, and were both more willing to donate their own organs and more willing to approach family members about donation (Gaber, et al.1990). Those respondents who had prior experience in caring for a

donor and in approaching families about donation showed a difference in willingness to solicit donation and to donate their own organs.

In a similar study, Stoeckle (1990) described ICU nurses' attitudes toward organ donation, compared attitudes of ICU nurses in a level-I trauma center with those from a private hospital with a level II ER, and explored the relationship between certain background and situational variables and the nurses' attitudes. This author found strongly positive attitudes toward organ donation (95%), but like Gaber, et al. (1990) found, these attitudes did not translate into as strong an inclination to donate one's own (86.4%) or a relative's (65.9%) organs. There were no statistically significant differences in attitudes between trauma center and private hospital nurses. Similar to Gaber et al. (1990), the respondents said that knowledge and experience caring for donors and recipients were the biggest influences on their development of positive attitudes. While a little more than half of the sub-sample of nurses (34) who had provided care to a potential organ donor found caring for organ donors to be a rewarding experience, 53% found it to be an emotionally draining experience. Sixty-five percent of these 34 nurses found caring for the donor's family to be more emotionally draining than caring for the donor.

Bidigare and Oermann (1991) attempted to identify nurses' knowledge of and attitudes toward organ procurement. A secondary purpose was to uncover correlations between these variables. Most of the 60 ICU nurses in this sample (96%) had positive attitudes toward donating their own organs. While most generally approved of organ procurement, most also felt some discomfort with the idea of approaching a family to obtain consent for donation. Seventy percent indicated that they would actively pursue

the issue of donation with family members of a potential donor. The authors found a positive correlation between previous experience in caring for a donor and the degree of comfort felt in approaching family members about donation. The average summed score on the 30-item knowledge tool, which evaluated nurses' knowledge of donor and brain death criteria, donor maintenance and law, was nine (sd=3). Although the authors offer no further description of this measurement, they report higher scores attained by those nurses who had previously cared for an organ donor, and that higher knowledge scores were positively correlated with more positive attitudes toward donation and procurement, and greater comfort in approaching families for consent.

Bidigare and Oermann (1991) cite the non-random selection of their sample and the use of a single hospital as limits to the generalizability of their results. Another limitation is that the instrument is not well described or tested, and the authors provide no information on its reliability or validity. The authors are not clear about whether the two-part questionnaire used to measure attitudes and knowledge was composed of open-ended or forced-choice questions, or what kind of scales they used to measure the extent to which respondents would participate in the care of an organ donor, or the extent to which nurses would attempt to influence family members to donate organs. In the latter case, it is not clear whether the family members referred to are the nurses own family or the patient's family.

Expanding somewhat on Bidigare and Oermann's (1991) findings that surgical ICU nurses scored significantly higher than nurses from other hospital units on knowledge of procurement procedures, Kiberd and Kiberd (1992) hypothesized that

nurses exposed to different aspects of organ transplantation and procurement would have different attitudes towards it. These authors developed their own questionnaire that required primarily yes/no, either/or responses with some space for narrative and additional comments. Results were obtained in three separate comparative analyses: responses between units, responses of those nurses willing to donate as compared to those not willing, and responses of the subgroup willing to donate comparing those nurses who had signed a donor card with those who had not signed a donor card. Similar to most studies in this field, these authors found a high percent of nurses answered yes to the question, "Do you support organ donation?", but fewer would agree to donate their own organs, and, of those willing to donate, still fewer had signed a donor card. Operating room nurses were less likely to answer yes to the question, "Would you be an organ or tissue donor?" or to have signed a donor card. Operating room nurses and nurses working in a medical unit which cared for renal transplant recipients were less likely to answer yes to the question, "Is transplantation worth every penny (cost effective)?" than were nurses working in other units. Operating room nurses were also less likely to have ever assisted in identifying, maintaining, or procuring organs from a donor, and gave a lower estimate of the percent of cadaver renal transplant recipients functioning at one year. Also of interest was the finding that only 40% of ICU nurses answered yes to the question, "Are you supported in your involvement with the organ procurement process?"

These authors found several differences in answers to questions on attitude between those nurses who would be willing to donate and those who would not (Kiberd & Kiberd, 1992). Those nurses willing to donate more often agreed that they support

organ donation, feel transplantation is beneficial and cost effective, agree that organ procurement is a professional responsibility, and were less likely to refuse to care for an organ donor than those nurses who would not be willing to donate.

Evanisko, et al. (1998) undertook a descriptive correlational study to compare the attitudes and knowledge of physicians and nurses, and to test the hypothesis that hospitals where the staff had more support, knowledge and training on organ donation would have higher donation rates. Using chart review to determine donation rates at the 28 participant hospitals, and a survey of critical care nurses' and physicians' attitudes, knowledges and training in organ procurement, these researchers entered mean index survey scores across subjects into a correlational analysis with hospital donation rate to determine what effect more positive staff attitudes and more knowledge of and training in organ donation has on hospital donation rates.

Using chi-square analysis, Evanisko, et al (1998) found the 675 nurses and 226 physicians who completed the self-administered, Likert-scale questionnaire differed in several respects (p# 0.05). Physicians offered more positive answers on the attitude questionnaire and significantly more correct answers on the knowledge scales than did nurses. The study found no difference in knowledge and beliefs surrounding brain death, except more physicians than nurses had received training on explaining brain death to a family. More nurses than physicians agreed that participating in organ donation is a rewarding part of their job.

Evanisko, et al (1998) divided hospitals into high performance (donation rate at least one SD above the agregate mean) and low performance (donation rate at least one

SD below the agregate mean). The staff at the high performance hospitals differed significantly from those of low performance hospitals in their answers to attitude and knowledge questions (p # 0.05). A higher percentage of staff at high performance hospitals agreed that they support organ donation and would consider donating their own organs. More staff at high performance hospitals agreed that the appropriate time to introduce the topic of organ donation is after brain death is determined. Higher staff training levels were significantly correlated with higher donation rates. The authors conclude that staff training in how best to request donation is likely to increase donation rates. These authors do not report the reliability or validity of their data collection instrument for chart review although the reliability of the procedure is said to be reported elsewhere.

Along somewhat different lines, two more studies attempted to further the description of variables that affect organ donation and procurement by adding prospective or clinical practice-based sections to their designs. Stark, Reiley, Osiecki and Cook (1984) described nurses' attitudes, but added the extra step of describing aspects of the actual procurement/donation as it occurred. Matten, et al. (1991) sought to identify how variables such as nurses' knowledge, attitudes, beliefs, perceptions, and reports of personal actions are correlated with the number of requests nurses make for organ donation and the number of consents obtained. Similarly, Siminoff, Arnold and Caplan (1995) attempted to examine the donation process as it occurred and correlate the attitudes of the health care professionals involved with their success at obtaining consent.

Taking the position that attitudes affect behavior, and that nurses' attitudes can affect a family's decision to donate or not to donate organs, Stark, et al. (1984) examined each instance of potential organ donation at eight different hospitals over one year. The authors recruited one critical-care nurse from each hospital ICU to act as data-collectors. Each time organ donation came up within the one year period of the study, the data-collection nurse filled out a seven-item questionnaire answering who recognized the potential for organ procurement and when, the general attitudes toward donation and procurement of family, nurses and physicians, and, if donation did not occur, why it did not.

Although Stark, et al. (1984) purported to "...investigate attitudes that influence organ donation in the ICU," their findings were purely descriptive, reported in percentages, with no correlational statistics applied. From the 26 questionnaires returned, the authors found eight donations had actually occurred and that 88% of physicians, 100% of nurses, and five family members favored donation, and the nurse was the first to identify the patient as a potential donor in 42% of cases. It is not clear from the report whether the data collection nurses were reporting on themselves or on co-workers. Was the research nurse reporting on her own attitudes toward donation or her impressions of another nurse's attitudes? If they were reporting on the attitudes of others, how did they discover these attitudes? It is not clear how the data collection nurses obtained the answers they did, what questions they asked, or how they drew the conclusions that the physicians, nurses, and families involved had positive or favorable attitudes toward donation. The researchers cited physiologic reasons and physicians' fear of litigation

(there was no brain-death statute in Massachusetts at the time of the study) as the main reasons donation did not occur.

In light of United States required request legislation which made it a legal obligation for members of the health care team to ask families about organ donation, Matten et al. (1991) undertook to "...assess hospital nurses' knowledge, attitudes and beliefs, perceptions, and personal actions with regard to organ and tissue donation and transplantation." A further aim was to identify variables correlated with the number of requests made and the number of consents obtained for organ and tissue donation. The authors collected data via mailed questionnaires from 1,683 nurses employed in 62 hospitals in the Southern and Midwestern United States. Eleven percent of the sample were licensed practical nurses; the rest were registered nurses from several different hospital units. The variables obtained in the questionnaires were selected after a review of the literature and included knowledge, attitudes, beliefs, attendance at inservice programs, perception of confidence in making requests of organs or tissue donation, personal actions of the nurses with regard to organ and tissue donation, professional education, number of years in nursing, title and position, and area of hospital assignment. The authors then attempted to discover relationships between these variables and the number of requests made and consents obtained for organ and /or tissue donation by each participant.

Matten, et al. (1991) found the mean knowledge score from 10 true-false items was 7.5 (∀2.05). Respondents were more knowledgeable about physiology than law; most could identify the criteria for brain death and recognized that organs could be

harvested from the brain-dead patient. Fewer nurses knew that the family must make the final decision about donation, and what required request laws involved. Like Stark, et al. (1984), Matten et al. (1991) brought in a component of practice by asking participants to report the number of times they had requested and obtained consent for organ and/or tissue donation. Variables found to positively correlate with requests and consents for tissues and/or organs ($p<0.05$) included number of years in nursing, bachelor of science degree, holding a head nurse or supervisory position, working in the emergency department, having signed a donor card, having discussed one's own donation, and a willingness to donate more family members' organs upon their death, higher scores on the knowledge, attitudes and beliefs scales, greater attendance at inservices, and a stronger perception of self-confidence in requesting consent.

Because of their similar purpose and design, many of the descriptive survey studies on nurses and organ procurement have drawn the same conclusions and offer similar recommendations. More knowledge about organ transplants, donation and procurement has been correlated with more positive attitudes toward procurement issues (Stoeckle, 1990; Gaber, et al., 1990; Bidigare & Oerman, 1991). Previous experience caring for donors has also been correlated with positive attitudes (Bidigare & Oerman, 1991), more willingness to donate ones' own organs (Gaber, et al., 1990), and more comfort in approaching patients' families about organ donation (Bidigare & Oerman, 1991). More knowledge and more positive attitudes have been correlated with having made more requests and obtained more consents for organ donation from patients' families (Matten, et al., 1991). Based on these findings, nearly every author suggests

education and training as the primary method to increase consent for donation and to increase the actual number of organs procured (Stark, 1984; Stoeckle, 1990; Bidigare & Oerman, 1991; Matten, et al., 1991; Kibberd & Kibberd, 1992). Because these descriptive-correlational studies are similar in background assumptions, purpose and design, they share many problems. One example is in measurement. Several authors claim to have measured attitudes and beliefs using instruments designed for their own research. All used written questionnaires, most involving a mixture of forced-choice and open-ended responses. Of the six reports reviewed here, only Matten, et al. (1991) described their instrument in any detail; Matten, et al. (1991) pilot-tested their instrument and report the reliability as 0.8717 for the belief subscale, 0.8255 for the attitudes subscale, and 0.6767 for the knowledge subscale. A panel of experts judged the instrument appropriate, clear, adequate in response options, and readable. The authors obtained a mean belief score of 62.29 (sd 9.01) from a 25-item subscale employing a 5-point Likert scale. The mean attitude score (obtained from a 10-item, 5-point Likert scale subscale) was 33.6 (∀6.26) with a maximum possible of 50. This type of scoring, while it lends itself to correlational analysis, implies that, like knowledge, there are correct and incorrect answers to questions on attitudes and beliefs. The authors make it clear that a higher score indicates more positive attitudes and beliefs towards organ donation and transplantation, and found that, "Positive beliefs and attitudes were significantly correlated with both requests and consents for organs and tissues." (Matten, et al., 1991, p. 164) If the respondents approached the attitudes and beliefs subscales as if they were being tested for right and wrong answers, and gave what they thought were more socially

acceptable answers, the validity of these results is questionable. The way the authors equate positive attitudes and beliefs with pro-donation implies a common understanding of organ procurement that may or may not be shared by the bedside nurse. Although the authors try to make a distinction between personal beliefs and professional attitudes, these questions might be measuring similar mental states.

Another common problem was sampling bias; the samples for all of these studies appear to be self-selected, or selected with potential bias, (although this is not clear from all the reports). Kiberd and Kiberd (1992) sent questionnaires to the ICU, operating room, renal dialysis unit, and two general medical floors of a small Canadian hospital where they were completed voluntarily. Matten, et al. invited the directors of nursing at 67 hospitals "...to have their nurses participate in the survey," (P. 159) but it is not clear how the final sample of 1,683 nurses from 62 hospitals was selected. Stoeckle (1990) selected a "...convenience sample of critical care nurses..." (P. 355), and Bidigare and Oerman (1991) said nothing about sample selection. These vague references to sampling might mean that only certain pro-transplant, pro-procurement nurses were selected, or that more nurses who were knowledgeable and had positive attitudes toward donation participated. Stark, et al. (1984) provide a particularly good example of sampling bias. By using self-selected nurses as data collectors, then providing them with written information on how to select a cadaveric kidney donor, and a day-long program on the state of the art in transplantation and procurement, the authors set the study up to find positive attitudes and a better-than-average ability to identify potential donors.

The appeal of the survey method is that it is an easy way to examine organ procurement if the phenomenon is problematized only in terms of a shortage, and if one takes an empiricist view of human activity. Empiricism understands the world and persons as independent entities with absolute properties. Empiricist inquiry is grounded in what are thought to be interpretation-free facts that correspond to an external reality and can predict causation. The assumptions behind the survey research on nurses and organ procurement is that attitudes, beliefs and knowledge are measurable, objective mental properties that can predict future action. This is reflected in the design, which examines and tries to measure attitudes, beliefs and knowledge as abstract, disengaged traits possessed by all nurses. It is also evident in the common recommendations for education to improve these traits, and/or the employment of specialists trained in obtaining consent for organ donation as a way to increase the number of organs procured.

Surveys cannot examine or describe the context in which each nurse found it appropriate or inappropriate to approach family members about donation, or how the nurse experiences organ procurement in a larger context of care of dying patients and their families. Survey research takes a limited, decontextualized and static view of organ procurement. These authors hope to solve the organ shortage by extracting the nurse from the situation and examining or measuring her or his attitudes, beliefs, and knowledge, and then reshaping these through education to produce the desired action (more requests for organs, done properly, which produce an increased rate of procurement). What these authors seem to fall back on is the unexamined assumption that

increasing the number of consents for organ donation would be a good thing no matter the situation, and examine nurses as if the possibility of other concerns in the situation should be subordinate to organ procurement. There are clearly many concerns that might influence a family's decision to donate or not to donate organs, and that might influence a nurse to bring up the subject of donation with any particular family or family member. By focusing only on the nurses, and in such a way that excludes context, this research cannot confidently conclude that educational programs that train nurses in the proper way to solicit and preserve organs will in any way improve the atmosphere surrounding organ donation and procurement, or contribute to an understanding of nursing practice in this situation.

Siminoff, et al (1995) did the one study that departed from the usual survey method. These researchers designed a correlational study to determine how health care professionals' (HCP) attitudes toward organ donation and transplantation affect their response when faced with a procurement situation. Rather than make up a sample situation, each week during the study period the authors reviewed the charts of all the patients who had died to determine each patients' eligibility as a donor. Once the researchers identified a potential donor, they interviewed the HCPs who had been involved in the patient's care. The interviews were done within a month of the patient's death and followed an interview schedule that was based on input from organ procurement organizations and piloted for one month.

The first part of the interview examined the HCP's ability to identify the particular patient's eligibility as an organ donor. The correctness of this judgement was

determined by the researcher's chart review with reliability reported as 98%. If the HCP approached the patient's family about organ donation, they then answered a separate set of questions detailing this process. If they did not approach the family, they answered a set of questions on their willingness to approach families about organ donation. The second part of the interview used two scales to measure the HCPs' attitudes and knowledge about organ donation and transplantation. The attitude scale was divided into two subscales: a belief scale which measured attitudes toward the donation process, and an efficacy scale which measured belief in the effectiveness of transplant as a treatment for end-stage organ failure. The HCPs' scores on these instruments were then compared on the outcomes of each patient situation, whether the HCP approached the family about organ donation and whether the family consented to organ donation, using a t-test.

Of the total sample of 1,791 HCPs, 887 were nurses; of the total sample, 568 HCPs were interviewed about organ donation, the rest were interviewed about tissue donation. It is not reported specifically how many nurses were interviewed about organ donation. The researchers found that scores on the knowledge scale were not associated with the HCP's ability to identify a particular patient as donor eligible. However, those HCP's who correctly identified their patient as eligible for donation were more likely to obtain consent for donation from the family than were those HCPs who did not identify their patients as eligible (p=0.000). Similarly, the higher the HCPs scored on the belief section of the attitude scale, the more likely they were to request donation (p=0.000) and the more likely they were to obtain consent (p=0.00). There was no statistically significant association between HCP scores on the efficacy scale and whether or not they

obtained family consent (p=0.278). Interestingly, those HCPs who requested donation had lower mean score on the efficacy scale than did those HCPs who did not request donation.

Siminoff, et al (1995) concluded that attitudes have the most affect on the HCPs' willingness to request organ donation and recommend educational programs to improve these attitudes in the interest of increasing the number of donors. They also concluded that knowledge does not play a significant role in the organ procurement process; that HCPs generally do not know the criteria that make a patient eligible as an organ donor does not tend to preclude donation or inhibit their willingness to approach the family about organ donation. These authors avoided the sampling bias common to the previous research reviewed here by selecting their sample based on the patient's potential to donate organs; they described their instruments' reliability based on Chronbach alpha as 0.62 for the belief section of the attitude scale and 0.80 for the efficacy scale. While they did not offer any evaluation of the knowledge scale, they avoided the problems associated with excluding context by using a real situation. The participants were asked to draw on their memory of a particular patient they cared for who had been a potential organ donor. But it is not clear from the research report how the interviews were conducted except that they followed a schedule; the authors say nothing about what form the interview responses took except in the tabled statistics referring to the attitude and knowledge scales.

Studies of Nurses' Experiences

Five authors have studied how nurses experience caring for the potential and/or brain-dead organ donor. As part of a larger investigation of the ICU nurse's roles in

organ procurement, Sophie et al. (1983) explored the cognitive and emotional aspects of the experience of caring for a potential donor. Borozny (1990), in a purely qualitative, phenomenologic study, sought to determine what meaning ICU nurses attach to caring for the brain-dead patient. Watkinson (1995) added a qualitative component to a larger survey project on nurses' attitudes, beliefs, and knowledge, while Hibbert (1995) used content analysis to describe the types of stressors experienced by nurses who care for organ donors and their families. Pelletier-Hibbert (1998) also used content analysis to identify types of coping strategies used by nurses when they are caring for organ donors.

In an often-cited study decribed as both qualitative and quantitative, Sophie, et al. (1983) described the experience of 245 nurses from 27 midwestern hospitals as reported in written answers to an open-ended question on a larger survey. Using content analysis, the authors found 24% of nurses were not bothered by providing care to a potential donor, although several reported donor care to be emotionally draining (21%). Some were concerned about the amount of stress the process puts on the donor's family, but may also have thought donation assists families to make sense of the death and to work through the grieving process. Some nurses found caring for the potential or brain-dead donor to be no different from caring for any other ICU patient, while some experienced the potential donor as no longer human. It is not clear from the report whether the same nurses gave seemingly conflicting answers; for example, did one nurse say she or he found organ donation stressful to the family, but also found that it assisted grieving? Or did the same nurse see the organ donor as no longer human, but provide care no different from any other ICU patient? Given the wide range of responses, it is not surprising that these

authors also found that nurses have ambivilent feelings about organ recovery, and find the experience emotionally draining.

Although the methods and methodology are not well described, Sophie, et al. (1983) point to some of the deeper problems nurses experience in caring for the potential organ donor. Intensive care unit nurses are often the first to identify the potential donor but these authors conclude that discordance between nurses and the institution causes conflict in the ICU; the hospital claims to be committed to recovering transplantable organs, but nurses see the organ procurement process as stressful, complicated, and too demanding of their attention (Sophie, et al. 1983). As a way to solve these problems, these authors recommend increasing ICU nurses' exposure to organ recipients, simplifying procurement procedures, and allowing nurses opportunities to ventilate their feelings.

Borozny (1990) conducted two to three in-depth interviews with each of eleven nurses in a phenomenological study of what meaning ICU nurses attach to caring for the brain-dead patient. This author found dissonance to be a unifying theme. Dissonance, defined as, "...the clashing of coexisting beliefs, perceptions, values, opinions, knowledge and actions..." (p. 19) showed up as personal dissonance within each nurse, and as interpersonal dissonance between the nurse and other nurses, physicians, organ recovery team members, or patients' families. Personal dissonance showed up in some nurses' inability to reconcile care of the donor with their own philosophy of nursing based on healing. Others found the intensive treatment required of the brain-dead donor as well as the patient's age (often young and otherwise healthy) conflicted with their idea of how

death should look. Other internal conflicts involved shifting focus from saving the brain-injured patient to saving the organs, and providing emotional support to the family while also providing technical care to the donor. Interpersonal conflict occurred when the nurses disagreed with the medical management of the donor. Nurses objected to physicians who prolonged donor care because they could not decide what to do, or pushed too hard for donation and disrespected the person who the donor once was. The nurses responded to dissonance by experiencing personal distress and then distancing her or himself from the donor, or focusing on the patient's family, on the organ recipient or on themselves as a way to relieve distress.

In a two-part study combining a quantitative survey of attitudes and knowledge with qualitative interviews based in phenomenology, Watkinson (1995) attempted to identify the problems and needs of nurses caring for potential organ donors and their families in the United Kingdom, and to find out if and how education could help them. The findings, illustrated with short text examples, focused on the nurses' reflection on their experiences and what they found important. The respondents found it important to spend time with the patient and family and to provide some bereavement follow-up and continued support. They had a good understanding of brain death, and even had some intuitive sense of when it had occurred. Like Borozny (1990), these authors found what they termed cognitive dissonance among nurses and adapted Borozny's model to include several other strategies for reducing dissonance. The author recommends implementation of an education program for both pre- and post-registration nurses. The program would provide information on the pathophysiology of brain injury, brain death and donor

maintenance, training on how to talk with and counsel patient's family members, and information on the benefits of transplantation.

Hibbert (1995), designed an exploratory descriptive study to examine the types of stressors experienced by nurses who care for organ donors and their families. Hibbert (1995) interviewed 17 nurses using general questions on what they found stressful in caring for donor patients before, during, and after donation. The text was subjected to content analysis and the author identified nine categories of stressors: helpless uncertainty as to whether the brain-injured patient would survive, providing for the family, the physician's hesitancy to intervene and inconsistent commitment to donation, informing the family of brain death and approaching them about donation, maintaining the donor, waiting for retrieval, and returning to an empty space after the patient is taken to the operating room.

Again using Lazarus and Folkman's theory of stress, appraisal and coping, Pelletier-Hibbert (1998) extended the work of Hibbert (1995). In order to identify different coping strategies used by nurses caring for organ donors and their families, this author took up a qualitative, descriptive study using content analysis and relying on interview data. Data consisted of audiotaped, transcribed interviews with a convenience sample of 17 nurses from two Canadian hospitals. Each participant was interviewed once based on a schedule of open-ended questions in which respondents were asked to identify stressful situations and their response in the situation. Based on these interviews, the author divided organ donation into three stages: anticipation, in which the nurse waits for brain death and identifies the patient as a potential donor; confrontation, in which the

family is informed of the patient's death and they are approached about organ donation; and post-confrontation, in which the patient either becomes a donor or support is withdrawn. Within these stages, nurses employ different coping strategies including control, distancing, maintaining normality, seeking emotional support, taking time out and positive reappraisal. Using short text excerpts, the author illustrates which coping strategies were common to which stage. Exercising control refers to the way nurses maintained their emotional composure and was associated with the anticipation stage. During the confrontation stage nurses coped by distancing or detaching from the situation in order to protect themselves emotionally, by maintaining normality be engaging in normal nursing care activities, and by seeking the emotional support of nursing colleagues. In the postconfrontation stage nurses coped by taking time out or taking a break after the donor goes to the operating room, and by positively reappraising the patient's death as a good thing because of organ donation.

These qualitative studies of ICU nurses' experiences reveal important aspects of organ procurement, and begin to expose the complicated and conflicted nature of this phenomenon. Like much ICU work, nurses found the work of caring for the potential donor distressing (Borozny, 1990; Watkinson, 1995; Hibbert, 1995; Pelletier-Hibbert, 1998) and emotionally draining (Sophie, et al., 1983), but part of their professional responsibility. But unlike other ICU care experiences, care of the potential organ donor involves different death criteria. The nurses' seemed to understand the technical aspects of brain death, but might not have connected it to their own experience of death of the

patient (Borozny, 1990). Also important was the seeming lack of institutional support for organ procurement.

Each of these authors has contributed to broadening our understanding of the lived experience of nurses caring for organ donors (Sophie, et al., 1983; Borozny, 1990; Hibbert, 1995; Watknison, 1995; Pelletier-Hibbert, 1998). Each of these qualitative studies offer a broader, deeper and more contextual perspective than the survey-based research. However, each has shortcomings. Hibbert (1995) claimed to have been guided by Lazarus and Folkman's theory of stress, appraisal, and coping, but the design and interview questions were not in keeping with this understanding. Hibbert (1995) categorized the stressors experienced by the participants according to previous research on stress in critical care nurses, and in nurses who care for organ donors. This author then extracted the stressors from the actual context in which they occurred and described them in objective, generalizable terms. Similarly, Pelletier-Hibbert (1998) used Lazarus and Folkman's theory to extract coping mechanisms nurses use when confronted with a donor situation. In contrast, Lazarus and Folkman (1984) describe the individual as experiencing stress, appraising it, and coping based on the meanings embedded in a particular situation. Stress occurs as the result of a person's grasp of the meaning of a situation for the self; this speaks to the importance of situation and meaning in a way that other theories of stress and coping based on decontextualized stressors cannot address (Lazarus & Folkman, 1984; Benner & Wrubel, 1989).

Using text examples, Borozny (1990) offered good, if brief, descriptions of the main themes, but then quickly reduced the nurses' experiences to a simpler model:

dissonance leads to personal distress which leads to distress-reducing behavior. Watkinson (1995) further expanded this model to include a wider variety of distress-reducing behaviors. By outlining the formal structures behind organ procurement, both Borozny (1990) and Watkinson (1995) have produced a formal abstraction intended to clarify the phenomenon. But because it separates action from context, the theory generated might offer a distorted picture of skilled activity (Packer & Addison, 1989a). Rational abstraction detemporalizes and decontextualizes the nurses' actions in much the same way as the survey research. What makes the qualitative work more interesting is not the theoretical models the researchers start or end up with, but the method they used. The short interview excerpts offered by Borozny (1990), Watkinson (1995) and Pelletier-Hibbert (1998), and the examples of answers to open-ended questions included in Sophie, et al's (1983) report offer a glimpse of the nurses' concerns in the situation and begin to clarify what skilled activity in the context of organ procurement might look like.

Efforts to Increase the Organ Donor Pool

In further efforts to increase the number of organs gained for transplantation, some authors have targeted more specific areas for study and others have moved toward testing interventions. Maleckie and Hoffman (1987), and Garrison, Bentley, Raque, Polk, Sladek, Evanisko and Lucka (1991) focused on the act of requesting donation from the next of kin. In studies of more specific aspects of the consent process, Niles and Mattice (1996), and von Pohle (1996) looked at the effect of timing on consent rates. Gortmaker, et al. (1998) looked at the effect of timing, participation of an organ procurement coordinator (transplant coordinator) and the setting in which donation is presented to the

next-of-kin on consent rates. Stark, Wikoren and Martone (1994), Shirley, Cutler, Heymann and Hart (1994), O'brien, Serbin, O'brien, Maier and Grady (1996), and Beasley, Capossela, Brigham, Gunderson, Weber and Gortmaker (1997) offered what they call Hospital Development Plans for improving potential donation and actual procurement.

Because many nurses are uncomfortable in approaching families about organ donation, and because the moment of consent is crucial to a successful harvest, some researchers have focused on this point in a effort to expose potential weaknesses in the procurement process. Malecki and Hoffman (1987) mailed multiple choice questionnaires to 124 nurses working in several different hospital areas, but who all had experience in asking potential donor families for a donation. In this descriptive-correlational study, the nurses rated their level of comfort in approaching families as comfortable and confident, sad but confident, or very uncomfortable. The authors then correlated these answers to the nurse's success or failure in obtaining consent for donation and found that 84% of families approached by nurses who rated themselves as confident consented to donation, whereas 100% of families approached by nurses who rated themselves uncomfortable refused donation.

Malecki and Hoffman (1987) did not describe their statistics or give p-values or correlation coefficients for their data. The questionnaire, though not well described, seemed very limiting; as a retrospective account it is suspect because it cannot allow for a full description of the event and so cannot account for other explanations. For example, maybe the nurses felt uncomfortable because the family refused, rather than the family

refusing because the nurse felt uncomfortable. The authors did not explore the relationship between the nurse and the family before or as organ donation came up, or describe the patient's condition at the time. It is also unclear from the report whether the nurse respondents were reporting their feelings related to a specific patient they remembered or to potential organ donors in general. Perhaps their most interesting finding was that 80% of the nurse respondents thought offering organ donation to the family was part of their professional responsibility. But again, it is not clear how this question was worded. Were respondents asked about "offering the donation option" or about "asking potential donor families for a donation?" This is important in determining where the nurses felt the weight of responsibility: offering the option to the next of kin, or getting the organs?

In a part retrospective, part prospective study, Garrison, et al. (1991), like Malecki and Hoffman (1987), focused on the dynamics of the request process in an attempt to determine factors in the request that might lead to successful retrieval of organs. In the first phase, the authors looked at the charts of all patients in Kentucky hospitals they identified as having a potential for organ donation during 1988. The authors looked at whether brain death was declared, when the family was notified, and whether any request for organ donation had been made. Of 173 potential donors for that year, 9 died during the first few hours of hospitalization, the family refused donation in 92 cases, and in 29 cases, "...the medical care system failed to make a timely approach to the family." Most failures were attributed to a physician not identifying brain death, not allowing the family

to be approached or delaying referral until donor stability had deteriorated; 38 yielded a useable organ.

During the second part of the study, Garrison, et al. (1991), through retrospective chart review, looked at 155 medically suitable donors over 12 months, specifically at the time the family was notified of death in relation to the timing of the request for organ donation. They defined a "decoupled approach" as one in which the discussion of death was temporally separated from the discussion of organ donation, and found a significantly higher rate of consent when a decoupled approach was used ($p < 0.05$, chi-square). Based on the findings of the second phase, the authors concluded that most potential donors were identified and referred, but only 22% of requests resulted in actual procurement; to them this indicated a problem with the consent process for which they recommend a decoupled approach. However, the authors offer no reasonable guidelines as to how to implement this plan, and actually seem to contradict themselves in describing the nine patients who died within the first few hours of hospitalization: "If these patients had received an aggressive resuscitative effort, all could have been salvaged for organ donation" Garrison, et al., 1991, p. 393). How, if one is to take a decoupled approach, can the medical team talk to the family about donation if the patient is not dead? And if these patients were hopelessly brain-injured, maybe the team appropriately offered the families the option of refusing aggressive resuscitation instead of the option of organ donation. Perhaps the physicians' failures were rather a concern for the well being of the current patient and her or his family at the expense of losing salvageable organs. Garrison, et al. (1991) did not address these questions.

Niles and Mattice (1996) compared consent rates based on the role of the requestor and examined the effect of decoupling and timing of the request on consent rates. This descriptive study was done by collecting data on 127 families who were approached for organ donation at 17 different hospitals. The organ procurement organization (OPO) coordinators used a data collection questionnaire developed for the study to guide a retrospective chart review of every donor referral made to their regional OPO within a 23 month period. Once data collection was completed, potential donors were divided into three categories: those approached about donation before death, those approached at the same time as they were told of the death and those who were approached after they had been told of the death. The authors found a higher per centage of families approached before (62%) or after they were informed of the death (57%) consented to donation than those who were approached about donation at the same time they were informed of the death (25%). Nurse requestors obtained a higher rate of consent (52%) than did physicians (49%) or OPO coordinators (40%). No information is offered in the report on whether or not these differences were statistically significant. Despite the lack of statistical analysis, the authors conclude that, "...families should not be approached for donation at the same time they are informed of death," and, further, that the requestor should evaluate the family's "...status in the grieving process" before approaching them with the organ donation option. The authors acknowledge that families who have recently lost a loved one will "...vacillate between the six stages of grief..." but offer no guidance as to how to determine when is the "right" time to approach. What counted as the timing of the consent was based on what was recorded in the patient's

chart, the accuracy of which is questionable; the authors conclude that usually the families in the "after group" were presented with the donation option after they, "...had had time to assimilate the information of the death pronouncement." How the researchers determined the family's status in respect to assimilation of the death pronouncement is not clear in the report.

In another study that relied completely on retrospective chart review, von Pohle (1996) looked at the effect of decoupling on the rate of family consent to organ donation. This researcher then compared physicians, nurses and transplant coordinators on the number of times they used a decoupled approach, and on the rates at which each obtained consent for organ donation from the family. Chart reviews of all deaths that occurred at the research site hospital over the two year period of the study revealed 81 potential donors, 38 of which actually became donors. The charts of the 81 patients were then further investigated to determine who was involved in care of the patient and whether or not family was offered the option of donation. For those patients whose families were offered the organ donation option, it was determined by further review of the chart who approached the family and when.

Van Pohle (1996) found that physicians used a decoupled approach less frequently than nurses, and that organ procurement organization representatives (transplant coordinators) used a decoupled approach more often than either nurses or physicians. The author also found a statistically significant higher rate of consent to organ donation in families with whom a decoupled approach was used compared to those families with whom a decoupled approach was not used ($p=0.05$). Based on these data,

this author recommends a decoupled approach be used with all potential donor families and further suggests that perhaps the OPO representative ought to do all the asking. Van Pohle (1996) runs into many of the same problems and questions as Garrison, et al (1991) along with the question of the quality of the data similar to Niles and Mattice (1996). It is not clear from the research report what the researcher counted as a decoupled approach or how the time between the discussion of brain death and the discussion of organ donation was determined based on a review of the medical record.

Gortmaker, et al. (1998) examined three factors that may lead to higher consent rates: decoupling, type of health care professionals involved in the request, setting in which the request was made. The authors also claimed that these three factors may better meet the needs of potential donor families, but the research reported does not address this issue. In this descriptive correlational study, the researchers used a standardized donor-tracking instrument. Forty OPO coordinators were trained for 3 days in the data collection method, use of the instrument, and how variables were defined for the study. No statistics on reliability or validity of this instrument are offered, but data were reviewed for accuracy and cross-checked with OPO referral reports and medical records. The authors constructed a "request process scale" from the three factors with one point given for each element present. Demographic information on the age, race, and cause of death of the patient, what hospital unit the patient was admitted to, and information on whether or not the hospital was a transplant center, and what OPO region was involved in the consent process was taken from the medical records of 707 potential organ donors at the 124 participating hospitals. The authors determined the differences between consent

and nonconsent groups using chi square with a 95% confidence interval then estimated the independent association of the donor, request process and hospital characteristics with consent and nonconsent using multivariate linear regressions with 2-sided p values and 95% confidence intervals.

With other variables controlled for, Gortmaker, et al (1998) found that progressively higher consent rates correlated with progressively higher scores on the request process scale. These authors concluded that with training in each aspect of the request process scale, hospitals could increase their donation consent rates by 37% based on attributable risk estimates. These conclusions seem well supported by the statistical analysis. But, based on the research report, it is not clear how the data on the standardized tracking form were collected. It seems like the transplant coordinators filled in the forms prospectively when they went out on a consultation at a hospital and then these data were checked against retrospective chart review. If this was the case, the data collection methods used in this study were stronger than any of those previously reviewed that relied solely on retrospective chart review.

There is, however, the question of selection of patients to refer to the OPO. Gortmaker, et al. (1998) found a higher consent rate associated with involvement of an OPO representative in the consent process. This finding may be attributable to pre-referral screening rather than to the benefits of OPO involvement. Which patients do the admitting physicians and nurses refer to the OPO and how do they make this decision? Perhaps those families more likely to consent are referred more often than those less likely to consent. A prospective study of this problem with randomization to OPO and

non-OPO groups may shed more light on the relationship between OPO involvement and consent rates.

In addition, Gortmaker, et al. (1998) did not say how they measured whether the needs of the families were better met when the consent process achieved higher request process scale scores; the researchers only measured consent rates and based the entire study of outcome on this point. Can it be assumed that those families who consented to organ donation had a better experience, or had their needs met better than those who declined? What the authors may be saying, although it is never clear in the report, is that the items included in the process scale are based on what they perceived to be factors that better meet the family's needs.

Further exploration of the organ donor shortage has led other clinicians and researchers to implement and evaluate plans intended to develop organ procurement programs in hospitals. Stark, et al. (1994) reviewed the literature and identified four elements to a successful donor program: awareness, recognition, offering the option, and bereavement. They then developed a program for training nurse requestors incorporating each of these elements. The program involved educating staff, developing organizational support, teaching staff to recognize the potential donor, developing a team of certified nurse requestors and a "carefully orchestrated bereavement program for the donor family" (p. 392) that "goes beyond the support offered in the medical center" (p. 393). Implementation of this program at one New England hospital resulted in an increase in the number of potential donors recognized, and an increase in the rate of actual donation (reported as number and per cent of total potential donors), compared to the nearly four

years before implementation although no p-values are reported. In addition, the team of nurse requestors became bereavement experts for their units who offer resources to other staff members. Shirley, et al. (1994) also implemented a hospital development plan involving quality assurance audits, donor activity reports and educational programs. The area organ procurement organization's implementation of this plan at hospitals in their service area increased the number of donors referred to the procurement agency for donation from these hospitals over the next year compared to the year prior to implementation.

In a quasi-experimental study, Beasley, et al (1997) implemented a large-scale intervention to increase organ donation rates in hospitals in three OPO service areas. The researchers collected baseline data by retrospective chart review to compare all participating hospitals before, during and after the intervention on rates of donor identification, rates of donor referral to the OPO, rates of donation request, and rates of consent to donation. The intervention was based on three process variables that have been shown in prior research to influence consent rates: privacy, decoupling, and OPO participation. The research team planned the intervention strategies based on a review of the medical records of potential donors at each participating hospital, and based on the characteristics of each particular hospital. While each intervention included the same elements, the specific methods for implementation varied according to the needs of the institution. The elements included ensuring referral of each potential donor to the OPO, ensuring a decoupled approach to the family, taking the family to a quiet, private place for the donation discussion, and ensuring the OPO representative's participation in the

donation discussion. Chi-square comparison of proportions of pre-intervention and post-intervention rates of donor identification, referral, request and consent based on each individual hospital and on the sample as a whole revealed statistically significant differences pre- and post-intervention in all variables except consent rates for the sample as a whole ($p<0.01$, authors do not report their set level of significance). The authors also found statistically significant differences in consent rates between those families approached with and without attention to the process variables with higher consent rates in instances where the approach to the family was decoupled, in a quiet, private place, and where the OPO representative was involved ($p<0.01$). The researchers conclude that this intervention was successful in improving organ donation rates, but it is not clear what role each aspect of the intervention played in consent rate improvement. It could be that the increase in donor identification alone accounts for increased consent.

Each of these studies of the effects of hospital development plans on number of donors relied on chart review as their data source. While this made the data collection simple, it raises questions about the accuracy of the charting. This is especially important regarding the issue of decoupling; how accurate was the timing of the charted information? In addition, the data in all of these studies tells us only whether or not a patient was identified as a potential organ donor, whether or not the patient was referred to the OPO, and whether or not the family consented to donation. It is difficult to draw any conclusions about variations in consent rates from these data since they say nothing about the process of identification of a potential donor before death and before contact with the OPO. Focusing only on these aspects characterizes donor identification as a

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static, unchanging point in time rather than as a process that evolves over time. For example, a family's decision about organ donation may be partly influenced by their experiences before brain death while treatment is still focused on brain injury.

Perhaps the most interesting aspect of these reports is each one's strong commitment to continuing the drive for increased procurement. This is reflected in the authors' language. O'brien, et al. (1996) were looking for "reasons for failure to donate" (p. 156), and described those patients who did not donate as "nonproductive donors" (p. 157). Garrison, et al. (1991) described "failures to obtain a donation," and the "failure to obtain permission for donation" (p. 392), and characterized 29 cases of potential donors of whose families consent was not requested as "the medical care [system's failure] to make a timely approach to the family" (p. 393). Shirley et al. (1994) described the medical records as showing "missed referrals" due to "problem areas" (p. 819) in the hospital that lead to a low procurement rate. This language of failure gives no weight to the real situation as it plays out; what reasons might there be for identifying and treating a severely brain-injured patient as something other than a potential organ donor? This research on hospital development plans did not ask or answer these types of contextual questions.

Summary

Since the beginning of transplantation, organ procurement has been problematized in terms of an organ shortage. Because of this, the nursing literature has followed this same pattern of argument. All the research on nurses and organ procurement has been justified in terms of moving toward resolution of the shortage. This justification has

limited the researchers' scope by structuring their questions and interpretations. Survey questions have been structured by and directed toward the assumption of a shortage. Measuring knowledge, beliefs and attitudes has always been in order to improve the rate of donation and procurement. Qualitative reports of the nurses' experience have been likewise structured, leading the researchers to develop theories of nursing behavior that might explain the shortage. Even though qualitative researchers have taken us further in understanding the nurses' concerns, by and large we are left with a body of research that speaks only to the organ shortage issue.

By focusing so much on the organ shortage, this body of research is set up to miss other concerns and meanings of nursing care of brain-injured patients who become identified as potential organ donors. Most importantly, this research leaves out any meaningful interpretation of what it is like for the nurse to care for the family of a patient who is suddenly and often rapidly dying, but who has the potential to save another's life. These clinical judgement aspects of nursing practice have been largely ignored by the rational-empiricist approach to research in this field. Nursing is a rich context dependent practice informed by particular concerns and emotional responses (Benner, Tanner & Chesla, 1996). Rather than seeing the particular brain-injured patient as an instance of abstraction (ie: potential organ donor) against which the nurse can instrumentally apply all known facts about organ procurement, the nurse might be solicited by other concerns for the patient and family's well-being. While nurses might consider organ procurement one of their general professional responsibilities, the literature in this area does not help us to understand what part it plays in relation to care of any given patient and family.

Chapter 2

Philosophical Background to Organ Procurement

Human organ transplantation is a life-saving technology that depends on the cooperation of the public and health care professionals. It is the lay public who arrange to donate their own or a loved one's organs after death. It is the health care professionals who identify a patient as having the potential to donate organs and it is often the intensive care unit (ICU) nurse who cares for the patient and family before and after the patient is identified as a potential organ donor. Whether or not the organs can be maintained until transplant, and whether or not any organs can actually be taken depends on the nature and severity of the injury, the declaration of death based on brain criteria, on the nurse's concern for the dying patient and family, and on the family's consent. Thus, the background to the possibility of procuring organs includes brain injury, brain death, and gaining consent for donation from family members.

Brain Injury and Brain Death

Pathophysiology of Brain Injury

The brain tissue, its blood supply and cerebrospinal fluid (CSF) are all enclosed in the bony, inflexible skull with little room for anything else. According to the Monroe-Kellie hypothesis, an increase in any one of the contents of the cranial vault (blood, CSF, brain tissue) can only be accommodated by a decrease in another component or by an increase in intracranial pressure (ICP) (Kandel, Schwartz & Jessell, 1991). This means that drastic increases in blood flow or CSF volume can compress the brain tissue and an increase in CSF volume or brain edema can compress cerebral blood vessels, all of which will raise the ICP (Kandel, Schwartz & Jessell, 1991). Under normal circumstances,

autoregulation maintains a constant and even flow of blood to the brain, and CSF is produced, circulated and reabsorbed at a steady rate. But when the brain is injured, autoregulation and CSF circulation can be impaired, and the brain can become edematous, all of which might contribute to increased ICP and compromised blood flow of life-threatening proportions.

Autoregulation is lost whenever the mean arterial pressure drops below 50 mm Hg or rises above 160 mm Hg (Eisenhart, 1994). Traumatic brain injuries such as gunshot wounds or blunt trauma are often accompanied by blood loss and shock which can easily cause the mean arterial pressure (MAP) to fall. Brain injury itself can also cause direct impairment of autoregulation. This means that the blood flow to the injured brain is variable and might be easily compromised. Add to this the cerebral edema common to brain injuries of all kinds, the possibility of impeded CSF flow and reabsorption due to blood in the subarachnoid space, and the fact that autoregulation is further inhibited at ICPs over 30 mm Hg, and it becomes clear why the main problems following brain injury is increased ICP and impaired perfusion.

Treatment of brain injury is aimed at lowering the pressure and increasing perfusion by decreasing the cranial volume and optimizing blood flow. Tracheal intubation and hyperventilation will bring down pCO2 and cause vasoconstriction in areas of the brain thereby lowering the ICP (Eisenhart, 1994). Ventriculostomy to drain CSF, and diuretics to decrease cerebral edema will also lower the ICP. Another treatment modality is to minimize brain metabolism and oxygen consumption through sedation, anticonvulsant medications and hypothermia (Eisenhart, 1994).

Resuscitation techniques have made it possible to sustain the lives of brain-injured patients while the injury is evaluated and treated. The patient's prognosis depends on the mechanism of injury, the initial examination, and response to treatment over time. Unfortunately, there are no effective treatments for the most severe brain injuries involving extensive bi-hemispheric and brain-stem tissue damage or which cause brain swelling to the point of herniation where the brain stem is forced down into the foramen magnum. At this point, ICP usually exceeds MAP and cerebral blood flow is completely impeded. If the injury is extensive and ICP cannot be controlled, the patient might be identified as a potential organ donor. Procuring vital organs for transplant can only take place after the patient is declared dead based on brain criteria.

Brain Death

The Harvard Committee

Brain death is a somewhat new concept in medicine and is intimately connected to organ procurement and transplantation. Transplantation of human organs began in 1954 when Thomas Murray, MD took a kidney from one twin and implanted it in the twin's identical sibling (Pence, 1990). By 1959, transplant surgeons had begun the first grafts between non-identical siblings and by the early 1960s surgeons claimed some success with cadaveric transplants (Fox & Swazey, 1974). The cadaver donors in the early days were non-heartbeating; that is, their hearts had stopped before the organs were removed (Fox & Swazey, 1974). When Christiaan Barnard, MD, a South African heart surgeon, did the first heart transplant in 1967, the controversy over the dead donor began. Barnard waited for the heart to stop beating before he took it from the chest of the severely brain-injured woman whose family had agreed to donate (Barnard, 1967). But the question remained, was everything done to save the donor? If

the heart could be restarted for the recipient, why could it not be restarted for the donor to save her life (Pence, 1990)?

Despite some encouraging results early on, transplantation from cadaver donors ran into two major problems: rejection and warm ischemia. In 1968 with the publication of the Harvard Committee paper, "A definition of irreversible coma" brain-related criteria for declaring death were first put into writing in order to, among other things, put an end to the controversy over obtaining organs for transplant. The Harvard brain death criteria cleared a major obstacle for transplant. In the early days, transplant surgeons had to wait for the donor heart to stop beating before infusing it with the cold fluids necessary for preservation. Because of this lag time, the organs tended to stay warm but unperfused long enough for them to succumb to the effects of the poisonous metabolites associated with ischemia. By writing new criteria for death, the Harvard Committee (1968) made it ethically acceptable to take vital organs from a donor whose heart was still beating thus solving the problem of warm ischemia. Following the Harvard Committee, several other similar definitions of irreversible coma were published.

Even though the Harvard criteria solved the problem of warm ischemia, transplantation did not really take off as a viable technology until the routinization of cyclosporine as the immunosuppressant of choice in 1980. Suddenly the world was faced with a shortage of organs. More and more people were placed on waiting lists as potential recipients while the pool of viable cadaver donors remained unchanged. Meanwhile, the procedure for declaring death was no longer standard across the United States (US). Some States accepted brain criteria, while others required cessation of heartbeat and respiration. This created the awkward situation whereby a person could be dead in one State, cross the State line, and be alive again. Although the Harvard criteria were very influential in shaping the clinical diagnosis of death in brain-injured patients, the Committee was criticized for lacking a philosophical base. Defining death includes conceptual and criterial components (Gervais, 1986). The concept answers the question, what does it mean for a living thing to die? In the case of human beings, the question might be what does it mean for a person to die? Once the concept is defined, criteria can

be developed to determine when death has occurred, and specific tests can be implemented to determine if the criteria are present (Gervais, 1986). The Harvard Committee never addressed the conceptual question of why irreversible coma should be equated with death, but only supplied the criteria for determining when a coma was irreversible and concluded that the patient could then be treated as dead.

The Uniform Determination of Death Act (UDDA). In response to these controversies, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (the Commission) convened to study redefining death and to come up with an actual, acceptable definition that could be used to unify cross-State laws. The definition of death promoted by the President's Commission is the irreversible cessation of an organism's ability to function as an integrated whole (President's Commission, 1981). The criteria used to determine death as listed in the UDDA include the irreversible cessation of all functions of the entire brain or irreversible cessation of heart and lung function. The President's Commission sought a scientifically sound, medically accurate standard that would be uniformly applicable regardless of the situation or even the species (Capron, 1988). In so doing, the philosophical stance of the Report includes a vision of death as a truth external to sociocultural context. The Report characterizes death as a fact with a distinct natural meaning separate from its human experiential meaning. Death can be recognized by a correct interpretation of physical manifestations.

Because death, as explained by the President's Commission, is a natural phenomenon, it can be recognized by the use of an explicit list of criteria that represent an actual, objective fact. "Although absence of breathing and heartbeat may often have been

spoken of as defining death, review of history and of current medical and popular understanding makes clear that these were merely evidence for the disintegration of the organism as a whole" (President's Commission Report, 1981, p. 58). This implies the common use of criteria in representing death and characterizes certain physical signs as an objective picture of the truth. Capron (1988), in his defense of the UDDA, also presented death as a natural concept: "Human death, like the death of any animal, is a natural event; ...death is an event whose existence rests on certain criteria recognized rather than solely invented by human beings" (p.157). Capron (1988) further emphasized the importance of uniformity in defining death; death should reflect an objective reality that looks the same for everyone regardless of cultural context or species.

The President's Commission goes on to state that loss of all brain function can replace heart and lung function as an indicator of death without changing the underlying conceptual definition of death as the irreversible loss of the ability of an organism to function as an integrated whole: "Physicians, in applying the traditional procedure that corresponded to societal expectations [i.e., measuring heart and lung function] were not maintaining that death *is* the irreversible loss of heart and lung functions. There were affirming only that the loss of those functions *indicated* that a person had died" (President's Commission, 1981, p. 56). The Report implies that the use of criteria is a common, socially accepted understanding of death without recognizing its bias toward reducing life to biology, chemistry, and physics.

A criterial approach to recognizing death comes from a rational empiricist approach to science. Knowing by this method requires extracting phenomena from the world and reducing them to component parts. The objectivity of this method relies on the

ability to view the world free of context and without interpretation; truth is received as a quantifiable physical fact separate from the subjective interpretation of the receiver. Medical science has relied on empiricist methods for many years; that disease, as a real, physical entity, is separate from the patient's perception of illness, and that only objectively quantifiable pathology counts as real are old ideas in Western medicine (Gordon, 1988). The President's Commission Report attempted to provide an objective view of death free of subjective interpretations of meaning to be used as the final word in cases of confusion.

While it claims objectivity, the recognition of the fact of death through the application of the UDDA criteria implies a background understanding and an enculturation into the social practices of medical science that allows certain physical signs to represent death (Guignon, 1991). The representation of death in this way also requires an ability to identify situations in which use of the criteria is appropriate. "Deciding what facts are relevant presupposes a prior mastery of the meaningfulness of the public situations in which they first show up" (Guignon, 1991, p. 84). In this way, subjective interpretation is always a part of the development and use of criteria; as Bayertz (1992) wrote, the dividing line between life and death provided by the UDDA does not "depend on natural facts but upon a moral decision, on the one hand, and the current state of technology, on the other" (p. 409).

Higher brain definitions. While the President's Commission sought a sound conceptual definition of death, equally important to the group was the development of a publicly accessible, medically accurate policy that was free from undue complexity (Capron, 1988). Balancing these objectives was more important to the Commission than

pure unerring philosophy. Perhaps because of this, and despite the Commission's attempt to give brain death a solid footing in science, philosophical controversy over the concept continues. The whole-brain criteria promoted by the Commission, and adopted by each State has come under attack by those philosophers and physicians favoring higher-brain oriented criteria. Consciousness and cognitive functions, these authors argue, are the most important aspects of human personhood, and their permanent absence should be the only criteria necessary to declare death (Veatch, 1981; Youngner & Bartlett, 1983; Cranford & Smith, 1988). Only these functions are essential to human life and only they, unlike vegetative brain-stem functions like respirations, heartbeat, and blood pressure control, which can be substituted by technology, are irreplaceable. The Commission sidestepped the personhood debate by turning death into a purely biological, organismic event (Lock, 1994). By so doing, they may have also sidestepped issues of central importance to any full discussion of death, that is, *who* has died (Lock, 1994). In response to this, philosophers and physicians have argued in favor of a person-oriented definition centering on the higher brain functions (consciousness and cognition), ignoring the vegetative functions of the brain stem which have nothing to do with the life or death of a human person (Veatch, 1981; Lamb, 1985; Gervais, 1986; Devettere, 1990).

Veatch (1993) argues that the whole brain criteria, because it draws an arbitrary but sharp line between the spinal cord and the brain stem, cannot avoid falling to a slippery slope argument. There is no principled reason why all brain-stem reflexes should count as integrative to bodily function. The same principle that lets us ignore spinal reflexes ought to let us also ignore at least some brain stem reflexes. But then why not ignore all brain-stem reflexes? According to Veatch (1993), a definition of death that

avoids the slippery slope is a higher-brain oriented definition based in the Judeo-Christian idea that a human being is an integration of mind and body. This provides a "bright line that would clearly distinguish the total and irreversible loss of consciousness from serious but not total mental impairments" (p. 21). But since it is dependent on particular religious assumptions, even this definition, Veatch argues, is not beyond dispute in a pluralistic society such as the twentieth-century United States. Veatch's solution is to allow each person to choose between the three major options: heart-, whole-brain-, or higher-brain-oriented criteria, with a default to a higher-brain definition.

Veatch (1993) sees nothing very disturbing in adopting a higher-brain definition of death.

> Since it is now widely accepted that anyone can write an advance directive mandating withdrawal of life support once one is permanently unconscious, any persons who favor a higher-brain-oriented definition of death already have the legal right to make choices that end up with them dead in anyone's sense of the term very shortly after they had lost higher brain functions. Permitting them to designate that they be called dead when they are permanently unconscious changes very little (Veatch, 1993, p.22).

What this philosopher fails to account for is how these patients are experienced clinically. Patients who are declared dead based on whole-brain criteria (including the brain stem) are in a permanent eyes-closed coma. They make no spontaneous respiratory effort, have no temperature or blood pressure regulation, and usually have no control of fluid balance. When the medical technology used to sustain them is withdrawn (e.g., ventilator, vasoactive drugs, warming devices, IV fluids, plus hormones to prevent excessive urine output), they do not breathe or make any effort to breathe and their hearts stop within minutes (Plum & Posner, 1981). By contrast, those patients who have lost only higher-brain function (i.e., consciousness), but retain brain-stem function, also retain all the

vegetative functions to a greater or lesser degree. The most common condition resulting from loss of higher-brain function is the Persistent Vegetative State (PVS) (Plum & Posner, 1981). The PVS patient might have sleep-wake cycles, during which their eyes are open (though they do not track) for periods of time. They maintain intrinsic blood pressure control, metabolize and often maintain their own fluid balance. Most importantly, when ventilator support is withdrawn, patients in PVS can breathe spontaneously for any number of weeks, months, or years depending on nursing care and as long as food and fluids are provided. If all support is withdrawn, PVS patients often will not stop breathing until they starve, dehydrate, or succumb to an infection. While withdrawing life support from a PVS patient will eventually result in death, treating a spontaneously breathing patient as already dead is, to say the least, counterintuitive (Truog, 1997) and might change quite a lot in clinical nursing practice. For example, if the PVS patient is considered dead, would the nurse then wrap the breathing, heart-beating body and send it to the morgue?

Other approaches to defining death. Along more deeply philosophical lines, Thomasma (1984) cautions against substituting scientific criteria for clinical judgement. This bioethicist defines death as an event that occurs in life and is experienced only by the living. Those arguing for a higher-brain definition of death distort "our linguistic and cultural understanding of the term "death" into a definition of privation" (Thomasma, 1984, p. 188), i.e., the absence of consciousness. While the absence of consciousness or the loss of integrative function may or may not describe what death is like to the dead, (we have no way of knowing), it says nothing about our understanding of death as part of life, as a concept culturally defined by the living and commonly understood in language

systems as describing life. As such, life is the temporary overcoming of its cessation; the cessation can only be experienced and recognized by the living, and only in terms of judgements about quality of life, not through scientific criteria claiming to define the absence of life (Thomasma, 1984). Thomasma concludes by claiming that a permanent cessation of existence, as judged by the best persons able, e.g., family, friends, those who know/knew the patient, relieves the physician of any moral obligation to continue treatment. Unfortunately, Thomasma (1984) does not say anything about when it is morally appropriate to remove vital organs which is not the same as discontinuing treatment (Fox & Swazey, 1992).

In contrast to Veatch's (1993) approach to the conceptual problems with brain death, others recommend abandoning brain-oriented criteria all together. The Danish Council of Ethics (DEC) proposed the cessation of brain function as an indication of the beginning, not the end, of the dying process (Rix, 1990). Death should only be declared at the end of the process when all brain, heart, and lung function has ceased. This is the point at which everyday experience tells us a person is dead.

> In everyday experience, the identity of a person comprises the integrality of consciousness and body, but, as identity relates no less to the body than to the mind, the process of death cannot be said to have ended while respiration and heartbeat continue, the body remains warm and the colours of the body normal (Rix, 1990, p. 6).

But since cessation of brain function indicates the irreversible beginning of the death process, organ procurement is acceptable at this point (Rix, 1990). This approach takes us back to the questions surrounding the first heart transplant with a new problem: if we define death as the end of heart, lung, and brain function, and if the donor's heart and lungs can be re-started in the recipient's chest, does the donor ever really die (Pence,

1990)? If the DEC's definition of death requires the end of heart, lung, and brain function, it seems to exclude the possibility of transplant.

Truog (1997) suggests we maintain a brain-oriented concept of death but revert to familiar and widely accepted heart-lung criteria for determining that death has occurred. At the same time, changes in the law could allow organ donation and procurement before death while the organs are still perfused and viable (Truog, 1997; Arnold & Youngner, 1993). This would involve what Truog (1997) terms justified killing based strictly on the accepted principles of consent and non-maleficence. As long as the patient or her or his family agrees to donate and as long as taking the organs would not harm the donor, causing the patient's death could be justified in order to obtain the organs. This assumes that killing someone who is dying or who has permanently lost, or, in the case of anencephalic newborns, never had, consciousness, violates no interest (Arnold & Youngner, 1993). It also leaves the same strange question as the DEC, that of when and if the donor actually dies.

Brain death and futility. It is interesting that brain death is never connected to arguments on medical futility and that the rich literature on futility never includes reference to brain death as part of the futility continuum. Given the continued debates on where to drawn the line clinically between life and death, and give the cultural diversity of many parts of the World and the post-modern emphasis on personal story and context, it makes sense that brain death be placed along a continuum of being and non-being open for each to draw his or her own line depending on life world and context. Separating brain death from futility sets up a dichotomy in which brain death is seen as part of an objective reality while futility remains subjectively debatable. While it is true that to be

hopelessly dying differs from being already dead, there is no clear and objective distinction that can be made between these two states in the case of brain death. Despite the President's Commission's best efforts, brain death is still a case of normative, not physiological, futility that relies on judgements about the worth of a severely impaired existence. This becomes more obvious when the President's Commission includes the statistics of recovery in their argument for whole-brain criteria. While no patient properly diagnosed as brain dead has ever recovered consciousness, there have been cases of brain dead patients surviving for prolonged periods in coma, dependent on ventilatory and other supports of physiologic function (Shewmon, 1998). This fact makes obvious the point that brain death is not about physiological futility. If physiologic functions such as heart beat, breathing and blood pressure are the goals of treatment, continued support of the brain dead cannot be defined as futile since it will accomplish these goals. If, on the other hand, as the President's Commission argues, integrated functioning of the organism as a whole is the goal of treatment, it becomes easier to see how brain death can be equated with physiological futility. But the integrated functioning of the organism as a whole is only one of several possible definitions of death that, as discusses previously, are still being debated in the bioethics literature.

Brain death and clinical practice. The debate over death might come down to what Lock (1994) has deemed a Kuhnian paradigm crisis: we are looking for commensurability where it is not and never will be. Philosophical discussions of how to define death and end the organ shortage might have little to do with the actual care of patients dying from brain injury. Today, brain death is said to have occurred when the patient permanently loses all function of the entire brain, including the brain stem

(President's Commission Report, 1981). A patient can be declared dead based on brain criteria when clinical examination reveals certain signs although the required tests might differ from hospital to hospital (for example, some, but not all require EEG confirmation). In practice, the line between life and death in the brain-injured patient is often a matter of a few primitive brain-stem reflexes like a weak cough or blink. Since these reflexes will change over time in the patient with a swelling brain, death can also depend on the timing and thoroughness of the neurologic exam. Because declaring death based on brain criteria involves a different approach than does treating the brain injury, the diagnosis also depends on whether or not the physicians and nurses involved in care have shifted their focus from treating the brain injury to salvaging organs for transplant. Preparing for the brain death diagnosis involves normalizing the patient's pCO2 in order to ensure apnea, normalizing the patient's body temperature and clearing all sedation in order to rule out other causes of unresponsiveness. All of these interventions conflict with treatments for brain injury as previously discussed.

As the debates over death continue, what are often absent are voices from clinical practice, and we are left with criteria that might not be so simple to apply. For example, ICU nurses might have a good grasp of what the criteria are, but have no clear idea of the circumstances in which they should be applied (Youngner, Landefeld, Coulton, Juknialis & Leary, 1989). While nursing practice in this context might be influenced by the debates, clinical judgement is driven by much broader and deeper concerns focused on the particular patient (Benner, Tanner, & Chesla, 1996). As Wros (1993, 1994) and others have begun to make clear, care of patients who are dying in the ICU is complex and full of emotionally heavy meaning for the family and staff. This is

probably also true when the patient is severely brain-injured and unconscious. But adding to the complexity in these cases is the professional responsibility to procure organs for transplant. In addition, nurses often practice in a rapidly changing context bounded by time. This is especially true with the critically brain-injured patient. As the patient care situation evolves, the nurse responds based on what is salient to this particular patient at a particular point in time (Benner, Tanner, and Chesla, 1996). The transition from dying to dead happens in a complex, emotionally-charged, and quickly changing situation; whether tests to determine brain death (no matter how it is defined) are relevant depends on the situation and on the way the nurse is involved with the patient and the patient's family. The brain-injured patient might never appear to the nurse as the abstract collection of objective criteria referred to in the UDDA, or as the decontextualized, free individual who has decided her or his own point of death (Veatch, 1993).

Selling Procurement to Nurses

Organ Procurement as a Professional Responsibility

Because organ transplantation can extend and improve the quality of life in patients suffering end-stage organ disease and because replacement has become a standard treatment for organ failure, organ procurement has become part of the ICU nurses' professional responsibility. Most attempts at increasing organ procurement have been based on an empirical model that discounts skilled know-how and emotion and assumes knowing the fact is all that matters. Grasping intellectually the benefits of transplantation, understanding the truth that brain death is death, and adopting an objective, disengaged stance at the bedside, where emotion is excluded, will all contribute

to improving the nurse's ability to identify donors and thus increase the pool of organs. But even when the nurse understands organ procurement on an intellectual level, she or he might still hesitate to approach families about donation. In answer to the hesitation nurses feel toward intruding on the family's grief with a request for organs, transplantation has been portrayed in the clinical literature not as a request for organs but as a choice the nurse is obligated to offer the family. Organ donation is further characterized as potentially helpful in resolving the donor family's grief.

Because organ procurement depends on the cooperation of the bedside ICU nurse, transplantation and donation must be sold to this market (Prottas, 1994). Prottas (1994) attributes the success of organ procurement organizations to "procurement [moving] away from the model of a medical supply service to that of a marketing and sales organization" (p. 39). The role of the procurement coordinator is "essentially that of a sales representative, marketing professional education" (Prottas, 1994, p. 38). The professional education is intended to win nurses over, to sell them on transplantation and motivate them to identify the potential donor and make an attempt to procure all available organs.

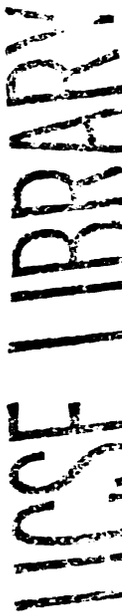
One attempt at marketing organ procurement to nurses is to convince them they are not asking the family for something, but are instead offering something (Albert, 1994). Nurses should "[realize] that the option of donation is offering to rather than taking from a family in grief" (Albert, 1994, p. 559). Organ donation is characterized as a choice the family should be given the right to make (Prottas, 1994; Lindsay, 1995). Offering this choice is presented as part of the critical care nurse's job, as part of caring practice in the ICU and the family's refusal to donate should not be seen as failure but as

success "in providing the family with the opportunity to make their own decision about organ...donation" (Lindsay, 1995, p. 59). In the U.S., offering the option of organ donation is also a legal obligation codified in the not-so-palatably-titled Required Request Laws (Savaria & Swanson, 1995).

Several authors have proposed that offering the option of organ donation to bereaved families, and the actual process of donation, can assist family members with the first task of grieving - accepting the reality of the loss (Bartucci, 1987; Lange, 1992; Albert, 1994). Others have implied that offering the organ donation option and organ donation itself can be beneficial by offering consolation to grieving families (Peele, 1989; Willis & Skelley, 1992). From the results of questionnaires completed by 34 donor families, Bartucci (1987) concluded that approaching families about organ donation could be "a major step toward recognition of the loss, the first task of grieving" (p. 308). This author further suggested that nurses might be more inclined to approach families in these circumstances if they view the opportunity to donate organs as "a vehicle for grief-work" (Bartucci, 1987, p. 308). In this way, organ procurement has been shifted from a request for organs to an offering of the opportunity not only to donate organs, but also to begin the tasks of grieving. Albert (1994) further articulated this position in the following passage: "The individual who approaches the family [about organ donation] should be convinced that donation is beneficial for the family by assisting them in dealing with the grief of sudden loss" (p. 559). Similarly, Lange (1992) stated, "the organ and tissue donation conversation can be a major step toward recognition of the loss of a loved one, which is the first task of grieving" (p. 26). These authors go on to suggest that nurses look upon organ donation as a means of grief work for the donor family (Bartucci, 1989;

Lange, 1992; Albert, 1994). Since those who do not work through and complete the given tasks are at higher risk for developing a pathological grief characterized by prolonged emotional distress, organ donation should be viewed as a beneficial intervention to prevent grief pathology.

While these views on organ donation as offering something to the donor family are intended to ease the nurse's anxiety in approaching a grieving family about organ donation, they seem less than honest and might actually undermine the process. The language of "offering the option" ignores the fact that the nurse is actually asking for something and that the whole point of asking is to solve the organ shortage. This motivation is alluded to by the review of organ shortage statistics that introduces many reviews of the procurement process (Albert, 1994; Dunn & McBride, 1994; Lindsay, 1995; Savaria & Swanson, 1995). It seems contradictory and contrived to then characterize the nurse's approach to the family as an offering. Offering organ donation as a benefit might also discount the important gift-giving and charity aspects of the donation act (Fox & Swazey, 1974, 1992; Gerrand, 1994). If nurses and families began to view donation as beneficial to the donor's family, the gift-giving aspects might be lost altogether in favor of a blatant marketing approach that is not far from financial incentive.



Organ Donation as Grief Therapy

In addition to the general problem of offering donation as a benefit, there are several problems with the task-based model on which the idea of organ donation as a vehicle for grief work is based. A task-based explanation of bereavement was originally offered as a way to empower the grieving person to take control of her or his life and to actively participate in getting used to the loss (Worden, 1991). Enframing grief as a

working through of tasks implies an active mastery of the grief experience. Worden's (1991) tasks have been taken up as a way to grant the grieving person control over the meaning of living with loss (Corr & Doka, 1994; Coolican, 1994). Coolican (1994) suggests that approaching grief as a series of tasks can help the bereaved to design new meaning or produce a new interpretation of life that includes the absence of the lost loved one. Tasks have become a way to work through the problem of grief by changing the perceived meaning of the loss.

Frameworks that outline tasks or phases of grieving or that normalize the process of grief-work and prescribe for a successful outcome often do not take into account the unique situation of the bereaved. To present grief as a staged process that begins with death and is either successful or pathological risks losing the contextual experiences of grieving (Lazarus & Folkman, 1984; Benner & Wrubel, 1989). What counts as stressful and what shows up as a possible coping strategy depends on how the person is engaged in the situation (Benner & Wrubel, 1989). In this phenomenologic view, stages or phases of grief are seen as different situations rather than as internal experiences that must be cognitively and emotionally worked through (Benner & Wrubel, 1989). Lazarus and Folkman (1984) suggest that stages may actually reflect changes in the situation or a progression of external demands rather than a change in the structure of the individual's psychic environment.

Contrary to the belief of many health care practitioners, death is not a problem that we can solve. It is the ultimate other, the unknowable and ungraspable (Levinas, 1947/1989). The loss that confronts us after the death of a loved one is not predictable or controllable. To approach the grief process as task-work that can be instrumentally

facilitated seems to trivialize bereavement and appeal to a fragile sense of absolute control and mastery over world that cannot be sustained in the face of death (P. Benner, personal communication, May 24, 1995). Staged and task-based models approach grief as a problem to be solved or as a potential problem to be avoided. Worden (1991) and Lindemann (1944) both view the prolonged distress of pathological grief as in many cases avoidable with the proper work. Grief counseling that encourages confrontation with the reality of the loss and the feelings it brings up can solve the problem of grief by helping bereaved persons put the loss behind them (Worden, 1991; Lindemann, 1944). But the loss of a significant and loved other cannot be confronted merely as a problem to be solved. Relationships set up a world; a loss that leads to grief creates a need to reconstitute a world (P. Benner, personal communication, May 24, 1995). Rather than offering direction for therapeutic interventions, the tasks outlined by Worden (1991) may only point to the way perception of the situation changes as the survivor's world changes.

The shortcomings of task-based models of grief are further exposed by the context in which the potential for organ donation arises. The potential to donate vital organs usually occurs after a sudden, often violent, injury such as an accident, homicide, or suicide. Coupled with the untimely and unanticipated nature of the injury, death is eventually declared based on brain-related criteria rather than the more traditional and familiar heart-lung criteria. The survivors are asked to accept as dead a body that is warm and pink, and continues to breathe aided by mechanical ventilation. If the family agrees, the body will be sent to the operating room where whichever organs the family agreed to donate will be removed. The ventilator and other support will then be ended and the body sent to the morgue.

Within the context of sudden death by brain injury, many conflicts can arise for the surviving family and friends. While they may want to engage in the altruistic gift-giving organ donation provides, they may also be disturbed by the significance of removing organs from the newly dead body, and by their inability to participate in their loved one's dying process (Fulton, Fulton, & Simmons, 1987). These concerns and conflicts cannot be resolved by convincing ourselves that donating organs or even offering the option to donate can help the newly bereaved come to terms with their loss. Organ donation is a gift that arises from a desire to help others that may never be completely understood. That some families do agree to donate suggests strong background or cultural practices of giving even in times of personal distress (P. Benner, personal communication, March 29, 1995). To turn this around and make organ donation into something nurses can recommend to help families with grieving seems to take away from the gift-giving aspects of such a selfless act. Perhaps nursing's approach to organ procurement should pay attention to and support these practices while not trivializing the stress of sudden loss.

Finding a stance for nurses who must approach family members about organ donation is difficult. No one wants to be the one to request a donation from people in such obvious distress for such obvious reasons. But framing the option to donate organs in terms of grief therapy is problematic. Advising nurses to think of organ donation as a way to facilitate the tasks of grieving is a simplistic answer to a complex question. If nurses convince themselves that organ donation is beneficial in assisting family members with the normal work of grieving, how are they set up to respond to the family who refuses to donate? With a normalized view of grief and grief-work, and organ donation

presented as a therapeutic intervention, refusing to donate seems pathological in itself. The hesitation that nurses feel at approaching family members about organ donation is deeper than this kind of reframing can uncover. Whether there is room for organ donation in the survivors' understanding and interpretation depends on their grasp of the current situation and on what coping methods are available to them (Benner & Wrubel, 1989).

Orchestrating Consent

In addition to the cooperation of health care professionals, organ procurement depends on the consent of families. As ICU nurses take up organ procurement as a professional responsibility in their care of brain-injured patients and their families, they risk subordinating caring practices to the instrumental goal of obtaining consent, a trend that is reflected in the literature. Citing the scarcity of transplantable organs and the long list of people dying or suffering unnecessarily for lack of new vital organs, some authors recommend a procedure for ensuring the highest rate of success in approaching potential donor families for consent. Given this set up, success can only be interpreted as consent for organ donation. The "proper approach" includes empathy coupled with objectivity and decoupling the declaration of death from the donation request.

Toward the goal of obtaining more organs, ICU nurses are advised to consult with organ procurement organization (OPO) nurses who are experts on the consent and organ procurement process (Dunn & McBride, 1994; Albert, 1994; Savaria & Swanson, 1995). The OPO nurse's, or procurement coordinator's, responsibilities include evaluating potential donors, counseling families, and coordinating organ recovery (Albert, 1994). Offering the donation option should be done in an objective manner disconnected form

the dying patient that ensures the family's choices are not influenced by the nurse's opinions. Because the procurement coordinator is called upon only after a patient is identified as a potential organ donor and is involved in the patient's care only related to organ recovery, she or he will be able to objectively assess whether a family is prepared for the donation request (Dunn & McBride, 1994). Anxiety and other emotions will not interfere with the OPO nurse's assessment of the family the way it might for the ICU nurse (Dunn & McBride, 1994). While the OPO nurse approaches the family with sensitivity, empathy, and concern, it is a carefully constructed and timed approach intended to ensure success (Dunn & McBride, 1994; Savaria & Swanson, 1995; Siminoff, 1997). ICU nurses are advised that "common courtesy and sensitivity to the family's grief are obviously important. A brusque approach...is usually unsuccessful" (Siminoff, 1997, p. 91), and to "provide donor families care in a carefully constructed, empathetic manner" (Dunn & McBride, 1994, p. 603).

Another important factor in obtaining consent for organ procurement is the timing of the request (Dunn & McBride, 1994; Savaria & Swanson, 1995; Siminoff, 1997; Albert, 1994). Organ donation should only be brought up with the family after they understand that their loved one is dead. The separation of death from the request for organs, or the decoupled approach, has been said to increase the chances that a family will consent to donation (Garrison, Bentley, Raque, Polk, Sladek, Evanisko & Lucas, 1991). Several authors cite the importance of decoupling to the success of organ procurement and lay out a plan for how to implement this in practice. Decoupling is "crucial to the outcome of the consent process" (Savaria & Swanson, 1995, p. 572). While implementation of this plan including an empathetic, sensitive approach and

decoupling might lead to greater success in obtaining consent for procurement, it might not be possible in actual practice.

The authors who recommend empathy and sensitivity in approaching families about organ donation realize the tragedy of the situation and how difficult the experience must be for the families (Dunn & McBride, 1994). But talking about empathy while at the same time describing a plan intended to yield the greatest return of organs makes empathy sound instrumental to the task of procuring organs. Similarly, allowing the family time to understand that their loved one is dying or dead could be an important part of end of life care. While this aspect is not lost in the literature on organ procurement, it is in the service of the organ recovery project (Dunn & McBride, 1994; Albert, 1994; Lindsay, 1995; Savaria & Swanson, 1995; Siminoff, 1997).

Decoupling offers its own practical problems. The procurement process as outlined in much of the literature assumes a controlled, step-by-step process in which the patient neatly progresses to brain death. In fact, the patient is dying and often all efforts are still being made to save her or his life. The ICU nurse is in the middle of treating the brain injury when the patient is identified as a potential organ donor. In addition, identification as a potential organ donor means only that the patient is likely to die; it is no guarantee of brain death. What should the nurses and physicians caring for the patient do when they realize the patient is hopelessly dying but not yet brain dead? If organ procurement were not an issue, they would most likely offer the family the option of withdrawing life support. If organ procurement is a possibility and the team is committed to a decoupled approach, all they can do is wait for brain death; but what do they tell the family in the meantime?

Summary

Organ transplantation is a life-saving technology that is full of contradictions. It is driven by what Fox and Swazey (1992) call a "bellicose, 'death is the enemy' perspective; a rescue-oriented, hubris-ridden refusal to accept limits" (p. 199). Yet transplant is also dependent on someone's death. Whether the need for a flow of organs for transplant might cause an indifference toward the violence in our communities is an open question (Lock, 1994). In one San Francisco neighborhood where young African-American and Latino people frequently die violent deaths, basketball player Michael Jordan stands a hundred feet tall on a billboard asking us to please sign our organ donor cards.

The professional responsibility to obtain organs for transplant rests partly on the ICU nurse. The nurse is expected to consider organ procurement while in the midst of caring for a patient dying of brain injury, perhaps trying to save that person's life. While the philosophical debates over death continue, the ICU nurse must try to convince the family that the patient is actually dead when declared dead based on brain criteria and approach the family about organ donation. The bedside nurse is said to be too emotionally involved and anxious to properly time the request for organs but at the same time is encouraged to use her or his empathy as a way to obtain consent. These contradictions make the uneasiness some nurses feel about organ procurement easier to understand (Lock, 1994). How nurses respond to these contradictions and how they balance care of the patient with the professional responsibility to procure organs are open questions of moral import.

Chapter 3

Interpretive Phenomenology and the Study of Nurses and Organ Procurement

In investigating nurses and organ procurement, there are many possible lines of inquiry that lead to a variety of specific questions. The choice of a scientific method should fit the questions driving the inquiry. Depending on the aim of the research, rational-empirical as well as hermeneutic or interpretive methods might be appropriate. As reviewed in chapter one, the bulk of research surrounding nurses and organ procurement has had as its aim the investigation of barriers to the procurement of adequate numbers of organs for transplant. Rational-empirical methods appropriate to these aims are less useful in gaining insight into human meaning and lived experience because they are theory-guided and examine questions outside of meaningful contexts.

Most inquiry into organ procurement has used empirical methods to identify the abstract, context-free criteria or characteristics that can explain or solve the organ shortage. Within this methodological framework, researchers have stripped human action of its particular circumstances and studied decontextualized responses to objective questions (questionnaires) or unreal situations (case studies) in a search for brute data (Packer & Addison, 1989a; Taylor, 1985). Brute data are, "...data whose validity cannot be questioned by offering another interpretation or reading, data whose credibility cannot be founded or undetermined by further reasoning" (Taylor, 1985, p. 19). The facts uncovered by the empirical method are said to be interpretation free, foundational facts that correspond to an external reality (Packer & Addison, 1989a). This method has been popular in the physical sciences as it is useful in describing objective properties like weight and mass (Packer & Addison, 1989a). Empirical methods have also been applied

to the human sciences to quantify the objective properties of people; for example, personality traits have been quantified in psychometric tests (Packer & Addison, 1989a). Taking this method up in relation to nurses and organ procurement, researchers have tried to measure nurses' attitudes toward, beliefs about and knowledge of organ transplantation, donation and procurement by administering written survey tests. Survey research tries to uncover the context-independent brute data that make up the nurse's trait or state personality and that might contribute to understanding why there is an organ shortage. At best, empirical researchers offer validity and reliability statistics for their test instrument in an effort to solidify the credibility of their results. According to empirical assumptions, the more reliable and valid the test or test instrument, the more sure we are that the results correspond to external reality.

By extracting human concerns from the context in which they occur in order to approach brute data and to approach universal truth, rational-empirical methods tend to distort the phenomenon under investigation (Packer & Addison, 1989a). Because the rational-empirical scientist is searching for the individual pieces of a problem that is abstracted from human interaction, she or he cannot account for the background meanings that make empirical questions possible (Taylor, 1985). An interpretive study starts in a different place. Rather than taking shared understandings for granted and building an abstract theory on top of them, interpretive phenomenology seeks to articulate background meanings and give voice to the distinctions that can only be made while engaged in an actual situation where things matter. Interpretive science makes a place for the study of shared or common meaning which forms the background to empirical science. Common background meanings are not reducible to brute data and are

embedded in particular circumstances. By starting with human understanding, interpretive science can take us further in understanding human response and action than can rational-empirical epistemology that starts at a theoretical level. Because she or he does not adhere to an empiricist paradigm, the hermeneutic scientist can ask different questions. For example, instead of working from a perspective that assumes an organ shortage exists and must be resolved, an interpretive line of inquiry might begin with what, if anything, does an organ shortage and organ procurement mean to nurses engaged in clinical practice, a question that can only be answered by looking at that practice.

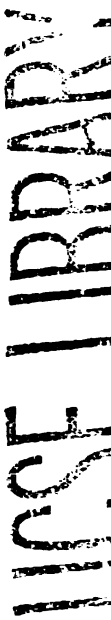
Interpretive Assumptions

Interpretive phenomenology diverges from rational-empiricism on a basic, ontological level. Where rational-empiricism assumes brute data are the foundation of truth, the interpretive scientist questions the possibility of uninterpreted data and presumes that there are no value-free descriptions. Interpretive scientists acknowledge that all science is conducted within an interpretive or hermeneutic circle in which there is no outside, objective reality against which one can judge the interpretation. Similarly, there is no vantagepoint outside the circle from which the interpretation can be judged. Hermeneutic phenomenology embraces the circle not as a trap, but as the only way to understand everyday practical activity and human interaction. Research embedded in social practices starts with an understanding or interpretation and goes on to further interpret the understandings and interpretations of participants. Interpretive scientists make different assumptions about the world and what it means to be human. These assumptions are derived from Heidegger (1927/1962) and further developed by Taylor (1985), Benner and Wrubel (1989), and Benner, Tanner and Chesla (1996).

Humans are the kinds of beings who share meanings (Taylor, 1985). Shared meanings are evident only in practices because practices involve other people and equipment; our responses to equipment and to each other are shared with our culture.

> It is not just that the people in our society all or mostly have a given set of ideas in their heads and subscribe to a given set of goals. The meanings and norms implicit in these practices are not just in the minds of the actors but are out there in the practices themselves, practices which cannot be conceived as a set of individual actions, but which are essentially modes of social relation, of mutual action (Taylor, 1985, p. 36).

In order to begin to articulate these background meanings the interpretive phenomenologist assumes human persons are self-interpreting beings who are embodied and who constitute and are constituted by a world, and express their being most often in ready-to-hand, unreflective, absorbed coping with equipment and responding to others (Heidegger, 1927/1962).



World

Being human involves a world in which things matter in a pervasive way. A person takes a stand on her or his being through involvement in a world. In the broadest sense, the world is one's most basic familiarity and involvement with equipment and others, and is the condition for the possibility of encountering any particular thing as a thing or any other person as other. Being situated in a world means a person has situated possibilities for action and ways of being involved (Benner, Tanner, & Chesla, 1996). One example of this is the nurse in the environment of the Intensive Care Unit (ICU). Organ procurement most often occurs in an ICU staffed by nurses for whom the ICU is familiar. The ICU nurse's world is her or his involvement with the equipment contained in the ICU, each part of which relates to every other part. The ICU nurse feels at home in

the ICU where equipment such as emergency drugs, moveable beds, monitors, ventilators, and intravenous pumps, converge into a whole that is more than the sum of each isolated piece. This interconnected totality of equipment is what the nurse recognizes as the ICU. The nurse experiences the equipment not as many isolated objects with properties but as a completely familiar whole of which she can take account without consciousness, mental representation, deliberation, or reflection (Heidegger, 1927/1962; Benner, Tanner, & Chesla, 1996). The nurse is always present in the ICU in three ways: she is disposed toward the situation, is absorbed in coping with equipment and other people, and is pressing into possibilities (Heidegger, 1927/1962).

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Disposedness

The nurse is disposed toward the equipmental totality of the ICU in a way that reflects her past experiences and training in nursing, as well as her broader cultural background. Unlike properties of mental content, disposedness can never be completely explicit, nor can it be chosen (Heidegger, 1927/1962). Disposedness is a public mood shared by all ICU nurses; it is the way the nurse is attuned to the situation as one in which certain things matter (Heidegger, 1927/1962). The nurse approaches the ICU and the particular patient situation based on how she was raised in the practice and on what the current standards of the practice or cultural norms allow. In the case of the potential organ donor, the patient often will have sustained a sudden and usually fatal injury to the brain. Given the graveness of the patient's condition, entering the room might call for a serious and attentive mood that entering the room of a patient who has just had an uncomplicated appendectomy, or entering the staff lounge during lunch time might not. A

mood comes up without reflection or decision on the nurse's part, but as simply what an ICU nurse does in this situation.

Absorbed coping

The nurse is always already disposed toward the world or situation in a certain way that is based on past experience. But the nurse is also always already coping in the world, absorbed in what is going on now. This absorption is an involvement with particular things or people that is, like disposedness, in a situation bounded by concerns or things that matter. The ICU nurse is able to take up equipment and use it transparently or respond to others without reflection because she or he is familiar with the equipment and situation. Unreflective or ready-to-hand absorption is the nurse's primary mode of being in a situation. For example, an intracranial pressure (ICP) catheter is a piece of equipment commonly used in the care of a brain-injured patient. It is a rubber tube that goes through the skull, into the fluid-filled ventricle of the brain. On the other end, the catheter is connected to a stop-cock and transducer that can measure the pressure inside the brain and, if needed, drain off fluid in order to lower the pressure. In practice, this equipment does not show up as an object with properties upon which the nurse reflects each time she approaches it. In smooth, everyday ICU nursing practice, the ICP catheter is ready-to-hand; it does not show up as a rubber tube sticking out of the patient's skull connected on one end to the cerebrospinal fluid in the brain, and on the other end to a plastic three-way stop-cock, drainage bag and transducer. It does not show up at all, but becomes transparent to the task of managing the intracranial pressure; the equipment recedes into the background and the nurse is directly connected to ICP.

Pressing into Possibilities

Having concerns, the larger purpose for which we take up equipment, makes it possible to immediately see what is relevant and respond to what the situation demands. Concerns set up how the nurse enters the situation, lets certain things show up as salient and others not, and sets up possibilities for how the nurse will act (Benner, Tanner, & Chesla, 1996). When the nurse enters the brain-injured patient's room, possibilities open up for her to press into (Heidegger, 1927/1962); it might make sense for her to do a neurologic examination, take a blood pressure, suction the endotracheal tube, or bathe the patient, among other things. These are all open possibilities within the nurse's involvement with the ICU and with this particular patient. The cultural norms of the ICU would allow the nurse to do any of these things. As she enters the patient's room, the nurse notices the patient's intracranial pressure is high; this situation brings into the foreground that part of the room that is relevant to the intracranial pressure. Because the intracranial pressure is high, it now only makes sense to do certain things. The nurse's understanding of the situation and of the particular patient makes some part of the whole stand out; drain the ICP catheter, raise the head of the bed, or ensure that the patient is well-ventilated, for example. There is a particular thing that calls the nurse forth, a particular possibility that draws her in. Perhaps in this case, based on her understanding of the particular patient in the particular situation, it is the ICP catheter that affords decreasing the intracranial pressure, and the nurse is drawn into coping with this piece of equipment in order to decrease the pressure. Rather than first sorting through all the other possible information or actions she could take, the expert nurse takes in the situation as a whole and, drawing on her familiarity with this patient's history, responds immediately to

the relevance of the raised pressure by opening the catheter without consciously taking account of the catheter's properties. This kind of response is immediate, unreflective and does not rely on rule-following (Benner, Tanner & Chesla, 1996). The nurse is solicited by her concerns for the particular patient rather than by a general formula or algorithm for dealing with increased intracranial pressure in any patient.

Embodiment

Being human involves a bodily intelligence that makes it possible for us to be skillfully involved in situations (Benner & Wrubel, 1989). The phenomenologic assumption of embodiment is in contrast to the notion of mind/body duality made popular by Descartes. Interpretive phenomenology assumes being human involves a body, not that human beings possess their bodies. The ICU nurse dwells in the ICU as a skilled body. Embodied intelligence allows the nurse to be solicited by and respond to the situation; the ICU nurse perceives and acts only because she or he is embodied. Embodiment makes disposedness, absorbed coping and pressing into possibilities possible. The world in which the nurse dwells, the possibilities which are open and the particular actions the situation can solicit are only possible because the nurse is embodied.

Self-interpretation or Taking a Stand on Being

The nurse is always already disposed, absorbed, and pressing into possibilities all at the same time (Heidegger, 1927/1962). Every present moment has a past and future built into it. The nurse is able to press into the possibility of opening the intraventricular drain because she has a certain disposedness toward the ICU in general and toward this particular situation as one in which intracranial pressure matters for this patient at this

time, and to this moment in which the ventricular catheter affords decreasing the intracranial pressure. These structures of being in a situation cannot be separated from each other or from the context in which the nurse finds herself.

Human persons are self-interpreting beings who take a stand on their being. When the nurse is absorbed and coping, equipment does not show up at all; it withdraws by affording an avenue to pursue important concerns such as decreasing the intracranial pressure. The nurse is solicited by the particular patient to protect and heal, two possible meanings embedded in ICU nursing practice. This is how something as simple as turning a stopcock is related to taking a stand on being; a person surrounds herself with equipment that points to her stand on being. Nurses work with such things as ICP catheters, ventilators, and intravenous lines as a way to take a stand on their being as nurses. When the nurse is in the ICU, she or he organizes all activity around being a nurse. In this way, nurses' identity and intersubjective meanings show through what nurses do, how they take up equipment within familiar circumstances, how they practice nursing. This is why examining attitudes, beliefs, and knowledge as internal mental content directed towards an external world gives a stunted and inaccurate picture of the nurse's practice. Attitudes might affect how a nurse is disposed toward the world or a situation, but examining mental content outside of context cannot get at disposedness, absorbed coping, and pressing into possibilities that includes the world, not just as a mental representation, but as part of the nurse's being.

Examining attitudes, beliefs, and knowledge as internal mental content, as an empirical researcher would, leaves out the background from which this inquiry is derived. How the nurse encounters the phenomenon of organ procurement and the organ donor is

from inside a world in which she is already involved, coping, and pressing into possibilities; she is disposed, absorbed, and pressing into possibilities as the situation constantly changes and solicits different actions. In order for the patient's status to change from brain-injured to potential organ donor or brain dead, the nurse must first have a disposedness that allows this possibility to show up. If the nurse's identity as a nurse does not include concern for maintaining organs for transplant, this possibility will not show up as intelligible in any situation. As the nurse copes, the situation changes and her approach to the patient and to the equipment changes. To return to the intracranial catheter example, if the patient has progressed from brain-injured to brain dead, the intraventricular drain might no longer show up as relevant, or might show up in a different way, perhaps as a piece of equipment that failed to save the patient's life. If the patient is brain-dead or dying, the nurse's concerns change. Instead of focusing on saving this patient's life, the nurse turns to other concerns that are also related to her identity; facilitating a good death, being with the patient's family in their grief, and/or preserving organs for transplant.

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Entering the Interpretive Circle: Background to My Interest in the Problem

Interpretive research articulates meanings as they are lived. Gaining access to the phenomenon requires entering an interpretive or hermeneutic circle in which the participants' understanding is developed. Interpreting lived understanding and meaning requires a stance of practical familiarity rather than neutral objectivity (Packer, 1989). The interpretive scientist enters the circle from an informed starting point in which the questions that began the inquiry, and the researcher's practical understandings and theoretical knowledge are thoughtfully acknowledged. Also acknowledged are potential

prejudices and misconceptions that might make aspects of the investigation challenging (Packer, 1989).

I came to the phenomenon of nursing practice and organ procurement from my experience as a nurse working in a neurologic ICU. The questions guiding my inquiry came from my concerns in caring for brain-injured patients identified as potential organ donors. The most disturbing part of caring for these patients for me has been the point where the patient is dying but not yet dead and is identified as having the potential to become an organ donor. I have felt that the possibility of organ procurement changes my relationship with the patient and family such that it takes on an uncomfortable, deceptive and sometimes manipulative quality. All of my personal experience and emotional responses as well as background theoretical and philosophical understandings and speculation contribute to my preunderstanding of this phenomenon. What do I already know about this phenomenon that will allow me to open up to it in a way that allows it to show itself to me in the most depth (C. Chesla, personal communication May 20, 1997)? As I enter the circle of interpretation and begin making explicit the understandings of other practicing nurses it is important that my preunderstanding stays open to change and that my interpretation is never just a restatement of my own understanding (Packer, 1989).

Research Design

The review and bioethics literatures have provided descriptions of the ideal process for obtaining organs for transplant. Death defined by brain criteria, grief as a step-wise, normalized project, and the use of organ procurement specialists are all part of an ideal procedure intended to generate the greatest number of transplantable organs

(Veatch, 1993; Albert, 1994; Bartucci, 1987; Coolican, 1994; Lamb, 1985; Prottas, 1994). Left out of this picture are voices from clinical practice, the lived experience of the nurse at the bedside. The philosophical background to organ procurement as reflected in the research and review literature opens up several interesting directions for further research in this area. The professional responsibility to obtain organs for transplant rests partly on the ICU nurse. The nurse is expected to consider organ procurement while in the midst of caring for, perhaps trying to save the life of, a patient who is dying of brain injury. While the philosophical debates over death continue, the ICU nurse must try to convince the family that the patient is actually dead when declared dead based on brain criteria and approach the family about organ donation. The bedside nurse is said to be too emotionally involved and anxious to properly time the request for organs but at the same time is encouraged to use her or his empathy as a way to obtain consent. These contradictions make the uneasiness some nurses feel about organ procurement easier to understand (Lock, 1994). How nurses respond to these contradictions and how they balance care of the patient with the professional responsibility to procure organs are open questions of moral import. Related lines of inquiry include articulating the moral sources of the ideal in organ donation and procurement, uncovering incongruities between the ideal construction and the lived clinical world, and articulating the nurses' practical, context-bound concerns in caring for the brain-injured patient identified as a potential organ donor.

The design of this study was descriptive and interpretive intending to articulate nursing practice in a particular area. Specific lines of inquiry pursued were:

1. The nurse's ideal construction of the care of a brain-injured patient identified as a potential organ donor, and of the organ donation and procurement process and how it compares to the ideal constructed in the professional and bioethics literature. By ideal construction I mean what the nurse thinks of as the best case scenario related to brain injury and organ procurement. Where does the nurse's ideal construction gain its moral weight and what part does the literature play in forming these ideas?

2. Articulation of the nurse's lived clinical worlds involving care of the brain-injured patient identified as a potential organ donor. What do good practices look like in this context? Do good practices involve living out the ideal? How does the nurse's visions of good practice help to define good practice as it is lived in relation to a particular patient and family?

3. Articulation of the nurse's practical concerns related to care of the brain-injured patient identified as a potential organ donor. How are these concerns expressed in practice and do nurses have concerns they are not able to express?

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Data Collection

In order to capture the everyday concerns and involvement of nurses caring for brain-injured patients and their families, it is best to obtain full narratives about particular episodes of care (Benner, 1994; Benner, Tanner & Chesla, 1996). Nurses come to the situation with an understanding already in place; getting them to re-engage through story-telling is the best way to get at this understanding without being in the situation. Narrative is as close to ready-to-hand understanding, or absorbed coping, as it is possible to get without observation (Benner, Tanner, & Chesla, 1996). Field observations of nurses actually engaged in caring for brain-injured patients identified as potential organ

donors further enrich the data and bring out activities and concerns that are so much in the background for the informants that they might not be mentioned in an interview (Benner, 1994; Benner, Tanner, & Chesla, 1996). Being in the situation with the nurse, hearing her or his concerns as they come up in a changing context provides the best data on ready-to-hand experience.

Data Sources

Based on these understandings of interpretive research the present study relied on three sources of data: 1). interviews with ICU nurses and transplant coordinators, 2). observations of ICU nurses and transplant coordinators engaged in caring for a patient identified as a potential organ donor, and 3). a background information form (appendix A).

Research Settings

Interviews were conducted with nurses from two ICUs in two different hospitals. Site one is a county hospital that serves as a trauma center for its geographical area. Site two is a private hospital about 30 miles from site one that also serves as a regional trauma center. Both ICUs are general ICUs serving medical, surgical and trauma patients. Interviews were also conducted with transplant coordinators from one organ procurement organization. Observation data concerning transplant coordinators were collected at four different hospitals covering a fairly wide geographical area. The transplant coordinators work for an organ procurement organization that serves a section of its home State and are required to attend potential donors in the ICU in which they are identified.

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Participants

A total of nine ICU nurses participated in interviews. Of these, two nurses participated in observations and six completed background questionnaires. The six who completed background questionnaires were all from site two. The nurses from site one did not complete background questionnaires and information on their background was taken from the interviews. A total of three transplant coordinators participated in interviews; two of these also participated in observation. All three completed background questionnaires.

The transplant coordinators in this sample were Caucasian women with an average age of 37 years and an average of 14.7 years of nursing practice. Two held associate of arts in nursing as their highest educational degree; one had a Bachelor of Arts in nursing. All three claimed no particular religious affiliation. Areas of nursing practice experience included medical/surgical floor, critical care, oncology, pediatrics and administration. They rated themselves as satisfied to very satisfied with their current job as transplant coordinator and rated their work environment as very comfortable although one participant did not answer the question about work environment. All the transplant coordinator participants had cared for too many donors to count; they could not estimate numbers.

The background information on the ICU nurses from site one was taken from their interviews since they did not complete the background questionnaire. Information on ethnic background, religious affiliation and the number of donors they have cared for is unavailable on these participants. These three nurses were all men with an average age of 35.5 years, the age of one participant being unknown. They had an average of 12.3 years

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of nursing practice experience in pediatrics, neonatal, psych, emergency room, neurology, post anesthesia care unit and ICU with an average of 5.5 years in their current job in the ICU. One held a diploma, one and Bachelor's degree in nursing; the nursing degree of one participant was unknown.

The ICU nurses at site two were either Caucasian of Western European descent (n =4) or Filipino or Filipino-American (n=2) women with an average age of 45.3 years and an average of 23.3 years of nursing practice. Two held diplomas in nursing, one an associate degree and three had Bachelor's degrees in nursing as their highest educational degree. They claimed Catholic (n=2), Christian (n=1) and Methodist (n=1) as religious affiliations; there was one atheist. Four were not active in their religion while two were somewhat active to active. Areas of nursing practice experience included medical/surgical floor, oncology, dialysis, post-anesthesia care unit and critical care. Four participants rated themselves as very satisfied with their current job and their work environment as ver comfortable; two rated themselves as satisfied with their current job and their work environment as comfortable. Four had cared for more than 20 donors; two had cared for 10-15 donors.

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Institutional Approval

This study was approved by the University of California, San Francisco Committee for Human Research. Informed consent was obtained for interviews and observations from all nurse and transplant coordinator participants (see appendix B).

Entre and Sample Selection

To gain entre to site two, I first contacted the nurse manager who introduced me to the staff. I then presented my project to individual nurses on all three shifts and within

a week I had more than six volunteers. I chose my sample to represent as much variety of experience and ethnicity as was available in this somewhat homogeneous ICU. Entre to site one was conducted in much the same way. There was, however, a much slower response. As I began to finish data collection at site two and as I began interpretation on those interviews, I found I had very rich data and decided to rely on the three interviews with the site one nurses from a pilot study I had done the previous year.

I gained entre to the transplant coordinators' practice through the regional director of the organ procurement organization who then spread the word about the project. After obtaining approval and support from the OPO regional director, I also made direct contact with individual transplant coordinators while I was doing observations with ICU nurses at site 2 and while I was working as a staff nurse in another ICU.

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Procedures

From ICU site 1, three nurses were interviewed once each following interview guide A (see appendix C). From ICU site 2, five nurses were interviewed twice each using interview guide B (see appendix D) for the first interview; follow-up questions generated after reading a transcript of the first interview guided the second interview. One nurse from ICU site 2 was interviewed once using interview guide B. One transplant coordinator was interviewed three times, and another transplant coordinator was interviewed twice using interview guide B for the first interview and basing the follow-up interviews on questions that arose from interpretation of the first. One transplant coordinator was interviewed once using interview guide B, and declined to participate in any further interviews. All interviews were conducted individually and in private. Each

one took 60 - 90 minutes and was begun by eliciting a narrative and then guided by that and subsequent stories.

Two ICU nurses were observed once each for 2.5 hours for a total of 5 hours. Two transplant coordinators were observed twice each. The first one for 4.5 hours, and again for 8 hours. The second one for 8 hours and again for 4.5 hours. The total time spent in observations was 30 hours. The observations took place in the ICUs of four different hospitals including sites one and two. I arranged for the ICU nurse participants to page me whenever a patient they were assigned to care for was identified as a potential organ donor. I arranged with the transplant coordinators to page me when they were called to a site to evaluate a potential donor. This meant that the patient was severely brain injured but not necessarily brain dead, that the patient had been identified as having the potential to donate but was not yet a donor.

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Data Analysis

Interpretive phenomenology seeks to advance our understanding of world, self and other (Benner, 1994). The purpose of a phenomenologic approach to research is to answer experiential questions and to present the voice of the participants; not a privatized, subjective understanding, but rather, "...an embodiment and lived understanding of a world and set of local clearings created by social groups, practices, skills, history, and situated events" (Benner, 1994, p. 101). Interpretation of interview and field observation data is directed toward articulating the participants' understanding. This understanding shows up by moving from exemplars or parts of the interview to whole paradigm cases that take into account complete episodes from practice related to particular patients. Also important to this research was moving from the nurses' reflection on her or his practice

accessed through ideological interview questions to the practice itself accessed through field observation and narrative interviews.

Paradigm cases are whole, self-contained examples of how the nurse takes up her or his practice in relation to a patient identified as a potential organ donor (Benner, 1994). They are whole stories that stand out in the interview as cases where particular concerns are strongly evident (Benner, 1994; Benner, Tanner & Chesla, 1996). Paradigm cases help the researcher to get closer to the participant's everyday understanding and lived experience and offer the possibility of articulating the nurse's understanding, concerns, practical knowledge and reasoning in a new way (Benner, Tanner & Chesla, 1996). A close reading of a whole paradigm case can reveal questions and contradictions that the interpreter may or may not be able to reconcile with the rest of the interview, subsequent interviews, or field observations. These contradictions and puzzles come out of the contextual experience of nursing where no one ever has all the information and where not every question can be answered (Benner, 1994). The researcher is not looking for a greater truth behind the text that can explain away all questions, but rather seeks to allow practices and meanings to show up in their own terms, as ways of being and knowing in their own right (Benner, 1994). The practical meanings that show up in paradigm cases reflect the meanings common to the practice, the shared meanings of the culture of nursing.

Exemplars are parts of the text extracted to demonstrate the nurses' intents and concerns within a particular context (Benner, 1994). In contrast to paradigm cases, exemplars are taken from many different narratives in order to provide context-bound, multifaceted and nuanced demonstrations of particular modes of engagement in nursing

practice. Keeping track of exemplars helps the researcher make qualitative distinctions and develop an understanding of the nurses' different modes of engagement. Particular exemplars can then be used to illustrate the nurses' concerns, intents and ways of engaging, and can demonstrate similarities and contrasts in patterns of meaning (Benner, 1994).

The following strategies were used in interpretive analysis:

1. I read the whole interview or observation for general themes, keeping in mind the interview questions and the lines of inquiry. In this thematic read I looked for meaningful patterns and concerns in the narrative and reflective aspects of the interview, and in the nurses' actions, concerns, and interactions in field observations (Benner, 1994).

2. New questions that developed as the analysis progressed were incorporated into the follow-up interview(s) and/or observations for clarification.

3. I undertook a deeper analysis of the whole text in discussion with my research advisor and other students in an interpretive research group. This allowed paradigm cases and exemplars to emerge from the narrative.

4. Analytic movement from parts of the narrative (exemplars) to the whole interview, and from one exemplar to others allowed a picture of the whole practice as it is lived to emerge.

5. I read the nurses' reflection on practice and stories from practice in order to articulate how these themes interact and what part each plays in the other's development.

Evaluation

Because it is not based in the rational, empirical correspondence theory of truth, evaluating an interpretive account cannot be done according to validity and reliability

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criteria. The interpretive scientist cannot attain a level of certainty that is beyond the circle of interpretation, the hermeneutic circle. All human meaning or understanding must always refer to some other meaning or understanding and the interpretive scientist can only offer interpretations of interpretations (Taylor, 1985). This means that interpretive inquiry must be evaluated in terms different from those of foundational science. Evaluation of an interpretive account is based on its adequacy in clearing up the questions that prompted the inquiry. An adequate interpretive account will have internal coherence and will ring true for those who live in the practice (Packer & Addison, 1989b). This type of evaluation depends on a certain level of insight and is unformalizable; that is, it is not based on an external reality but depends ultimately on common experience and shared truth (Taylor, 1985).

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Chapter 4

Making the Transition from Care and Treatment of the Brain-injured Patient to Maintenance of the Organ Donor

Identifying the Potential Donor

The Ambiguity of Prognosis

Predicting outcome after brain injury is fraught with uncertainty. The difficulties nurses encounter when caring for critically ill brain injured patients is compounded by the unpredictable nature of the brain's response to injury and the less than optimal classification systems used for this population (Thibault, 1997). The Glasgow coma scale, and the Hunt-Hess and Fisher grading systems for subarachnoid hemorrhage are somewhat helpful in predicting functional recovery but not as helpful in judging whether any given patient will live or die. When organ donation is involved even predicting death is not good enough. In order to donate organs, the patient must be declared dead based on brain criteria. So while it may be possible to judge based on grading systems which patients will not wake up or not be able to return to a meaningful life, it is nearly impossible to know which ones will go on to become brain dead.

The difficulties in predicting which patients will progress to brain death are highlighted by the possibility of organ donation. Nurses report always having organ donation in mind as soon as a severely brain injured patient presents to the ER or ICU unresponsive or exhibiting reflex responses like decorticate posturing. Organ donation becomes a possibility when the patient's injury is bad enough that the nurse thinks he may not survive. But predicting which patients may not survive takes many forms and there seems to be no consensus among nurses even as to where to look; does prognosis

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show up in the CT scan, in the clinical examination, in the mechanism and severity of injury or in a combination of all of these sources? Some nurses are willing to give up on the patient who exhibits certain clinical signs. Others judge a patient's condition hopeless based on information from CT scans. Some nurses refuse to judge prognosis at all, preferring to wait until the patient becomes brain dead to initiate the organ donation process. The variety of predictive techniques and the unevenness in reliance on prediction shows up the ambiguity of prognosis in brain injury.

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LD: So from the first day, did you get the sense that he would die? Or did you have a sense that he might come through it?

2E: I didn't really know. I mean, you know, he was very stable. I thought if he, if he survived it would be a very long haul and probably there wouldn't be a lot, um, of high function left. But I've seen so many people that come in like that that walk out that I don't make those judgements. I just go day by day. Like I tell the families, you have to go day by day. You know, a CAT scan is useful, but it's not the be all end all. And I just assume that people have a chance of waking up until they prove me wrong. (2e1.int, 6, 228-236)

2E: [pause] I tend to be a little more optimistic, I think, than other people, because I've seen a lot of people wake up when I was told they wouldn't. And the reverse is true also, you know, people come in and look fine and herniate on you in an hour. So, you just can't predict, you just have to give it time.

LD: So by the third day, did you have any other sense?

2E: No, actually I thought he was doing a little better 'cause he was starting to move, seizures were now, um controlled, he wasn't having seizures, and he was, you know, posturing a little more which is better than not posturing at all, um. I still didn't have a feeling that he was aware at all. And third day is minimal day when you have this kind of injury.

LD: So the third day, you would wait at least three days, you mean.

2E: Oh, I'd wait longer than that. I'd probably wait a week before I decided that somebody was either gonna make it alive or make it dead. Because you just don't know, I mean things happen, you just can't explain. After a week, you get a feel that maybe they're not gonna wake up and do real well, but a lot of people we get here have brain stem injury and that takes a month, um. You get very little response for the first two weeks and then after 21 days and, and after that you start seeing more response and many of them actually do wake up. But if the brain stem is sheared or involved in any way with swelling or stroke, it just takes that long, you know. So I-I give people any kind of edge, I give them a month before I really know, if they're still there.

LD: And is this to, specific to trauma, or is it...?

2E: Yeah, pretty much to trauma because of the, the types of injuries that the brain stem can undergo in a trauma, the twisting, the shearing type injuries that cause a global edema and once that edema's there, if it's not enough to, to herniate a brain or block the circulation, it just takes that long for that brain stem to recoup and start coming... And usually after two or three weeks either people are donors or they're not. I mean they're either totally comatose and coming around or they're not coming around, they're not doing well and they've plateaued. Usually the brain stem, a couple weeks, three weeks, you start seeing small changes occur. They don't continue to deteriorate. [pause] (2e1.int, 7-8, 253-283)

2E: To the fact that we really don't know when anybody comes in what their outcome's gonna be. So I don't want to make an assumption that they're gonna die and miss something in case they don't. You know, you want to make sure you don't get contractions in the feet so that if they should survive they can still walk, you know. You focus ahead.

LD: And how did these goals change over time as you worked with him.

2E: Well, after about three days, it became obvious that he probably was not going to return to full function, but it was still not clear whether or not he would survive because I only had him that first segment, um, and he was not brain dead at that time. And it was those first three to four days when the things get worse before they get better that I was directly involved in his care. After that period of time, I think I was working charge most of the time so I didn't really directly take care of him. And at that point, then your focus shifts a little bit to family support. You can see that things are not progressing. (2e2.int, 3, 76-89)

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LD: And now you said this, again just now in a different way, but, um, before you said that you assume that patients have a chance of waking up until they prove you wrong.

2E: Right. I have to go on that because that way I can do what I need to do without thinking it's futile.

LD: Um-hm, OK. So that sort of keeps you...

2E: It keeps me focused, keeps me focused and...directed, better directed in one direction at a time [laughs], OK, 'cause you can't do both ends of this at the same time, really. You always have in the back of your head, you don't want to damage this end of it, but, your focus has to be either treat or don't treat.

LD: OK.

2E: And until that becomes clear that you're not going to treat, I have to treat all the way.

LD: So what do you take as the proof?

2E: Um, I'm tough to prove it to. I, I tend to be more optimistic than many people. I do not rely on CAT scans. I do not rely on X-rays, but I do rely on, um, clinical changes. Three or four days down the road you should start seeing either stability or improvement and, especially after a week. And if things keep getting worse and worse and worse despite what you do, the odds get lower and lower and lower and lower, um. I don't take proof of being a donor until I see herniation. Because I've seen a lot of people just hang on and they never get brain dead. So until I see herniation I don't assume someone will be a donor for sure, and focus in that direction totally.

LD: [pause] So that point at which you give that last dose of mannitol,

2E: Or lasix, or whatever,

LD: that last treatment to preserve the brain, to try to reverse that pressure, um... and when you see that that doesn't work, you're in

2E: Then I switch modes.

LD: OK.

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> 2E: Then I start thinking this isn't working, this person's gonna code, um. I have to get an order from the physician [not] to code this patient even though they're brain dead. A lot of times the docs will tend to write no code orders at that point. And you have to remind them, you say, yeah, but we really want to resuscitate this person until we get a definite no as far as organ donation. Then that's usually when you call the donor network. And then, you know, they, they can stabilize 'em long enough, most of the time, to talk to families and get through that. (2E2.int; 4-6; 119-208)

The nurse in these examples, 2E, characterizes herself as optimistic. She claims to make no judgements about prognosis because she has been wrong in the past. She plays it safe by assuming every patient has the potential to recover until the patient proves her wrong. As time goes on, if the patient's neurologic condition does not improve, his odds drop. Odds of what she does not specify. Does she mean the odds of him recovering or the odds of him surviving? In reference to organ donation, she is more specific: she does not focus on organ donation until she has proof that the patient will become brain dead. The proof comes late; she does not predict the patient will die until the patient is dead. That is, she takes all the clinical manifestations of brain death described as herniation as proof that the patient will not survive. The certainty of her prediction is guaranteed since she does not predict death as the outcome but only recognizes it when it occurs. 2E believes there is nothing that can reverse the process of herniation once it starts but is willing to try mannitol one last time before making the transition from caring for the brain injured patient to maintaining the organs. She does not call the procurement organization (OPO, or donor network) until the patient is brain dead and about to cardiac arrest (code).

There are problems associated with 2E's approach. She recognizes a patient's worsening neurologic condition over time as indicative of poor odds, but does not seem

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to make the connection to organ donation until very late. Instead of instituting measures to promote organ perfusion when she sees the patient continue to deteriorate, she waits until the point of brainstem herniation, a point of relative instability when the heart rate and blood pressure are in extreme fluctuation. By not making any predictions about the patient's outcome she risks being caught unprepared for the instability associated with brain death. 2E's approach does not mean she does not think about the possibility of organ donation. At another point in the interview she says she thinks of it, has it in the back of her mind for every severely brain injured patient that comes into the ICU. But she realizes that she cannot both treat and care for the brain injured patient and preserve the organs for donation. So she waits for a clear point of demarcation, brain death, to tell her when to make the transition.

> 2A: Well, basically I knew that this surgeon wasn't going to'to treat him. And I kept wondering if it was because he was being so conservative'or just him, him being an older kind of surgeon compared to maybe somebody who was younger. But I thought this, this particular surgeon was very conservative in approaching somebody who's, who was, um, who had that aneurysm. But the fact that he started posturing and he just deteriorated, then'I know that there was really nothing we can do in terms of treating him, or actually reversing the process where there ac, I mean, he is basically progressing to being brain dead. And, when I think about it, there's really'nothing, I mean'when we're treating patients who are, who are organ don, or who are potential organ donors, and we're trying to basically resuscitate them and brain-resuscitate them by giving them all this mannitol or, wh, when we were hyperventilate, lating them before. And they would improve a little bit, but then you <u>know</u> that they're just getting worse and they're starting to, you know, become less responsive, they're, they're starting to lose their reflexes. Then, they're basically saying, well, at least <u>I</u> feel, that, you know, you're, you have to start treating them more like a potential donor and think about them as that than as a patient that you're trying to save and who will, somebody who will survive this insult. Because, I think at a certain point, you know, despite what we do'you know, nature will take its course. And I think there's only so much that, that medicine can do. And'I really think sometimes we're over'I mean, we, we give families or patients'a lot more aggressive treatment than, you know, if we would have, I mean if they were maybe in a

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different country? I mean, sometimes I think we're just too aggressive. Yeah, I think...I just think that there's, there's really a point where we are over-treating patients. But when somebody who comes in as a, a really severe head injury, then, you just have, I just have an inkling that, you know, most of us do, I mean you have that inkling that you know that they're going to just progress to being an organ donor, and, you know, I think the mentality becomes different' I think sometimes' people are, well, not, not people, but, you know, families are very hope...I mean, you, they keep saying, well, give, give them hope, you know, that's the best thing you can do for families. But then, in some ways, I think it's very unrealistic to give them hope that somebody who's really suffered a severe injury like that would, would survive. So, I tend to be a little bit more, I think, pessimistic in terms of like, when I tell families that, you know, they're, they're not doing well, then I basically go through, you know, reiterating that they're not doing well. So, I mean, some nurses tend to be a little bit more optimistic and it makes me kind of angry (laughs) you know, because it's, it's unrealistic, it's, sometimes it's really unrealistic to say, oh, he's going to do well, you know, but you know that he's not. So, I think as a care-giver, you want to, and you do what you can when you've got somebody who's, you know, who you know will improve, but for somebody who won't improve, then I think you have to just be factual about it. (2a1.int; 4-5; 142-182)

LD: Um-hm. 'You said something about being in a gray area.

2A: Um-hm.

LD: Can you talk any more about that?

2A: Well, this is the point when they're still barely alive. They still have reflexes, they still have a blood pressure and they haven't been declared brain dead yet. So the doc, we're still relying on the doctors to give us treatment and most of the time, you know, they, well now we have that, um, standard, standing order for severe brain injured patients, but, before, I re...I mean, when they're in this gray area, and certain doctors are not 'very good about it. You want fluids, you want, you know, when they're in DI [diabetes insipidus] they start putting out a lot of urine, you want to treat all this with certain medications or fluids and here they are, there's nothing I can do, they're telling me. And at the same time we're, we're calling the donor network who's telling us, well, treat, treat it aggressively, we need more, to give him fluids, we need to give them, you know, increase their rate, or, incr...when they're, you know, they're ventilator, I mean, put them on 100 percent. And, you know, they're not really in the picture yet, I mean, but they know that in order to maintain perfusion they, you still have to treat them at that, at that point before they're actually declared brain dead by the two, you know, two doctors. I mean, they can, the, the donor network becomes basically

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suggests treatment before they've been declared, but then the doctors are still, you know, the ones giving the orders. But, that, that's basically that, that point before the network actually when, when they start saying, OK, you know, we're taking over, they're brain dead, we can do anything now, I mean we've got all these orders, but then, you know, that's where you ha...it's before that that you have to start treating them a lot more aggressively. And that's just, that's the frustrating part for, for me.

LD: Treating them more aggressively...

2A: In terms of, you know, resuscitation for their or...organ resuscitation, I'm talking about organ resuscitation. You know, maintaining kidney perfusion and it's, it's that point that we're basically treating them. Because sometime I think that once the doctors know then they ba...basically say well, there's nothing I can do now. Sometimes they're even hard to get a hold of, you know, some of them are hard to get a hold of because they're, you keep calling them, they ask for, you know, certain treatments and they're, they're saying, well, there's...

LD: What treatments would you be asking for.

2A: Fluids, fluids, sometimes when they're in DI, ddavp [desmopressin, antidiuretic hormone]. Uh, they're, you know, they're um, I think sometimes, usually we don't order labs yet. But their FIO2 is low, they're set at a lower FIO2 and you still don't put them on 100 percent. But basically fluids. I think that's, that's our biggest, I mean that's what, I mean sometimes we even treat them before the doctors say OK, you can....but, you know, usually to back, back you up as a, a nurse, as an RN, I mean, sometimes I think we do things more aggressively than what the doctors would say, you know, treat this, kind of situation. I mean we start running the fluids a little bit faster than...

LD: And what's your expectation for the outcome in that kind of a case?

2A: Basically what I, I expect the doctors to give up and have the donor network take over. (2a1.int; 7-8; 277-321)

2A: So...usually when they start, when they come in posturing with a severe head injury. And then, the one that stands out the most when I remember somebody, you know, becoming a donor, is when they start to, their heart rate starts to go up, you know, and their blood pressure's going up. And then, we're at this gray area where, you know, you can't, you're calling the doctor, and the doctor said well, there's really nothing I can do, and you're also calling the organ donor network and saying, we have this donor and they're starting to say, well, you know, can you try and get orders for this and that, and... That's the, I guess the hardest part

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> when, just before they're actually declared a donor ready. I mean we've got just that, that area between somebody who's basically, you know, getting close to being brain dead and somebody who, who's not quite brain dead. I mean, that's when you know that you really need to get the organ, I mean the, the donor nurse, the transplant nurse to come in and maybe identify, I mean, at least make the call telling them, well, I've got a potential donor. And tell them that, then they start asking you questions. And then based on that, then they basically come, decide to come in, or wait a little bit longer. But most of the time, they're pretty good about coming in. (2A1.int; 3; 93-109)

The nurse in these examples, 2A, shows a tenancy towards pessimism. She starts off talking about a particular patient who deteriorated after subarachnoid hemorrhage and did go on to become brain dead, but quickly begins to talk in general terms about all severely brain injured patients. It is easy for her to predict when a patient will die. The prognosis becomes evident through clinical examination; the patient deteriorates, begins to lose his reflexes and becomes less and less responsive. At the point when this downward trajectory becomes evident, it is hopeless to treat the brain injury even though she may go through the motions of giving mannitol. At this point it is evident that the patient is on his way to brain death and ought to be treated as an organ donor. She seems quick to judge a patient's condition hopeless and finds it unconscionable to be anything but honest with the patient's family when she believes the patient will die. But the clinical examination she is waiting for before judging the patient's condition hopeless is quite specific: the patient becomes progressively less responsive and loses his reflexes. In the second section she adds to this the development of DI or diabetes insipidus. This is a simple description of what happens in brain stem herniation progressing to brain death. The cranial nerves in the brain stem produce reflexes like pupil constriction, corneal and occulocephalic responses that are progressively lost with the brain compression that happens during herniation. With the lack of perfusion produced by brain swelling and

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compression, the pituitary gland become incapable of producing regulatory hormones, the most obvious being antidiuretic hormone. So her description is one of a severely brain injured patient who is actually dying. Her estimation of the hopelessness of the situation may be less accurate. Brain stem herniation can be reversed by diuretics like mannitol, hyperventilation, sedation, CSF drainage, and, possibly hypothermia. But, by the time DI shows up, in combination with the lack of responsiveness and absence of reflexes, the patient is probably in fact brain dead.

In the second section she points to the importance of outcome prediction when she talks about a gray area before brain death when the patient is in her judgement clearly dying. At this point she wants to give up treating the brain injury and begin to treat the patient as an organ donor by increasing IV fluids, increasing oxygen delivery and turning over treatment decisions to the organ procurement organization. Although the patient is not brain dead in the gray area, 2A is certain he will become brain dead shortly. She is so certain that she will institute measures to ensure organ perfusion, begin what she calls organ resuscitation, without considering what effect it may have on the brain. Based on the certainty of her prediction, 2A makes the transition from treating the brain injured patient to maintaining the organs. She expresses frustration at the fact that the physician in charge of treatment has not made this transition when he tells her there is nothing more he can do. She agrees that there is nothing to be done for the brain injury but at the same time recognizes that it is time to institute measures to protect the organs and preserve the possibility of donation.

2E tells a similar story about herniation and the short time between severe brain injury and brain death which she describes as a 'fine grey line.'

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LD: OK. What does herniation look like?

2E: What does it look like?

LD: Yeah.

2E: Um, you get a sudden change in heart rate, usually a extremely fast, um, your pupils change and you'll, you will get a dilation of one and then your blood pressure shifts way high and then bottoms out. It's just classic, the, the triad happens. Your systolics and diastolics both go up then the diastolic drops. And once that diastolic drops then you can be pretty sure that systolic is not far behind. And when that drops down then you've got 'em on pressors, you've got 'em on dopamine and usually by then you've lost cough, gag, you've lost your reflexes, they're no longer triggering the ventilator, pupils have changed. That's pretty specific, that's it. That's brain death, basically, then all you're doing is waiting for calorics or apnea test. But y-, you pretty much know you're not gonna get anything [laughs], after that. It, it always just seems to have that pattern, that herniation.

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LD: Is there any treatment that you implement during herniation that can reverse it?

2E: I haven't seen it. I mean, you can, you can treat up to that point, you can c-, try and keep ahead, you can see pupillary changes, um, you can get an irregular pupil in one eye, you get less response, they have less, um, posturing or they have more posturing as the swelling goes up depending on what little part of the brain's getting messed with at the time. And you can give mannitol and give lasix and you can cut back on fluids, you can treat temperatures, you can do the best you can to keep that swelling down. But once you see those signs, those, tachycardia of a hundred and sixty, and no blood pressure and they're on the dopamine, you, there's really not much you can do. The mannitol, even if you give it at that point, they're so far on the edge that it's not usually gonna do anything. Generally you go ahead and try it.

LD: Um-hm. So you do go ahead and try it at that point?
2E: Yeah, yeah. I mean you're not gonna hurt anything, 'cause the measures that you use for that are not harmful. They're either gonna work or they're not gonna work.

LD: They're not harmful.

2E: Well, that, the patient right at that point is so near dead, it's like, a real fine, grey line. So whatever you do, if it's gonna work, it's gonna work and it's gonna work quickly. Otherwise it's not gonna work. You sort of don't think it's gonna work even when you do it, but you're trying. You know that they've already had

the mannitol, they've already had the lasix, you know, they've already had all these things before they got to that point because they'd had signs of swelling. But they got to that point anyway. So you may give one more dose of mannitol, you know what I mean, or at that point, if you have an ICP line in, generally the doc'll finally say, well, pull it out, or we can't treat it anymore. You can watch it but there's nothing more you can do. You can only give mannitol so many times and it'll rebound on you. So if you've been giving it all along and it's, obviously it's starting to not work any more, there's just not much more you can do. [pause] When you get to that point and it doesn't work, then you shift your focus to preserving organs. Which means at this point you stop watching fluid intake, you want to get 'em off the pressors, you don't have a brain to protect any more, and you push the fluids, you get the blood pressure up with fluids, and try and bring the dopamine down, you give the hespan, you give volume, that you don't give prior to that point because you're trying to control edema. But now you've already gotten edema you can't control. And what you've done to control it isn't working. So you now no longer have a blood pressure, you can't circulate a brain with no blood pressure, so you treat the blood pressure, then, and, go with that.

In the next excerpt, another ICU nurse points to a similar gray area.

2D: A, a, a severe injury or gunshot wound to the head and they're, they're herniating before your eyes. And you know, you know it's coming and, um, you're gonna have to start supporting them. Well we do that catastrophic head injuries orders at [this hospital]. You heard about those? You know, it is basically to, they're not quite brain dead, but it's to support them with standing orders which the doctors can just sign, with IV fluids, urine outputs, um, dopamine, just to support them in that interim phase before...

LD: Interim phase.

2D: The interim phase of not quite being brain [laughs], not being brain dead, but their systems are, you know, when they've herniated and their blood pressure is 60 over 40 and you have a, you know, we don't know about organ donation and so it's really kind of a, a good, a good thing that we have that we can just call 'em and say, you know, we're gonna just start the catastrophic head injury, and they'll say yeah and they'll sign it. And uh, standing orders at [this hospital].

LD: Ah, so it's called the catastrophic..

2D: Catastrophic head injury. And, um, and that's when things, you know, y-, go, can start going very fast and you just need to, um, you feel, at least, you know, we feel that t-, I feel that time is of the essence then, um. I, technically we could wait, I guess, until, but, technically we could wait, yeah, we could technically wait and see if the dopamine works and all that, yeah we could, yeah. Um, but usually, you know, when we get a patient in like that, into the ICU, the donor

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> network is called immediately and say we have a potential organ donor. So they know early, as early on as the patient rolls in the door, pretty much, that we have a potential organ donor.

2E, 2A and 2D all identify a point at which they make a transition from treating brain injury to maintaining organs. This point is connected to the patient's prognosis. In severely brain injured patients, prognosis and prediction of outcome take on new significance when there is a potential to donate organs. Because of the hemodynamic and fluid balance disturbances that accompany brain death, the ICU nurse must make the transition quickly. If the nurse only recognizes the patient as dying but overlooks the possibility of organ donation, she has no motivation to resuscitate the patient. This means she takes the physician described in 2A's example at his word: there is nothing more to be done. At the point of brain death, treating the brain injury becomes futile. If the nurses continue to focus their concerns only on brain injury, the patient will die in such a way as to preclude organ donation; the patient will sustain a cardiac arrest or code, as 2E points out, and, because the patient is brain dead, there will be no purpose to instituting resuscitative efforts. But as 2E also points out, she wants to resuscitate even a brain dead patient, when there is clearly no hope of brain recovery, in order to preserve the possibility of organ donation. She reminds the physician of this at the end of the excerpt. Similarly, 2A is frustrated when the physician claims there is nothing more he can do for the patient because he fails to realize the potential for organ donation when she has already made the transition that has shifted her concerns from treating brain injury to preserving organs.

BRAIN

This motivation to preserve the organs in the brain dead patient is balanced against the ambiguity of prognosis in the brain injured patient. 2E does not want to make the transition to donor care prematurely. She keeps the possibility of donation in mind while talking a lot about her inability to predict the patient's likely final outcome. She cannot treat the brain injury and at the same time protect the other organs so, as long as the patient is alive, she chooses to treat the brain injury. 2A describes a similar position but from an opposite perspective when she talks about the gray area. She does not want to wait too long to make the transition to treating the patient as an organ donor and actually advocates switching modes before the patient is dead. 2A gives up hope sooner than 2E and calls in the OPO earlier, before the patient dies, and asks for recommendations on how to manage the dying patient. While 2A says she wants to aggressively resuscitate the organs before brain death, when the patient still has a blood pressure, reflexes and is barely alive, she does not make her case to the physician and must work with the fact that the OPO will not take over treatment until after the patient dies.

The nurses are able to recognize signs of herniation and impending brain death on clinical examination. The heart rate and blood pressure rise then suddenly fall, and the patient begins to put out liters of urine. This makes brain death a logical point of transition. Before this point, the nurses are hesitant to make any firm judgements about the possibility of organ donation although 2A is more secure in her earlier prediction of the final outcome. When the patient herniates and becomes brain dead, the nurses push the physician, upon whom they rely for treatment orders, to take up the organ donation project. 2E preserves the possibility of organ donation by reminding the physician to

stabilize the patient after brain death and even to treat cardiac arrest (not to let the patient code, or not to write do not attempt to resuscitate orders) until the family makes a decision about organ donation. 2D implements standing orders for treatment of catastrophic head injury which are focused on preserving organs rather than on treating brain injury.

The Danger of Errors in Prognosis

When caring for a severely brain injured patient, there is always the chance of getting the prognosis wrong, as 2E points out. Yet prognosis plays a major role in identifying a patient as a potential organ donor and in prompting the nurse to make the transition to donor care. The potential organ donor must be severely brain injured and show signs of deterioration. An incorrect prognosis means a patient may be misidentified as a potential donor or misidentified as having the potential to survive and/or recover. The real danger in getting the prognosis wrong and identifying a patient who will recover as an organ donor is in how that identification plays out in the care and treatment of the patient.

The transition from care of the brain injured patient to maintenance of the brain dead organ donor is a philosophically heavy transition considering the deontological background to Western biomedical ethics. Once the nurse begins treating a patient as an actual organ donor she stops treating him as an end in himself and begins treating the body as a means to another end. Kant's (Kant/Paton, 1956) categorical imperative, the grounding for deontological ethics, forbids treating persons as mere means. In this theory of ethics persons must always be treated as ends in themselves and never as a means to

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another end. For example, Kantian ethics forbids taking organs from a living person even though to do so may save the lives of three or four others.

To avoid the mistake of treating a person as a means to another end, 2E keeps donation in the back of her mind while fully treating the brain injury and caring for the person. She does not make the transition until the patient is dead, that is, no longer a person. In contrast, 2A thinks the OPO ought to take over treatment when the patient's prognosis is poor enough that death, although it has not arrived yet, is certain to arrive shortly. The danger in this approach is not just the chance for error in the prognosis, but also in violating the categorical imperative by treating the body as a means to another end when the person is not yet gone. When notified of a potential donor, the OPO sends out a transplant coordinator to review the case and, if the patient is brain dead, to take over maintenance of the body.

The transplant coordinator is fully qualified in donor maintenance. He or she knows how to sustain a brain dead body for the hours it takes to get it to the OR for harvesting. The transplant coordinator is not qualified to treat or manage brain injury. As discussed in Chapter two, the treatments required to maintain a brain dead body are sometimes in conflict with the treatments required to sustain a brain injured person. Treating the person as an organ donor is not in that person's interest, but only in the interest of the potential organ recipient. The OPO avoids conflict with Kant's ethical standard by not getting involved in treatment until the patient is dead. While they want to be notified early of an impending death, they will not take over treatment of the body until it is dead. The OPO's policy, along with the physician's refusal to prescribe

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treatments that may conflict with care of the brain injured patient, check 2A's inclination to make the transition to donor care prematurely.

2A's inclination to implement organ resucitation measures when the patient is still alive highlights the difficulties in balancing care of the brain injured patient with the institutional and government mandate to salvage transplantable organs. While the moral danger in beginning organ resucitation too soon is evident, there is a physiologic danger in waiting too long. Patients sometimes become unstable during and after brainstem herniation, and if the official declaration of brain death is delayed, the nurse may be at a loss as to what treatments to implement as the patient deteriorates into cardiac arrest and the patient's life as well as the organs are lost. 2E alludes to this scenario in her description of brain death, the point at which she begins to implement organ resucitaiton strategies. Because she is able to recognize impending brain death and take the initiative in beginning organ resucitation at that point, 2E avoids the morally questionable practice of treating the body as a donor before the patient is dead. In the scene she describes she also avoids the physiologic problems associated with waiting too long. In the best possible world, organ donation would always go this smoothly.

Making the Transition: Balancing Ethics and Physiology

Unfortunately, the transition from brain injured patient to brain dead organ donor is not always as smooth and easy to recognize as 2E presents it. Sometimes brain death arrives in stages that are easily mistaken for evolving brain injury in need of further treatment. Even 2E cannot clearly distinguish or offer a decision rule for when it is time to forgo one more dose of mannitol. The signs of brain death are clear in retrospect but

may be less identifiable in the middle of providing care to a brain injured patient. This is illustrated in the following excerpt from another interview with 2A:

> 2A: Uh-huh, you do. Basically, you know, you start, um, she was on Nipride, but I kept increasing and increasing it and, and her pressure bottomed out. Then, you know, it was time for dopamine, it's like, dawned on me. It's like oh, she's gone, you know. It's like, and then, it took another nurse to come in and just remind me, you know. It's like oh, she is gone, you know. But here you are trying to basically keep increasing the dopamine and all, then she dropped and, oh, gosh, you know, she's, she's gone. (2A2.int; 5; 179-185)

2A's surprise that the patient is gone shows the ambiguity of this space. While 2A is busy trying to save the patient's life, switching from nitroprusside (Nipride) to dopamine when the blood pressure drops, then increasing the dopamine to support the blood pressure, another nurse reminds her of the signs of death. It is not that 2A is unfamiliar with these signs: rising blood pressure that then crashes down to nothing are signs of brain death she pointed out in a previous interview. But in the context of scrambling to do the right thing to help the patient, 2A interprets these signs differently. This can happen to any nurse in this context. To minimize the risk of missing the signs, nurses often identify patients as potential organ donors early before they really get involved in caring for the patient.

> 2C: Right. So, um, like, there's one that stands out for me is the [name] was the name of the patient. It's a male that has been, um, brutally injured from some assault, um, you know, and, uh, he has so much injuries to his head like about, the. The CAT scan shows 32 fractures just to the skull alone. And it's amazing he's still alive. And so, Dr., I think, [name of doctor] didn't want to do any surgery because of the impact and all the bleed, that's scattered around the brain is not really a good thing to do a surgery. And the edema that this patient gonna go through.
>
> LD: The edema.

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2C: Yeah. So he didn't think the patient would survive. So the family, you can approach the family as soon as the patient hits the ICU, which I have to take over any way. I took the patient, I had the patient in trauma and followed through to ICU 'cause I was the first admit. So I kinda, you know, it's the shock to the whole family, but I got that patient for almost a week, and the patient survived actually.

LD: Wow!

2C: But the family agreed for donation if it even happen. But we have kinda have it implied as the time goes on. 'Cause the first three days we gave them 72 hours, if he doesn't wake up in three days, he's not gonna make it, you know. It kinda put it down the line 24 hours and that's it. But, going through the process of the grief from the family, the worst part is because there you are. Standing there, you can't do much, but just be supportive, do whatever you can. But for them to know that you're doing everything is a lot for them, even though they know the patient's not gonna pull through. But amazing enough, because of all those fractures, he has room all for the swelling, he didn't herniate at all. That's the reason why he survived [laughs]. I didn't know why, but the bleed was all small, but scattered all over. But we don't know then how the prognosis was because it's so much fractures, broken everywhere. Everywhere. So that's the, the, uh, emotional thing I kinda, you know, have so much involvement as far as my experience as trying to initiate it. (2C1.int; 1; 5-33)

2C: Yeah, I brought, yeah, and I brought the patient to CAT scan. 'Cause I thought we're gonna go straight to surgery 'cause he was, uh, he's full of blood in his head and, you know, just kinda have all these lots of cuts. And all I did is just kind of pack his head just to keep it from bleeding so much. We had to do CAT scan quick, so we went to CAT scan and Dr.[name] was with us. And he was looking at, you know all the film and I said after this are we going straight to surgery? [text deleted] But after, uh, hearing what the, uh, what the injuries were, well, there's no way he will be able to do it anyway. Even any miracle doctor cannot fix the whole thing up, you know, and still prevent swelling. So, I figure, well.

LD: And what had you done for him since then?

2C: Uh, he wants, he said there's, don't have to put the ventriculostomy because he's already oozing everywhere so, it doesn't really matter. He had, um, gee, we cannot get a pressure real good so the trauma surgeon, I pushed her to put a A-line, can't get much of a blood pressure, I said to her, put it in. [laughs] And it's a new trauma doctor that was on that night, she's kind of not comfortable yet, the

new one. She put one in, took her a while, but she put one in. It was a kind of hard work as far as, because you gotta be doing the care and pushing the doctors to do, do that. So I did is just, I did all I, you know, nursing-wise. Fluid, keep a pressure and, not enough, but not too much because of the brain too. We're, we're bi-, we're in between keeping pressure and not too much for the head. The position, not too much stimulus. What else can I do?

LD: Had, did anyone think about organ donation at that point in the trauma room?

2C: I did. I called the donor network as soon as we got here, actually, I have, um, [name], [name] was the charge nurse. So I said place a call to the donor and I'll talk to them. So as soon as the, we got here, got him settled, I spoke to the donor representative. And they kind of keep an eye on that one, that case. They keep on calling pretty much every shift.

LD: So what was his status like when you got him back here? What was he like, your exam of him?

2C: Well, he's totally comatose. He's not responsive, um, let's see, that was like, he moves his, one of his legs, that's it. And the other one he doesn't. So he was like, we don't know how bad the injuries were, you know, as far as motor whatever is involvement. It's too much to really see for the first eight hours. That's why they said we just have to see and wait, Dr. [name] was saying.

LD: He said you just have to wait and see?
2C: Just, you know, at what, what's gonna happen. 'Cause sometimes his pupils will dilate, sometimes they will react. So it's not consistent, the, that's why it's hard to move him or do anything with him.

LD: So you're implementing treatments for his brain injury.

2C: Right.

LD: But you, you also thought about organ donation?

2C: Oh, yes. Immediately, because the picture was like, I, I didn't think the patient was gonna survive. Anybody say, no way anybody can survive that. I mean, that's why I even suggested, we're, we're still in CAT scan I said to Dr. [name], I'm gonna call, uh, donor. Oh, OK. Go for it. So, and he came out. He is in a rehab now. (2C1.int; 6-8;227-300)

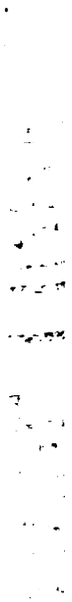
2C's story illustrates the risk in identifying a patient as an organ donor too early. Yet her mistake seems to have done little harm. Based on the patient's condition, CT

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scan and on the trauma surgeon's response, 2C identifies the patient as a potential organ donor in the trauma room, her first contact with him. She notifies the OPO as soon as the patient is settled in the ICU, and discusses the patient's poor prognosis with the family. The family agrees that if the patient dies, they do want to donate. But even though 2C has identified the potential for organ donation and opened this possibility to the family, she continues to treat the patient as a brain injured person, not as a brain dead donor. She talks about managing fluids to give him enough but not too much, keeping the environment quiet, and taking time to wait and see how he progresses, all measures to protect and monitor the brain. Unlike 2E, 2C can do both sides at once; she is surprised that the patient recovered but not disappointed because she has made only a tentative commitment to organ donation. 2C's approach also differs from 2A in that she does nothing that risks inducing brain death; she stays clear on the fact that the patient is still alive and in need of life-saving treatment and does not push for the OPO to take over treatment.

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2C balances caring for the patient as a person and an end in himself with preparation for the physiologic instability that can accompany brain death. Since she has the family's consent for organ donation before brain death, she will be clear on what to do when she sees the signs of impending herniation: resucitation will not be controversial in light of the family's desire to donate. Or, if the family had declined donation, 2C would know to withhold resucitation at the point of brain death, when nothing more could be done to save the patient's life. In contrast, 2E resucitates the brain dead patient, when the patient is beyond saving, without knowing the family's or the patient's wishes.



Brain Death

Signs of Brain Death

When a brain injured patient presents with certain signs, the ICU nurse recognizes the closeness of brain death. As discussed in the previous section, the signs are similar in each nurse's story. Progressive loss of reflexes followed by increased blood pressure and pulse rate followed by a rapid decline in both are signs many nurses point to as indicating impending brain death. It is at this point that the patient's prognosis becomes certain. Because these nurses all work in a trauma center where brain injury and brain death are familiar, they all know the signs.

> 2B: Anyway, back to, back to this patient, um, so fam, so he herniated at about, I think at about four o'clock in the morning, blood pressure went up to, you know, 200's over 100's and his heart rate went 180's and pupils blew, um, totally areflexic at that time. Um, and I don't think he had been assisting the ventilator for quite some time. (2B1.int; 2; 75-79)

> 2D: A patient that's... alright, let's say brain dead but not officially brain dead. Brain dead when they lose their blood pressure, they become bradycardic, they can, um after they usually [laughs], you know, they're. My experience is that they're, you'll see their blood pressure and heart rate shoot up to a-, sky-high limits and then almost immediately go down to nothing practically [laughs]. You'll have the, you know, I have the patients that will just level out, you know, and their blood pressure stays OK and that, for a while. But, um, anyway, so, yeah, so it's, I guess you could say it's they're brain dead but not officially dead. They're brain dead but not officially. (2D1.int; 16; 689-697)

> 2D: He lived with his grandmother, um, and when I came on, took him over at 7:30, um, he had not been declared brain dead but somewhere between the five and six range in the morning, uh, he became clinically brain dead, um, there were no brainstem reflexes. Um, he, um, he maintained his blood pressure, um, it had gone sky high and then it had come down and his heart rate had gone sky high and come down. And no, no reflexes um, that the nurse could test at the bedside anyway. So he had not been declared brain dead but that was when they kind of pointed to when he actually herniated, you know, brain stem. And, um, stopped

doing anything that he'd been doing before, no movement, nothing, pupils gone. (2D2.int; 1-2; 33-42)

2E: Um, you get a sudden change in heart rate, usually a extremely fast, um, your pupils change and you'll, you will get a dilation of one and then your blood pressure shifts way high and then bottoms out. It's just classic, the, the triad happens. Your systolics and diastolics both go up then the diastolic drops. And once that diastolic drops then you can be pretty sure that systolic is not far behind. And when that drops down then you've got 'em on pressors, you've got 'em on dopamine and usually by then you've lost cough, gag, you've lost your reflexes, they're no longer triggering the ventilator, pupils have changed. That's pretty specific, that's it. That's brain death, basically, then all you're doing is waiting for calorics or apnea test. But y-, you pretty much know you're not gonna get anything [laughs], after that. It, it always just seems to have that pattern, that herniation. (2E2.int; 4-5; 145-156)

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These nurses are each talking about a pattern of signs they have seen in every case of impending brain death. These signs are, as 2E says, classic. But the signs cannot be taken in isolation. As is evident in all the excerpts, signs taken as indicating brain death happen as the patient's condition evolves. The patient must have progressivly lost responsiveness and brain stem reflexes including pupillary response, cough, gag and corneal reflexes before the sudden rise in blood pressure and heart rate can be taken to indicate herniation or brain death instead of, for example, pain or anxiety. In addition, the nurses are always aware of the mechanism of the patient's injury and the results of any other relevant diagnostic tests like CT scans. The combination of these conditions helps the nurse to recognize when the patient is making the transition from brain injury to brain death.

Confirmation of Brain Death

Despite the certainty of the clinical signs described above, brain death must be confirmed by another set of tests. These confirmatory tests vary from institution to institution. The Quality Standards Subcommittee of the American Academy of Neurology (1995) recommends testing for apnea before officially declaring the patient brain dead. If it is not possible to test for apnea, another confirmatory test such as a blood flow study, must be done. These tests are generally recognized as confirmatory. By the time a patient is tested for apnea, it would be surprising if he or she turned out not to be brain dead.

In the nurses' stories, the apnea test is mentioned as a formality done only after everyone is certain the patient is brain dead. It involves taking the patient off the ventilator and waiting for the partial pressure of carbon dioxide in the arterial blood (PaCO2) to rise to a predetermined level. If the patient makes no effort to breathe, he or she is declared dead. The idea behind the apnea test is that in a person with a functioning brain stem, high levels of carbon dioxide (CO2) in the cerebrospinal fluid (CSF) will stimulate the respiratory centers and the patient will make an effort to breathe. Because it is easier to collect and measure, and because it is commonly assumed to have a similar level of CO2, arterial blood is used instead of CSF. An accurate apnea test requires that the patient's drive to breathe come from carbon dioxide levels. In patients with certain pulmonary diseases that cause them to chronically retain CO2, and in whom hypoxia serves to control breating, an apnea test may not be appropriate as a confirmation of brain death, as these patients may not breathe even with very high levels of CO2.

Confirming and officially declaring brain death is the physician's responsibility. California State law requires two licensed physicians to confirm a diagnosis of brain death. Because the declaration of death is based partly on the results of the apnea test, many institutions require at least one physician be present when it is done. This physician then reports the findings to the second and they both agree the paitent is dead. Other medical centers leave it to the ICU nurses and respiratory therapists to conduct the test. Two physicians then declare the patient dead based on the reported results. Whether the test is done by nurses, physicians, respiratory therapists or a combination of all, the concern is that they understand the idea behind the test and that they carry it out properly. Perhaps because they see it as simply a formality, some physicians may tend to become sloppy in conducting the apnea test or choose to skip it entirely, a choice generally frowned upon by neurologists.

The following excerpt is from a field note. The patient has been declared brain dead by clinical exam including a formal apnea test. A surgeon, MD, who is not involved in the patient's care or treatment is at the bedside placing a central line with the assistance of the patient's nurse, 2C.

> They are setting up for the central line and some confusion comes up about putting the bed in Trendelenburg. 'Not the best thing for this kind of patient,' MD says. 2C says, 'Not really.' MD asks what has her ICP (intracranial pressure) been running? 2C informs him that it has not been measured. She turns the spot light on and slants the bed head down, the Trendelenburg position. 'She has been declared brain dead?' the MD asks. 'Yes,' 2C says, and offers to move the bed so he has more room. He's standing at the head of the bed kind of squished into a corner. 2C has set up a pulmonary artery line transducer. The transplant coordinator orientee comes in to ask 2C to witness a consent. 2C says she is too busy assisting with lines. The ventilator alarm goes off and 2C silences it. She takes out a pulmonary artery line then goes out to ask the transplant coordinator if she wants a swan or just a triple lumen central line. She comes back with a triple lumen catheter. The ventilator alarm is going off periodically.

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> 'She's breathing harder in that position,' 2C says. The ventilator alarm continues to go off; the machine is reading the patient's respiratory rate at 38. 'Did they do an apnea test?' I ask. No one knows. MD says to take her off the ventilator right now to do a 'quick apnea test'. 2C disconnects the ventilator tubing from the patient and silences the alarm. We stand there for about three seconds watching the patient's chest. 'Nothin' MD says. 2C reconnects the ventilator. MD wants to know what tests have been done to confirm brain death. 2C goes out to look at the chart. She comes back and reports that they did dolls eyes, corneals, and an apnea test. MD thinks the ventilator was misreading while she was in Trendelenburg because of the position of the endotracheal tube. (2C1.fn)

This excerpt from an observation illustrates a misunderstanding of what an apnea test is and what it is used for. The determination of apnea is used as a confirmation of brain death. If the patient has been declared brain dead, the patient ought to be apnic whether an official apnea test has been done or not. That 2C can think both that the patient is brain dead and that the patient is having trouble breathing shows her unfamiliarity with the true meaning of brain death. Likewise, her uncertainty in the beginning about what effect a head down position will have on the patient points to discomfort with the concept of brain death. The physician in this example is equally confused. His quick apnea test shows his lack of appreciation for the physiologic underpinnings of the procedure. He has no idea what the patient's CO2 level is either before or after 2C removes her from the ventilator. It is encouraging that he wants to know more about how brain death was determined.

These kinds of misunderstandings come up often in practice. It seems very few nurses and physicians fully appreciate the meaning of brain death and the purpose of the apnea test.

> The MD is finishing up the arterial line and will stay for the apnea test. The apnea test starts at 1512. 2E leaves the ventilator connected to the patient but changes the settings from assist control to CPAP [continuous partial airway

pressure, a ventilator setting that requires the patient to breathe spontaneously] of 5. Another nurse stands by the ventilator and presses the alarm silence button whenever the alarm goes off. 2E informs everyone that the patient's systolic blood pressure is 75. The other nurse has now left the room and the ventilator alarm is going off continuously. 2E spends some time at the bedside monitor explaining the waveforms to the MD. 'How do we know if he breathes unless we watch him?' the MD asks. 'We'll know when we do a blood gas and his pCO2 is 125,' 2E answers. The other nurse comes back in. 'The apnea test started at three twelve and thirty seconds so we'll finish at three twenty-two and thirty seconds,' she says. 2E says, 'I don't know if he'll make a whole ten minutes. His sats [oxygen saturation measured by pulse oxymetry] are dropping.' The other nurse remarks that the patient's blood pressure is 68/40. She dresses the arterial line and the MD leaves. The two nurses think the patient needs more fluid and they both leave the room, I'm not sure why. Now I'm the only one in the room with the patient. I'm watching his chest. It's still. I wonder what I should do if he tries to breathe while I'm alone with him. Lucky for me he doesn't. The second nurse comes back after 45 seconds and silences the ventilator alarm. She goes out again to get a blood gas kit and comes back in 30 seconds and at 1519 she prepares to draw a blood gas from the arterial line. There is a lab tech waiting to carry it in. 2E comes back in and starts cleaning up the line tray, disposing of sharps. The nurses discuss what the MD will need in order to check 'cold calorics.' The second nurse suddenly gasps, 'I could swear I just saw him take a breath.' 2E points to the ventilator. 'There's no volume,' she says. 'He's doing this quivery thing,' the other nurse says. She thinks it's a muscle spasm. She draws the blood gas and sends it off with the lab tech. 2E changes the patient's ventilator setting to assist control. The MD comes in. 'So he's back on the vent?' 2E answers yes and adds, 'He didn't breathe at all.'

As in the previous story, this story shows the nurses' and the physician's misunderstanding of the purpose of the apnea test. During the apnea test, no one was consistantly watching the patient. The nurses came in and out of the room and at one point left the patient completely alone with me. They knew I was not watching the patient since I was usually following 2E. 2E said she would know whether or not the patient breathed based on the results of a blood gas. But the blood gas will tell her nothing about the patient's effort to breathe only about how effective his breathing is.

Even if the PaCO2 had been 125, the patient may still have made an effort to breathe, though ineffective, during the time he was on CPAP.

The idea behind apnea as a confirmatory test is that all other bedside tests, including cold calorics, be done first. When two physicians are convinced by the evidence obtained on physical exam that the patient is brain dead, they then do an apnea test to confirm the diagnosis. As a confirmatory test, the apnea test should be the last thing the team does in the process of declaring brain death. In the example involving 2E, the physician had not yet tested the patient's occular movement with cold calorics. In this test, each ear is irrigated with ice water and the eyes are watched for deviation. If there is no eye movement, the patient lacks the brainstem function to generate the reflex. The team in this excerpt did the apnea test before all other bedside tests for brainstem function had been completed.

California State law does not specify how brain death be determined but only that it must be declared independently by two licensed physicians. It is up to the physicians involved to decide what tests are appropriate. I once cared for a patient who was declared dead by two neurosurgeons without an apnea test and after they tested the response to cold calorics in only one ear. The attending neurosurgeon in charge of this case explained his actions as in compliance with State law. This and the examples previously cited highlight the sometimes cursory nature of testing for brain death. The apnea test is a formality that confirms what the physicians already know and is often treated as such in practice.

It is disturbing to think the nurses involved in the examples did not have a clear understanding of the purpose or have a sensible method for conducting an apnea test.

They leave the declaration of death to the physicians, but they are the ones providing the information on which the physicians base their declaration. As such, the nurses ought to have a better grasp of their intentions. The standard of practice as outlined by the Quality Standards Subcommittee of the American Academy of Neurology (1995) requires that physicians conduct confirmatory tests in every case of suspected brain death. In many institutions, physicians carry out apnea testing. If the patient is too unstable to complete the apnea test, some other confirmation must be done like a radiologic procedure to determine whether blood is flowing to the brain and brain stem. As a further safegaurd, the area OPO requires an apnea test or some other confirmation of brain death (usually a brain blood flow study) before they take a patient to the operating room for organ recovery. The transplant coordinators like to be present to witness the apnea test in order to be sure it is done properly; if the physicians will not do an apnea test, the transplant coordinators will do it themselves. But, in cases like the ones described involving 2E and 2C, it is impossible for the coordinators to know when or how the test was conducted.

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The Transition from Person to Body

The nurses' stories point to an experience of brain death that is more about a feeling of transition in the patient's status than formal testing. The testing is important to determine the patient's potential for organ donation as is evident in the OPO's practice of requiring confirmatory tests. But for the nurses caring for the patient and family, brain death is a point of transition preceded by certain physiologic signs and ending in a different relationship with the patient/body.

> 2F: Uh, basically she was a very stable patient, if I recall, um. You know, suctioned her, repositioned her, um, cleaned her up if, you know. I, it's, when I get a patient like that, you know, you, you take care of them physically. But, um,

you know, I, I feel, you know, if you know that patient's already dead. And you can tell, you know, the body's different, you know, and stuff like that, so. I don't feel emotionally attached to the body, so. You take care of the body physically, turn it, suction it, whatever, check the urine, you know, do all the vital signs and all that kind of stuff. (2F1.int; 4; 124-132)

2F: And usually even if they're paralyzed or heavily sedated, there is still some movement in there, like the eyes and stuff like that. So you know, there's a difference. You know, if they are heavily drugged or something like that, you may not talk to them as much as you would as to somebody who's reacting with you, but still, you explain to them what you're doing, you know, I'd give them a longer back rub [laughs], you know. For the other patient it's like, OK, get the skin circulating and that's it, you know. But this patient, you know, I'd figure I know they're probably stiff or something like that. So I'd be more careful of their positioning and stuff like that and, um, you know try to be more, hopefully, anticipating what they might need or want. So,

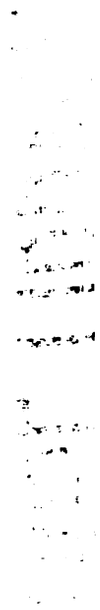
LD: So you, you, that's absent from the...

2F: Oh, yeah, well, I mean, what do they need? They don't, they don't want anything. They don't want me to sit there and hold their hand and say OK, you know, just take it easy. You know, go with the flow, 'cause the flow's already gone. It's like, but, when I have a, a dead patient and I've got a family member in there, I would touch the patient like they are, well, ali- you know, maybe hold their hand and ask them, say, gosh, you know, your son's awfully handsome. I bet you're really proud of him, or something like that, to kind of get them to talk a little bit about, you know, their child or something, or to talk about the good things about that kid. You know, or husband or wife or something like that. So, I'll try to humanize the patient for the family. I'll, won't you know, just kind of pick up the arm and say, yep, that's dead meat, you know, something like that, so. That's a little bit different. And the, you know, be sure the patient's face is clean, if they're drooling or something like that, you know, just to make them not feel like, uh, you know, I don't know. 'Cause that is someone that they love, you know. To me, it's a dead body, but that's their dead body, [laughs], so, you have to remember that, I think. (2F1.int; 4-5; 158-185)

2B: So my concerns changed from giving them, talking to family, supporting the patient, you know making sure he was stable again, lab work, those kind of things, those same goals. But then thrown in there also was the comfort measure. I think that's what, that's the big thing, is I don't know if this is my loved one, you know, if this is me, I always put myself in that situation, you know I want to be turned, I don't want my arm like that, you know, those kind of things, um. If

he can sustain, if his blood pressure's not too labile maybe give him a little morphine here and there, because you don't know, um. And so that's how it changed from, and then talking to family about what if's, you know, and those kind of things as opposed to when I came on after he had herniated. That was a brain dead person there, a brain dead'I don't think of it as a body, it's still a patient to me, you know, it still is, I mean it's still Mark. But prior to that I'm talking to him saying, ' Mark I'm going to turn you, Mark, I'm going to suction you, Mark I'm going to do this,' um, whatever day it was, I, I, my days are mixed up. Um, but on that day after he herniated, that day that he herniated, I didn't go in and say, 'Mark, I'm going to do this.' OK, I made, I mean that's, that's not appropriate either. That's not appropriate when you're, what kind of message, to me also, if, if I would hear somebody doing that, that would just make me cringe. Because what kind of message then are you sending the family? You know, you're, this is, this is, this person's brain dead, I mean they don't hear you. Up until then the reason I'm talking to him before is because he might hear me. Now, he's not hearing me, you know, if he, whatever your belief is, you know, he might be up there watching me but he's not, I don't need to tell his body that I'm going to turn it, you know, it's, it's brain dead. And so therefore that's how I've changed my feelings. My feelings have definitely changed. You know, I'm not caring for a patient anymore, I'm taking care of this body, I'm maintaining this body to keep, get it, send it in the best shape that I can to OR. So, does that make sense?

2B: My primary focus when I'm taking care of an or,- organ donor, especially in this case when they're stable like this, is taking care of the family. Um, and, and making sure that that patient's stable. And if they get unstable, that's the nice thing too, it's so different. I mean I, you're kind of off the hook even, you know, I mean, it's, it's a, it's kind of an ideal situation as far as nursing goes because you can't do anything wrong [laughs], you really can't, you can't give them the wrong drug, you can't hurt them by not doing something either, um. You do what you can and you're not calling, you don't, you don't have to make any decisions in these cases whereas a lot of times in your regular day-to-day nursing, you know, you walk into a patient's room and they're fine and you listen to their lungs, and three minutes later they've got crackles two-thirds up and they're in fulminating pulmonary edema and you've got to call the doctor and say hey, this is what's going on and, and then do we give Lasix 'cause their blood pressure's only 80. I mean you've got a lot of decisions to make. Organ donation, there's none, because the patient's a donor, you've got your transplant coordinator there, you give them your data and they, they tell you what they want; well hang Hespan, hang Plasmanate, you know, do this, do that, give them some calcium chloride 'cause, you know, your lab values back. And it's kind of fun because you actually look at, you look at your lab values and you say well, and, and they're doing it. (2B1.int; 1044-1064)



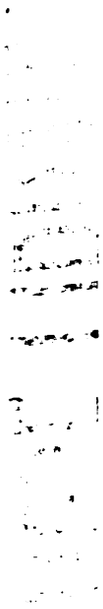
The nurses in these examples describe a change in the patient's status. For both nurses brain death is a point of transition from person to object. What is not acceptable in the presence of a living person becomes appropriate when the patient's status changes from person to body or object. When caring for the brain injured patient, the nurses are concerned with the patient's comfort and emotional well-being. Once the patient dies, they no longer worry about him or her as a person but only as a physiologic entity. While the nurses still treat the body carefully out of respect for the family and for the newly dead, they shift their focus from caring for a person to supporting a set of organs.

Supporting the organs is, in 2B's experience, much easier than managing the care of a critically ill patient. Supporting the organs is fun because it involves less judgement and fewer things are likely to go wrong. 2B feels let off the hook because the transplant coordinator is closely involved and will make all the decisions, and the patient's emotional needs and comfort are no longer issues. Both 2B and 2F stop talking to the body after death, and 2F characterizes it as without needs. While the body does need physiologic support, it does not want anything like, for example, the emotional support a living patient may want. 2F believes the brain dead body makes no distinctions between comfort and discomfort or between pain and pleasure, and that it is alright to forgo the comfort measures (for example, back rubs) she provides living patients.

After brain death, the body is an object, but it is an object with significance. 2F claims she has no emotional attachment to the body but shows respect by handling the body gently and keeping it clean. She uses interaction with the body to initiate conversations with the family about who the patient was. She talks about the patient as if

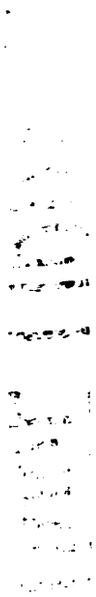
he were not there, something nurses are inclined not to do with a living patient. Given her position that the brain dead body is no longer in need of comfort, 2F's actions are for the benefit of the family. The body belongs to the family and 2F wants the family to know she appreciates the body's significance and understands that it still represents their loved one.

Despite the seeming certainty with which these nurses speak, the brain dead body's status is not always completely clear. All the nurses recognize brain death in a legal sense. The time of brain death is what will be entered on the death certificate, not the time the heart stops. Yet sometimes nurses who understand this seem confused about how they ought to relate to the brain dead body.2B: Feelings, I mean, they change, but the overall sadness was always there, you know, but the, probably maybe my feeling towards the patient changed. I mean, I don't know that my feelings, I still was sad, I was still upset, you know, I mean all those feelings that you have, um, I still was hurting for the family, um. But I, I was more, and I don't want to say I was detached because I did, I don't feel detached, I mean I didn't, there was no difference really. The difference was is that I was not going to, and sometimes I had, I mean, I, it was a conscious thing too, making sure that when the family's there and I'm doing something I'm not going to be talking to this, this body. I mean [laughs] that wouldn't be appropriate. And sometimes it's a conscious effort, I have to stop myself, you know from doing that. 'Cause it's hard to, you know, it's, it's, it's a fine line there, you know, I mean, to, you <u>know</u> in your, in your head that this is not a person anymore that this is just a body, it's brain dead and, and there's no chance of survival, there's no, I mean, the person's dead. There's, there's nothing else there. But then, you know, as a nurse, as a caregiver, you still want to do all



those things, I mean we still do. We still bathe people, you know the night nurse gave him a bath, no he didn't, no I gave him a bath that day. Because he had herniated and she was busy with that. I gave him a bath that day. Um, I changed his sheets, you know, I mean. We still do those kind of functional things, but I didn't talk to him while I was doing it, whereas before I would have talked to him. But I still did skin care and, you know. Probably didn't have to, but you just do. I mean it's not going to make any difference 24 hours later in his tissue donation, you know it's really not. [long pause] (2B1.int; 16-17; 734-785)

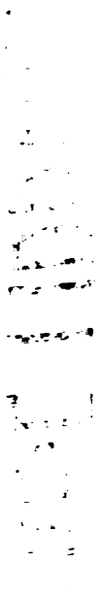
Even though in the previous excerpt 2B took a strong stand that the brain dead body is no longer a person or a patient, here she seems uncertain of her relationship with the brain dead patient/body. She has to talk herself out of doing routine comfort care, like talking to the patient and giving him a bath, even though she knows he will not benefit from these things and that doing them may give the family the wrong message. Part of 2B's confusion stems from the fact that there is no place for extended post-mortem care in American ICU culture. This, along with the fact that organ donation has been formally recognized as part of the ICU nurse's practice for a relatively short time, contributes to 2B's seeming discomfort. She is confronted with work for which she has no familiar category. She finds herself relying on habits of practice that she recognizes may not be appropriate but that are all she has. Nurses caring for brain dead organ donors are forging new boundaries as they create the space for care while respecting the fact that the patient is dead.



Summary: the Best Method

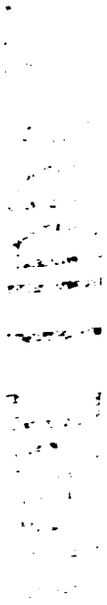
There is no best approach to making the transition from caring for the brain injured patient to maintaining the brain dead organ donor. The three nurses highlighted here show three possibilities. All three of these nurses are committed to their apporach and recommend it as a rule; to them, the responses are not contextual but generalizeable to all situations in which organ donation is a possibility. The desire to codify a rote approach to organ donation that can be followed by any given nurse in any given situation is reflected in the literature. Articles reviewing the organ donor identification process are hoping to outline a structure upon which all nurses can rely. Unfortunately, the ambiguity of prognosis and the rapidly evolving physiology of brain injury and brain death make it difficult to recommend one approch in all contexts.

2C's is the approach to organ donation closest to that recommended by the OPO: early identification of the potential to donate and early contact with the OPO. The risk with this approach, as discussed earlier, is that the nurse will make a premature transition to donor care, a risk 2C seems to have avoided. Another risk is the possibility of losing the family's trust. This is what the OPO is afraid of when they recommend not disclosing the possibility of organ donation to the family until after the patient is declared brain dead. While 2C's approach seems more honest in that it keeps the family informed of the ICU team's plans, the OPO would rather she not mention organ donation so soon. 2A's recommendation that the OPO take over care before brain death is checked by the OPO's policy against it and also by the physician's understandable hesitation to transfer treatment while the patient is still alive. Still, her early identification of the patient's



potential to donate and her early involvement of the OPO are both in keeping with the OPO's recommendations.

The most interesting approach is that advocated by 2E. Waiting until the patient is brain dead before notifying the OPO seems the most ethical response. 2E claims she cannot both care for the brain injured patient and have her mind on organ donation, a stance echoed in informal conversations with many staff nurses. To avoid a conflict of interest, and to avoid the danger of treating a living person as an organ donor, 2E puts organ donation to the back of her mind while caring for the brain injured patient. While this approach seems ethical, it is frowned upon by the OPO and has never been recommended in the literature on organ donor identification.



Chapter 5

Care of the Patient's Family: Bringing the Family in and Keeping Family Members Informed

Throughout the process of caring for the brain injured patient identified as a potential organ donor, the nurses and transplant coordinators take up care of the patient's family. Often when the patient's prognosis is so poor there is nothing left to do for him the nurse shifts her focus to the family. In many ways care of the potential donor's family does not differ from care of the families of other ICU patients. The nurses provide information and access to the patient and, as it is possible, emotional support. Because the patient's prognosis is usually poor, the nurses must coach the family to help them come to terms with the fact that their loved one is likely to die. And the nurses themselves must come to terms with their own helplessness in situations where all they can do is witness the patient's death and the family's grief.

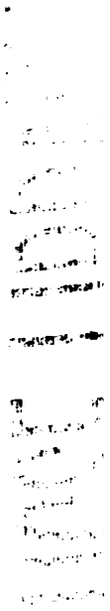
Coaching the Family from a Distance

In many ways, both the ICU nurses and transplant coordinators build their practice involving the brain injured potential organ donor around the patient's family. The ICU nurses talk about how when the patient is beyond saving, after brain death, they shift their focus to the family. The nurses coach the family to make the transition from severe brain injury to brain death, and help them to understand the prognosis and understand what brain death and organ donation mean. The ICU nurses inform and educate the family while keeping busy with the technical aspects of treating the patient or maintaining the organs. Because of the time it takes to stabilize the patient, the ICU nurses often do not have time to get close to family members and often find themselves

outside the family's tragedy witnessing it from a distance. This distancing from the family's tragedy is evident in many of the nurses' stories. The following excerpts are from an interview with a staff nurse who is telling the story of a patient she took care of, a 21 year old African-American man who crashed his car, injuring two friends and killing one other. The patient is brain dead and 2F is describing her interactions with some of the friends and family who visited him.

> 2F: There was this woman who was, mm, late 40's, early 50's, I guess who came in and basically kind of crumbled to the floor. We ended up having to put her in a wheel chair and wheel her out and everything like that. I mean, this, this guy had a huge, huge family. And, at that point, you know, it was like, I was not being too strict on the visit, you know, it was like, he had lots of cousins. And that's OK, you know, he, he probably had some friends and stuff like that. So, it's like, at this point, it's not gonna hurt the patient. But even though I hadn't realized that the brain death note had been written, I knew pretty much that this guy is very probably defin-, brain dead. So, I knew that, uh, lots of visitors weren't gonna affect his outcome at all. And, so, he had lots of people come through including the cousin that I told you about who definitely believed that he was dead. But people were having a real hard time and at that point I wasn't telling [them] that he was dead. I was saying, um, this looks very, very bad. Um, we think he is brain dead and there's really nothing that we can do. You know, basically, depending upon what the family, they asked, you know, I let them ask questions, and I pretty much try to answer them as honestly as I can, you know. Kind of trying to judge from what they're saying as to what they can handle and what they really want to know. People usually don't ask questions that they don't want to know the answers of. It usually works out OK. And, um, he had that aunt that came in and she collapsed and it was just a huge scene, lots of people. I was trying to keep it down to a low number 'cause he was like right in front of the nurses' station. And, um, so, after the aunt came in and collapsed we had some, you know, young men who came through and they were OK. I answered all their questions and stuff like that. (2F1.int; 10-11; 395-418)

> 2F: There was one gal, pretty little girl who was 16, I think she was, you know, with the braids and just a beautiful face, and she came in and she spent the night at [another hospital], she'd been in the same car. And she came in and, with her mom. And, um, she looked at him and she said, is he gonna be OK? And I was like, no. I said, you know, I think he's, I think he's, you know, if he doesn't have



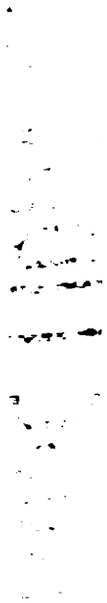
any oxygen to his brain, I think he's brain dead. And she goes, couldn't they give him a brain transplant? It was like, [groans] [laughs]. It was like, my first thing was like, oh my god, you know. That's so sweet but really dumb. [laughs] You know? But it was, I felt so bad for her, you know. And I encouraged her here, take his hand. I always ask people if they want to hold his hand. You know, I try to keep one hand that doesn't have crap in it, or whatever, so that they can hold his hand. Sometimes if people feel comfortable I'll say, you know, give him a hug, give him a kiss. You know, if there's enough room, or you can, you know, encourage them to touch the patient to, uh, make it, you know, more, yes that is so and so. But she was just really, you know, had a hard time. And, um, you know, what are you gonna do? (2F1.int; 12-13; 508-524)

2F: Basically I would tell them brain death is when there's no blood getting to the brain and therefore there is no oxygen getting to the brain. The brain needs these very much and it dies quickly if it doesn't have it. And once it's dead, there's no bringing it back. And I basically tell them, your brain does a lot more things than you realize, I said. It runs your whole body. And I said, you know, it's kind of like, you might say it's kind of like the computer that regulates the hormones and regulates this and regulates that. And how many things you do unconsciously that you don't have to think of. You know, like I say, you know, if you, um, try to stop breathing your brain'll take over and say, OK, breathe, you don't have a choice. If that's gone, eventually the body's not being regulated properly and eventually it will pretty much, you know, stop to run because there's nobody at the controls, so.

LD: Um-hm. And how did they respond to that?

2F: Um, well, I wouldn't talk like that unless somebody's really asking me some heavy duty questions and stuff like that. Sometimes they come back with a question to try to clarify, like, in order to see if I say something else. And I'll just kind of say, well, no. That's, you know, it's really, that's the way it is, um. Um, if they don't want to understand it they won't and if they do they will. I might try to rephrase it a little bit if it appears like they don't get it. Like I said, you know, it takes different amount of things. For this one guy, I just had to show him his eyes. And he knew he was dead, that was all it took for him. That's brain dead, nobody's home. And if they say, I tell 'em that the part of him that you knew is basically, it's gone. You know, his personality, you know, it's gone. Like the girl who wanted the brain transplant, I said, well, it wouldn't be the same, you know. He's be a little bit different [laughs].
LD: Is that what you said to her? I was gonna ask how you responded to that.

2F: Well, I said no, there's, I said, um, I think I told her, I said no, that, that's not possible. And I said, you know, I said, he wouldn't be the same 'cause it



> wouldn't be his brain, you know. I, I forget exactly, I kept it pretty simple though 'cause she was, like, shell shocked. You know, you could see that she just was like probably going oh my, you know, like this coulda been me. You know, I mean, oh god, it's just a whole, yeah. So I didn't want to load her up with, well, you know [laughs], come sit right down here, young lady, and I'll explain this to you. No. I talked with her mom a little bit and, you know, gave her a bit more, so she could probably explain it to her if she had some questions. (2F2.int; 15-16; 613-646)

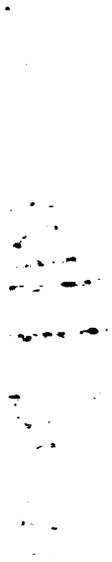
The stories 2F tells about her concerns in caring for the family are reiterated in many interviews. 2F does not avoid the family. She is in the patient's room when they come in. She answers their questions as they come up but chooses not to volunteer information the family may not be ready to hear. Her answers are competent and informative and she stays involved with the family but at a distance. She is outside the tragedy looking in and while she can begin to imagine the family's grief and fear, she does not indulge in it or make intimate connections. Her relationship with the family is emotionally distant but not completely disconnected or meaningless. She is their line to information they need about the patient's condition and prognosis. Information is one of the things the family needs most when a loved one is critically ill or injured (Hickey, 1990). This nurse provides the family with an essential link to understanding and interpreting the patient's condition while seeming unable to support them or understand their responses.

Providing the family with information is an important job of the ICU nurse. Because she is with the patient moment to moment, 2F can give the family the most current evaluation of the patient's condition. 2F does not shy away from bad news; she tells the family it does not look good, that she thinks the patient is brain dead. Even

without the confirmation of a physician's brain death note, 2F takes the initiative and gives the family her honest thoughts on the patient's prognosis. At the same time, she does not force them to hear what they are not ready for. She gauges her disclosure by the family member's questions and tries to match her response to what she judges to be their potential for understanding. The techniques 2F uses go beyond simple imparting of information or informing the family. She approaches the family with caring attentiveness that is tailored to their experience.

At the same time, 2F keeps her distance from the family. Later in the interview, 2F explains her lack of connection with the patient's mother. The mother stayed in the family waiting room because she was so distraught she could not bring herself to come in to see her son. 2F could not take time away from what she describes elsewhere as a stable patient to go to the waiting room and meet the mother. When the aunt collapses on the floor, 2F's response is to get her into a wheelchair and get her out to avoid the emotional scene. She tries to limit the number visitors because the patient's room is right in front of the nurse's desk, a place where expressions of grief may disrupt the unit.

The story gives a sense of things going out of control, or of having the potential to erupt into chaos. The family is big and wild, and while she feels bad for the family, 2F seems overwhelmed by the size and unwilling to expose herself to the enormity of the tragedy. She is not sure of the relationships among family members or even who is family and who are friends. 2F is trying to maintain some order and stability in the ICU while giving the family access to the patient and space to grieve without involving herself in the family's grief and without forming intimate relationships with any individuals or

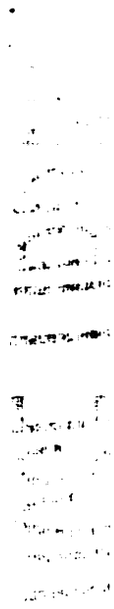


with the family as a whole. Her story illustrates several important concerns nurses have in caring for brain injured patients identified as potential organ donors.

Overcoming Obstacles to Allow the Family Access

The ICU nurses take the importance of providing access to the patients very seriously. Clearing space in the room for the family, bending visiting rules and encouraging family members to get physically close to the patient are all examples of this. Site two is located in a county where the coroner sometimes impedes the family's access. This came up in nearly every interview with this group of nurses. When a patient who is accepted as a coroner's case is declared brain dead, it becomes against the law for the family to touch the body. This rule could be used as an excuse to exclude the family. Instead, the nurses are offended by its senselessness and try to work around it to allow the family as much contact as possible.

> 2B: that was one, it was a female, and the patient had gotten hit by a car and she was severely head injured but wasn't brain dead yet, y'know, organ had gotten involved, organ donation, family, um, had said yes. The hardest part in that situation, again, this was where the coroner, y'know, in this county the coroner's very strict as far as once the patient is declared brain dead, the family is not allowed to touch the patient, allowed in the room. And that was, with this case, I mean the organ donation and everything went very smooth, but it was that other part of it where legally, especially this one was hit by a car so the coroner's gonna want to be involved. Doesn't make sense because you've already bathed this patient, y'know, eight times, you know, you've done all these things and yet they have this silly rule that once they're declared brain dead, even though the family's been huggin' 'em and kissin' 'em. That once a brain death notice is made, family can't go in there. So in this case, the family understood but that was very difficult for me to go and talk to this family about that and say, y'know this is, this is the rule. I know it doesn't make sense but I'll tell you what, why don't you pull chairs up and sit at the bedside, not at the bedside but right like the, the door, the room is here and sit right outside the door. We have glass doors, so they, and it opens so I opened the glass all the way and they sat at the edge of the room. Because sometimes the coroner can, sometimes they can really make your life

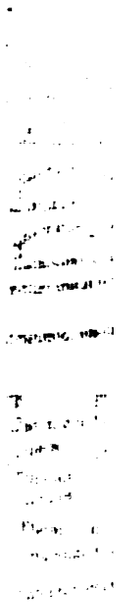


miserable. Actually they even threaten to arrest you because you've broken the law. (2B2.int; 16-17; 576-597)

2B: OK. And they say, um, they can't, they can't touch them once they're pronounced. So, um, to get around that we kind of, you know, make sure the family is aware of that and make sure that they, you know, do their hugging and their kissing and all that stuff, you know, before hand and just really prepare 'em for that because the coro. And in this instance, um, that would have been the case, but the family, um, didn't come back after we talked, after they talked to the donor, and I was in on that also, filling out all of her forms and explaining everything to them about the, what was going to happen. Um, I thought they were gonna come back in and I missed it 'cause I didn't get to say goodbye to them, But, um, the mom, the biological mom and then his girlfriend came back in and I did allow them to go back into the room briefly and say goo, their good-byes. And I expected the whole rest of the family to come back in and they didn't. (2B1.int; 4-5; 183-194)

2D: Um, so when I took over, he'd not been declared brain dead and soon after that the neurosurgeon arrived and did, we did the apnea test at the bedside and he did calorics and, um, actually wrote the brain death order about, sooner than I wish, wished. Because, as I told you before, as soon as they write the first brain death, you have to notify the coroner. And, and they're often times, when it's a coroner's case, as he was, homicide, um, the coroner will not let any family members or anybody in the room after that. Even though they'd been coming in all night. But, uh, so we, we tend to try to orchestrate that a bit, you know. Uh, [laughs], uh, not Kosher, I suppose, but it's, you know, it's, it's, it's just something that we, we do for families. (2D2.int; 2; 50-59)

2B: Yeah, we just had a case, we just had a case the other day that, um, family, not family, but , um, a brain death notice was written in the evening and then the doctor just, I don't think the patient was gonna be an organ donor. Well, I think there was that consideration that that might have been a possibility depending on the family, but the brain death notice was written in the evening and then the neurologist, or the neurosurgeon, y'know it was late, you don't blame 'em for not wanting to come back in and write a second brain death notice. So he didn't come in until like seven in the morning, seven or eight in the morning and wrote his second brain death notice. And the nurses didn't keep the family out of the room until after the second one was written. Coroner said, coroner came down on 'em. They were very happy with the way we, we, 'cause then the police wanted to come get blood, and, y'know we said no, this is, you have, if, he wasn't, if he would have done it before, I think legally they could have but then after he's brain

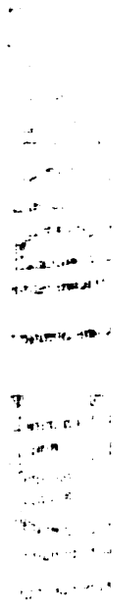


> dead they can't. Anyway, there's all these different rules. So we, um, the coroner was happy with initially how we did everything. And then once they found out that the family was allowed in the room after the first brain death notice, they called our supervisor. And said, y'know, this one guy threatened to have the nurse arrested that let them do that. Y'know you have to follow these rules. I think a lot of this is because [,this county] has a high conviction rate. And, I think maybe they fee like it's 'cause they're so tough and firm on their rules, but. (2B2.int; 14; 599-618)

In the first story, the nurse, 2B, makes space for the family even though they are not allowed to enter the patient's room. She follows the law because she fears the threat of arrest, but makes it clear to the family that it is not her idea. In the second excerpt, 2B allows two family members back in the room to say their good-byes after the patient is declared dead. She is prepared to let the whole family go in, but only two are still in the hospital at that point. Both 2B and, in another excerpt, 2D, describe a way in which the nurses get around the coroner's rule: by delaying the official declaration of death, the family can have time to be with the patient without technically breaking the law. But once one brain death note is written in the chart, the body officially belongs to the county coroner. 2B knows the risk; she explains the risk of arrest in the last excerpt. It is not clear from these interviews why 2B felt comfortable breaking the law with the family in the second excerpt but not the first.

The policies of this particular county's coroner may not be widespread. The point is that the nurses' response to the policy shows their concern with providing the family access to the dying patient and to the dead body.

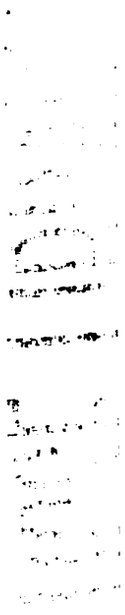
> LD: Have you ever, have you ever just not, like this nurse, whatever happened between the brain death notices where he or she let the family come in, have you ever done that, just said...?



> 2B: Um-hm. Well I did it with this person. Was he relea, no 'cause he wasn't released, um, with the one I had, clipping the hair off. Y'know, I let them go in and hug him and say goodbye. You just, it's being human. And we all do that pretty much. We don't tell it to the coroner, but. So, actually I shouldn't say all of us. Some nurses are just pretty...sticklers. Go as far as putting up yellow tape.
>
> LD: Oh, really?
>
> 2B: No, I'm teasing. (2B1.int; 16-17; 700-709)

To 2B, allowing the family access to their loved one's body is part of being human. She says all the nurses break the coroner's rule at some point to allow the family in. But then she corrects herself. Some nurses strictly adhere to the coroner's rule and use it to keep family out. Because she was not aware of the brain death note written in her patient's chart, 2F inadvertently broke the law when she continued to allow visitors to go in the room and touch the patient, a fact she points out herself later in the interview. It is not clear in the interviews if 2F would have followed the coroner's rule or whether she would have broken it to allow the family continued access.

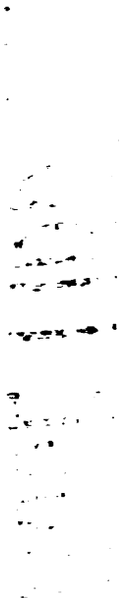
Most nurses are willing to make an extra effort to include the family when the patient's prognosis is poor and the only decision left to the family is whether or not to donate organs. In this situation nurses are comfortable bending or breaking visitation rules in order to make the dying or dead patient available to the family. 2F points to the fact that allowing unlimited visitation can no longer harm the patient since he is already dead. This implies a relaxation of usual vigilance; perhaps these nurses would not allow such free visitation if they thought the patient had a chance to recover.



Making or Avoiding an Emotional Connection

Making space for the family, and providing them with current and accurate information about the patient are concerns that come out in all the interviews. Nurses get emotionally involved with families to differing degrees. This partly depends on the time they spend with the family and the type of connection they are willing and able to make. Sometimes nurses actively avoid such involvement claiming it may compromise their ability to provide technical care to the patient/donor. At other times, grieving with the family comes naturally, and while the nurse may not necessarily seek it out, she or he also cannot avoid emotional connection. How connection with the grieving family comes about depends on the time the nurse has or makes to be present with the family and on cultural similarities between the patient/family and nurse.

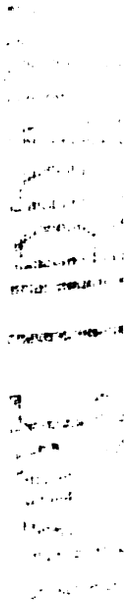
> 3A: Time. You spend so much time with the family, um. Not even talking, maybe holding the hand, maybe just giving a pat on the back, um, giving them information. You don't connect with every family, but when the family's there and you're, they're staying there until they go to the OR, you spend a lot of time. And it's amazing that you can develop a relationship in 12 hours, but you're developing a relationship that's based on need for that family and my need too. My need is to comfort that family and to try and take care of them. It's a nurse's role, it's a nurturing role to support and provide for that family. And sometimes you feel like there's not enough that you can do. I want to say, you know, thank you so much for this and what else can I do for you? But with all the time that you have with that family, talking and, and they're talking about, you know, what they like to do, how they raise their kids, um, you know, how he helped everybody else, you develop a sense of rapport. They give you information and you're there to listen to them. And I have the time most of the time to do that, with the nurses trying to do the nursing care and I am, yes, giving orders for management and helping her turn the patient or suction the patient and being involved in that patient care, I'm not the sole person doing that. So I have the time to also be involved with the family. And you develop a, a relationship. And maybe also because we were so close in age and situations; I was pregnant, she was pregnant, you know, I hadn't lost my husband, but you can relate to it, you know. You have somebody that's your age or your mom's age or your dad's age



or your brother or sister's age and you think, it could be my brother, it could be my child. You know, you kind of thank goodness that you're not in that situation. But we could be in it at any point in time. So I think that's how you develop a relationship. When the family signs the consent and leaves, you don't have that same relationship as when the family spends time and you sit with them at the bedside and you touch their loved one. (3A1; 8-9; 354-380)

2B: A-and, you know, how big was the stab wound, those kind of things, and just providing them with all the information. And, and they understood, like I said, you know, some families don't, but this family did, they understood that when you (stupid fly, try to get him off) when you, you know, when you cut an artery, you know, you can bleed to death. And that, and I let them know the scenario too, I mean, I told them, you know this is what happened, I mean, they knew this, they knew Mark had beat this other guy with a bat after he was stabbed before he, he before he called for help, or before somebody got him help, um. And I also told them, I said, he was only in the trauma room not even a half an hour before he was in OR. I said that's how quickly he got there, I said, so there was not, and when he, and I, I, you know, I and I think that helps too. Just giving them information. He was awake when he came in, he was talking, you know, he was breathing, he was, but, I said you know he had this stab wound and, and once, and, you know explaining to them that it's probably that, that blood in there had probably stopped the bleeding but once the doctor put that tube in, you know, and, and let all that blood out, I said, then it just continued to bleed, which, you know, [laughs] you have no choice. So, um, that, that was their big thing is they just really needed information. And to understand and so they felt better knowing that and then, like I said, they had each other. So they really didn't need a lot of sometimes it's interference, you know, sometimes you have to know when to stay away. Some families are very needy and some families need to just, you know, they have each other. And you know, they don't, they don't need you as much. So. (2B1.int; 15-16; 674-696)

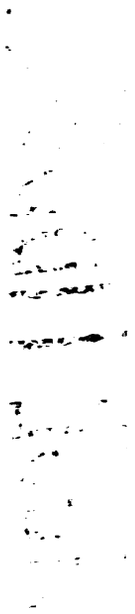
In 2B's excerpt, the nurse recognizes the family's primary need as information. She provides very clear and honest facts about the patient's situation and what lead to his death. The nurse characterizes this family as not needy, as not a family who needs her to be around a lot because they have each other. What they do need her for is information. The nurse has information about the situation that the family cannot provide for themselves. The nurse feels comfortable leaving the family members to provide for their



own and each others' emotional needs while she readily takes up and satisfies their need for information.

> 3A: And, um, I'm a pretty emotional person, I cry a lot with the family and watching his wife say goodbye and she is seven months pregnant and struggling, knowing that this is the last time she's gonna see him warm, and see him with a heart beat. Um, it's, it's tough and I cried. I cried saying goodbye to them, I cried walking into the OR, um. One of the transplant coordinators that came for the heart came with a friend of mine. And thank goodness because she kind of, you know, I have a role once I get into the OR and I was a basket case. It took me, you know, 20 minutes to regroup, to try and, you know, be able to function again as in my role instead of as somebody in grief. I think that's one of the things that happens is, at least with me, you know, I said again, I believe that the patient is gone, I believe he's in a better space. But the family brings that patient alive to you or not alive, he, he's dead, but brings that patient real to you. And you learn about that member of the family and you learn about who he was and you can sympathize with the family. And it breaks your heart, and I grieve for these people. And then wheeling that patient out into the OR and watching them, you know, watch you, I just am a basket case. It doesn't happen every time, thank goodness, but there are those times that it's so difficult, you know. Your perfect scenario is if the family goes home early and you can kind of regroup and become a transplant coordinator again and look at the patient in a very clinical manner instead of looking at the patient as somebody's husband, somebody's father. I'll always consider them that, but I know they're gone. It's the family that makes them real. So, it's tough. (3A1.int; 8; 330-351)

In this excerpt, 3A, a transplant coordinator, is burdened with her emotional response to the family's tragedy almost to the point of being unable to do the technical work required to recover the organs. Unlike the ICU nurses who witness the family's loss but do not take the loss up as their own, 3A characterizes herself as grieving. 3A does not choose to take on the loss; it comes to her because of the type of person she is. She turns to a friend for support and is able to regain her composure. 3A identifies her ideal case as one where the family is gone and she can look only at the patient's



physiology without being confronted with the person he was. This points to the involuntary nature of her response.

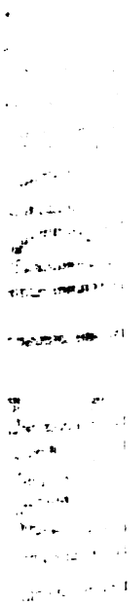
In a previous excerpt, 2F was physically present for family members as they came in and out of the room, but she may not have wanted or been able to be emotionally available to share their grief. 2F takes an informative approach to family care and does not pursue intimacy. In the long run, this may have undermined her ability to assess and provide information to the family. By avoiding the patient's mother and skipping over her experience of the loss, 2F ultimately gives in to the worst of emotional blackmail evident in the following excerpt from the same interview. Prior to this point, the patient's mother and father, who are divorced, had agreed to organ donation. But after the mother's sisters brought in a preacher to pray over the body, the mother withdrew her consent for donation.

> 2F: He [the patient's father] was in there later in the evening and I told him at that time that, you know, OK, um. I, I guess I must have because I told him, please tell everybody, you know, we can have visitors in here but at eleven o'clock we've got change of shift so we'll have no visiting from 11 'til 12:30, um, and could you please pass that on, so that anybody who wants to come in, you know. 'Cause an hour and a half is a pretty long time, you know, to be, not be able to come in. So if there's anyone who wants to come in and see him, you know, tell them. So he said OK and he had some people. And apparently he didn't communicate too well 'cause at 11:00 we got this call saying I want to come in and see this patient. I said [sighs], it's change of shift and I told them, this woman hung up the phone, just walked in, hostile as could be, walked in, looked at the patient, I just kind of looked at her, she walked out. It was like, well, OK, at least she just passed through. It was like [sighs] oh god, probably one from the other side of the family. So.
>
> LD: So you were angry with them when, when they then refused d-. How did that that affect how you, how you reacted to them?

> 2F: Oh, [pause] I probably, you know, I, I, felt like I still will, you know, I was nice to them, like I said I told the, the dad, you know, that they could come in and visit, and, to, you know, just try to make sure everybody came in and stuff like that. But I think, for me, I kind of withdrew from them a little bit and it's like, well, I'm gonna finish up my paperwork, you know. I felt like, um, not as connected and as sympathetic, perhaps, in some respects. Like when that woman called at 11:00, it was like, [sighs] and I just told them, you know, and I was, you know, it was like, guy, you know, I just told them, to tell him, you know, and this woman just didn't want to hear that and she just walked in and I was like OK, fine. But it was like, otherwise, normally I might pick up the phone and say, well, OK, just tell her to come in for a minute. But my reaction was I just explained to them, you know, it's like, damn it, you know, [pretend shouts] what more do you want from me? No, not really, but, you know, it's just, it was just a real taxing sort of thing and, you know, it was right at change of shift and I was tired, you know. And, um, you know, like, OK, I've had it [laughs]. You know, you get to a point where you can give so much emotionally, and you get to the point, it was like, this isn't going anywhere, time to stop, you know. So, I didn't really, I don't know, I think I might tend to give a little bit more emotionally than some people do. So, you know, I just kinda go back to a normal level [laughs], or whatever, you know. (2F1.int; 22-23; 909-944)

When the mother changes her mind about organ donation, 2F withdraws from the family and becomes more emotionally and physically distant . She leaves the room to finish up her paperwork and tells the family they can not visit again until her shift is over. 2F withdraws when the mother changes her mind about donation after being influenced by an outsider, the minister. 2F is disgusted by this charlatan and is appalled when she finds out he had come to visit another patient and had only just met her patient's family in the waiting room. 2F's pull away from the family comes partly because of her experience with the minister.

2F's actions could be interpreted as punishment: she punishes the family members for the mother's decision not to donate by making access to the patient more difficult and by making herself unavailable for questions. Another way to read this excerpt is that 2F



became as involved as she could with the family and, toward the end of her shift, when a new problem arose, she was exhausted and unable to maintain this level of engagement.

2F's level of engagement with this family shows that she made an effort to provide care to the family. While full involvement with a family or family members can yield valuable information and insights, it is not always possible for nurses to pursue a family's or certain family members' experiences and feelings. Had 2F been able to make more of a connection with the patient's mother and find out about her experience and feelings, she may not have been as surprised by the mother's last ditch attempt to save the patient through prayer. But this family is big and complicated, and may require a higher level of care than 2F felt able to manage while at the same time treating the patient. Few ICU nurses feel capable of fully involving themselves in the complexities of family care (Chesla & Stannard, 1997).

It is difficult for anyone to maintain the level of attunement and responsiveness needed to offer appropriate emotional support in every situation and to every family. Nurses become emotionally involved with family members to the degree they and the family are available. If the family is physically absent or unable to or uninterested in engaging with the nurse, or if there are language and/or cultural barriers, nurses may be unable to make robust connections (Benner, Tanner & Chesla, 1996). This is illustrated in the following excerpt in which the nurse has been caring for a brain injured Latino man who had recently been declared dead. The patient's mother declined organ donation, preferring to disconnect her son from the ventilator. In the excerpt, 2D describes her feeling of connection to the mother.

> 2D: Well, my connection with the patient's mother, it was, we, we connected, she was an easy person to connect to. And I think the nurse before me felt the same way. She, um, she was a very easy person to connect to, really. Um, as far as, um, [pause] hm, as far as talking with her, giving her information, she made it very easy for that. Um, I just, I felt, you know, I kinda felt that this woman, once she breaks, she'll really, 'cause she hadn't, she hadn't that whole time. She'd been, sort of kept it all together. And I, I was concerned. And I'd said to a couple of family members when they walked out, you know, I'm concerned about her because she's been in such control in, in this. And just take good, take good care of her. Keep your eye on her. So, um, um, but she, you know, she's a very sweet, sweet person, um, uh, loved her family, you could just tell. Um, you could just tell it was a very, and even though it was a divorced family they, they seemed to be OK all together, the different relatives from the two sides there. (2D2.int; 5; 203-215)

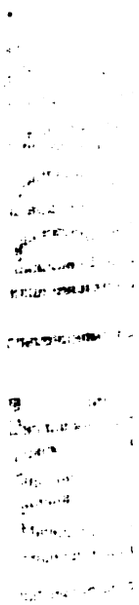
In this excerpt, the mother is very much in control of her emotions. Rather than pour out her feeling to the nurse, 2D thinks the mother is holding them in and is afraid she will explode later. The story gives a feeling of distance not on the nurse's part, but on the part of the family member. This mother manifested her grief in a way that contrasts with the mother and aunt in 2F's story. In this story there is no threat of emotion careening out of control although 2D anticipates the woman will at some point break and give in to what the nurse identifies as her hidden feelings.

Shared culture and language may help nurses form connections, as illustrated in the following excerpt from an interview with an ICU nurse.

> 2A: I think sometimes when you meet somebody who's, when I meet somebody who's Filipino, or somebody meets me, it's like, the first thing they ask is, where are you from in the Philippines. Well, I, I haven't been there in (laughs), I mean, it's been, I left in 1970, and it's been a long time. I mean, I, I, came back nine years la, later, but then people always ask you, where are you from in the Philippines? And then I tell them, you know. Oh, my parents are from here, my mom or my dad's from here. That's the first thing they'll usually ask you. And I think, I don't, I don't remember if that conversation, you know, came, but then

> you have a sense of, like, hm, some kind of comerad... I me..., I mean, somebody who's probably because, maybe they're the same race. I, I don't, you know, I don't consider myself very, very Filipino in the sense of, you know, having the same tradition, or just, I don't consider myself that. And I don't know if she did, but, I mean, we, we had a sense of closeness. So, and even, I remember, you know, it really stood out because this other Filipino nurse was crying, I mean, I don't think she even knew this patient, but when she came in and saw this, this patient, I mean she was in tears. So, I think it was just identifying with somebody, I mean, I've, I don't know, I'm trying remember an incident where these other nurses who work in the unit were taking care of somebody who was, uh, a very good looking blond, you know, kid who became a donor, and, and they were blond, I mean these nurses were blond. So I think they could, I don't know if it was because of that that they could identify with them, but I remember them being a lot more attached with, you know, with that particular patient and the family, more so than, than I was, you know. Because, I remembered it, this was such a big, you know, big, big incident, I mean issue with this kid being a donor and mainly because he was young. But everybody seemed to think that he was, the family was just, you know, great, and they were just a wonderful family. Well, I didn't, you know, I couldn't really see myself identifying with this particular family. So, I think maybe because of the race is...of race or the fact that they were the same, you know, they were Filipino made it a lot easier to have a sense of, like, bonding with the family. (2A1.int; 204-232; 5-6)

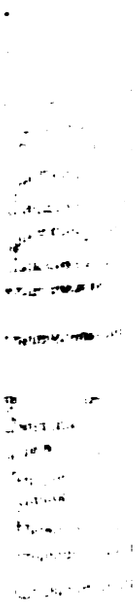
2A finds bonding with the family easier if they are Filipino because she shares their cultural heritage and finds it easier to relate to their loss. Another nurse took up the work of informing a couple of the death of their son via long distance telephone call in part because he, too, was from the United Kingdom. Later, he attended the young man's funeral for the same reason; he felt a cultural connection with the family because of a shared background. These examples of the influence of culture bear further investigation. Because it was not the specific aim of this research to investigate cultural influences on end of life care, the picture here is sketchy at best. There may also be cultural aspects to 2F's relationship with the family that were not explored in the previous story.



The Emotional Burden of Being Present for Dying and Death

At the end of the last excerpt from 2F's story, 2F perceived her absence as an emotional withdrawal. This speaks to the nurses' experience of the emotional burden of caring for families in this situation. While she did not seem to have actively participated in the family's grief and seemed to be distant from the start, 2F felt relief of the burden only at the end of her shift when she physically withdrew from the patient and family. 2F's experience and her response to the mother's change of heart points out the burden of bearing witness to tragedy even while not becoming intimately involved with the sufferers. This is the stance most often taken by the ICU nurse at the bedside and is evident in many stories including the following excerpt. 2D tells the story of a man who suffered prolonged cerebral anoxia after bleeding from a stab wound. The patient's family wanted to donate his organs but it took seven or eight days for the patient to meet brain death criteria.

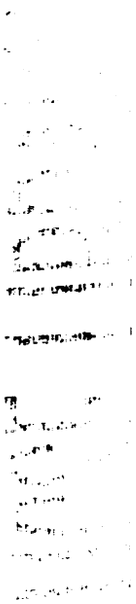
> 2D: An-, it was more, it was more the emotional part of dealing with the family and is this gonna come the way that they wanted it, you know, and I, I really, there wasn't anything I could do [laughs] to facilitate that, that happening, you know, and, and um, other than just be there. They knew there was just a certain number of us that took care of him, that's kind of the way we do it. So they kind of got to know the nurses who took care of him and, um, it, you could see was definitely taking its toll on them as days went on, um. Because from my experience, definitely, most people become brain dead from trauma, [sighs] head trauma, and they, you know, herniate and, and its pretty fast, usually it is within a day or two. So this was, this was kind of different, this was different, um. And so it was, um, you had to kind of pace yourself I guess, you know. Um, knowing that I, if I, if I knew I was coming back the next day, you just kind of can't [laughs], put all your emotional thing into one...so, but, but this, this, this family and his fiancee they were absolutely, they were understanding people, they were,



> I think it was just, uh, it was just kind of an amazing thing, um. They just were kind of gonna hang in there until, until it really, and, you know, one way or the other. So, um, so, yeah, but, the, the part that was hardest taking care of him was, was going day after day. Even if I had a day off in between, I was thinking about him and the family, yeah, I was. So I was very surprised when I came back after that one day I was off and he had gone for harvesting, you know. Pleased, pleased, you know, I was really pleased about that because I knew how much they wanted it, so. Physically he was, he really was stable. His, um, you know, and, amazingly stable. (2D1.int; 5; 197-218)

In this excerpt, the nurses and the family are waiting for the patient to die in such a way that will make organ donation possible. Even though 2D mentions that the family got to know the nurses and that the family was very understanding, the main focus of her description is on waiting. The emotional burden 2D experiences, her concern for the family and patient all relate to waiting rather than acting. As 2D says, there was nothing she could do other than be there. The patient's physiological status was stable and, as comes out later in the interview, the family members were able to support one another emotionally. 2D describes the emotional burden of witnessing the tragedy, of simply being present for it, over an unusually prolonged period. The weight of just being there is reflected in the fact that she feels a pull toward the situation even on her days off and seems almost elated when she comes back to work and discovers the patient has been taken for organ recovery and the family is gone.

In all the interviews, the ICU nurses are present for the dying process and for the actual death of the brain injured patient. Physical care of the patient demands the nurse's presence and attention, and although her level of involvement with the family's emotional experience varies, the nurse cannot escape the burden of witnessing the tragedy. In one field observation, the nurse and family of a brain dead sixteen year old



boy spoke different languages and had only a few minutes to interact before the family was informed of the boy's death. As the family assimilated the information and began to grieve, the nurse stood in the background while others who spoke their language, including a priest, social worker and transplant coordinator, offered comfort to the family. Even though her emotional involvement with the family was limited, this nurse later told me she would be affected by this experience for a long time. At one point during the observation, the situation prompted the nurse to take a break in order to telephone her own children.

Nurses experience and respond to the emotional burden of being present for death and grief in different ways. Some nurses describe trying to protect themselves against the burden by distancing from the situation. 2F's story speaks to this; she stays engaged in the situation to a point, but in the end withdraws physically and emotionally. Unlike 2D in the previous excerpt, 2E has trained herself not to think about her work when she is not there. She works her eight hours and leaves it behind. Sometimes taking on the full experience is too difficult. Another nurse talks about how a full appreciation of the tragedy may impair his ability to provide adequate care to the patient/body. He chooses not to think about the death but to focus on the technical support of the body. This does not seem so much a lack of care and concern in favor of cold technique as a way to handle the enormous emotional burden of witnessing death.

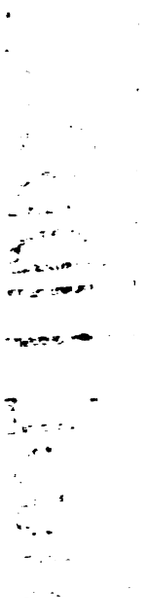
Summary: the Work of Family Care

The nurses interviewed here were concerned with providing the family information about and access to the patient. The nurses spoke gently but honestly to

families about the patient's condition and made special efforts to bring the family into the room. These concerns are highlighted in the literature on general care of families in the ICU (Hickey, 1990). Families surveyed and interviewed in various studies reported two of their top needs to be accurate information imparted in a sensitive manner and being with their loved one. This body of literature is not specific to dying patients nor does it offer any insight into how the situation may be different when there is a potential for organ donation.

When the situation involves a dying patient who is identified as a potential organ donor, the nurse is also concerned with protecting her or himself emotionally while being present for the tragedy and offering varying degrees of support to grieving family members. Neither the literature on care of the brain injured or brain dead organ donor, nor the literature on family needs in the ICU articulate these concerns perhaps because each is focused in other directions. The literature on donor care primarily articulates the ideal method for identifying and preserving donors while gaining consent from the family. The family needs literature is mainly concerned with identifying family needs in a general sense.

The present study is limited in that it focused only on the nurse's experience and concerns and left out direct articulation of the family's experience. Even though their concerns match the literature, none of the nurses pointed to studies on family needs when asked what influenced their practice in care of patients identified as potential organ donors. This may mean they are not familiar with the primary sources but that the ideas have filtered into practice in a modified way. Letting the family have free access to the

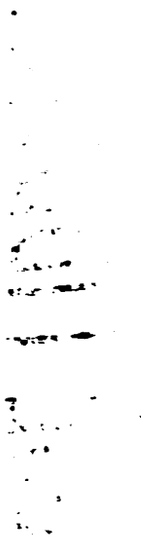


patient's room did not seem to be a usual practice but something the nurses pointed to as specific to care of the patient who is irreversibly dying or already brain dead. At least one nurse cited the fact that the patient can no longer be hurt by the family's presence as her rationale for giving them free access, and many nurses brought up the issue of family access as specific to care of the potential donor. This implies nurses give free access to the patient as a special privilege to families of dying patients, and that it is not general practice in the ICU.

Providing information is something all the nurses take up as part of standard care. The ICU nurses talk with families about mechanism and severity of injury, clinical condition and prognosis freely and honestly. Unlike in times past, these nurses do not wait for the doctor to break bad news but take it upon themselves to begin discussions with the family. The nurses impart information to the family in a sensitive manner by following each family member's lead. Rather than simply providing a bunch of meaningless data, the nurses show family members at the bedside how the patient's condition is changing and coach them toward discovering the truth.

The emotional burden of bearing witness to tragedy is a responsibility passed over in much of the nursing literature. It is an experience no nurse can avoid but also something no one quite knows how to approach or articulate. The different levels of emotional involvement described by different nurses speaks partly to this ambiguity. What levels of involvement are available depend on the situation. But the one thing that is constant is that the nurse is always present as a witness to the tragedy of a death in the family. In the face of death, the ICU nurses are able to stand outside and offer their

presence not as participants in the tragedy but as concerned observers. This stance allows the family to fully claim the death as their own without being distracted by the emotional needs of others. At the same time, it offers a community of support there for the asking.



Chapter 6

Opening the Possibility of Donation

Before the OPO can recover organs for transplant, a member of the potential donor's family or some other person with decision-making authority must agree to the procedure and sign a consent form. The transplant coordinators usually obtain consent for organ donation from one or two members of the donor's family. It is not enough for the donor to indicate his or her intent to donate. The family must ultimately give consent by signing a detailed legal form. The consent required for organ donation is similar to the consent required before one undergoes some medical procedures or before one agrees to participate as a research subject. Organ donation is more akin to certain forms of the latter in that it promises benefits to others but not to the donor. This can be contrasted with consent to undergo a medical procedure which always offers at least the hope of benefit to the patient himself. Organ donation also differs from both of these situations. The potential organ donor must be dead before procurement can be realized and consent must always come from a surrogate. The burden of deciding whether or not to donate weighs on the family and/or friends of the deceased soon after or, sometimes, immediately before, the death; contemplating whether or not to donate organs may mark a transition from hope to despair. While the family may have been actively involved in treatment decisions up to the point of death, the decision to donate organs is unrelated to their loved one's health or comfort, the focus of most other health care decisions. In this situation, the possibility of organ donation may come as a surprise to family members who have not thought of it or discussed it. All of these factors contribute to make

offering the family the option of organ donation more than a routine matter of informed consent.

Principles of Formal Ethics

Obtaining informed consent for organ donation is consistent with respecting the autonomy of individual persons since voluntariness of action is prerequisite to freedom and accountability. In order for a person to voluntarily act, and therefore be accountable for the consequences of that act, she or he must know what the act is, and must not be manipulated or coerced into acting (Aristotle/Thomson, 1953; Kant/Paton, 1956). What this boils down to in medical ethics is that valid consent from a competent patient or patient's surrogate must be informed and voluntary (Beauchamp & Childress, 1994). In their discussion of informed consent, Beauchamp and Childress (1994) expand on the themes of providing information and ensuring voluntariness by distinguishing between influence, manipulation and coercion. In the view of these bioethicists, manipulation and coercion violate the tenets of informed consent while influence does not.

Morally permissible influence includes providing information, arguing honestly, and making a truthful case for a particular way of thinking. This kind of influence is necessary if only to allow for the honest exchange of information and opinion. Manipulation involves tactics such as withholding information, providing misinformation or providing information in a misleading way in order to persuade a person to agree with the persuader. Coercion is present if persuasion is backed up by a threat of harm or deprivation. Manipulation and coercion are widely considered morally reprehensible as

means to obtain consent to undergo a medical procedure, to act as a research subject or to donate organs.

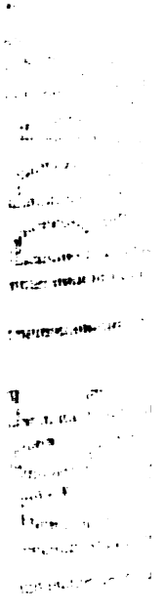
Formal ethics principles underlie and provide the groundwork for much of the transplant coordinators' and nurses' approach to discussing organ donation with a family. The bioethics literature defines in specific terms what influence, manipulation and coercion involve and transplant coordinators and nurses agree that consent must be informed and voluntary and perhaps influenced to a certain extent but never manipulated or coerced by anyone (Beauchamp and Childress, 1994). The nurses and transplant coordinators recognize the sensitivity of their position; being close to a grieving and vulnerable family could easily allow them to abuse their influence and manipulate the family into donating. Despite these concerns about the family's vulnerability, the transplant coordinators and nurses approach to the family involves more than simply providing information. The nurses and transplant coordinators condone a range of practices that influence the family's decision but that they distinguish from coercion and manipulation. The important distinctions between these terms are worked out in practice and demonstrated in the ways nurses and transplant coordinators approach the family. Because the distinctions between manipulation, coercion and influence are qualitative, relational, and time and context dependent, influence differs from manipulation and coercion in ways that can only be described by a particular situation with a particular family or family member.In addition to providing information and finding the moral boundaries of influence, there is a way in which the transplant coordinators and nurses bring up organ donation with a family that shows a concern for propriety or

appropriateness. Embedded in the transplant coordinators' and nurses' practice in this area are actions that demonstrate the etiquette of offering the option of donation. An appreciation for etiquette and the connection between etiquette and ethics show up in the transplant coordinators' and nurses' practice as paying attention to timing and as discovering and responding to the identity of each family member in an effort to hold open for the family the possibility of saying yes to donation as well as the possibility of saying no.

Etiquette as the Condition that Allows Ethics to Act

Etiquette is concerned with the conventional requirements of proper social behavior. A convention is a social agreement or rule established by common usage or custom (Random House, 1986). Unlike traditional ethics which is concerned primarily with decision making, etiquette is determined by the particular situation and relationships between and among participants, and focuses on the propriety of actions within the boundaries of ethics.

The decision to obtain informed consent for organ donation is driven by a decisional ethic that takes into account respect for the autonomy of persons. Because the decision to obtain consent comes from respect for autonomy, true consent must not be manipulated or coerced (Beauchamp & Childress, 1994). While it is of great importance to make ethically sound decisions, how these decisions translate into action is not clear. Answers to questions about appropriate action come from inside a situation or context. The fact that consent must be obtained does not change; this is a decision that was made in a large, general context and that covers all situations. But how and when one should



approach the potential consentee, what demeanor the consenter ought to adopt, and what kind of language ought the consenter use? The answers to these questions will be different depending on who is approaching whom about what.

Within the context of ethical decision-making there is another aspect of ethics that puts these decisions into action. This aspect is supported by etiquette. For example, it is well established in the United States that it would be unethical to take organs before a patient is dead or without the knowledge and consent of the family. Ethics requires the practitioner to make sure that the patient is dead and that the family agree to donation before organs are harvested. Within this ethical context, there is an agreed upon etiquette that gives the consenter a sense of how to approach the family, of what actions are appropriate to take and when to take them.

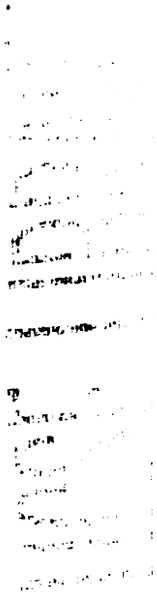
In this way, etiquette can be seen as a continuation of ethics in which ethics shapes etiquette while etiquette holds open the social space in which ethics can be acted out. That is, if there were no etiquette, if there were no way for us to enter a particular social space, ethics would become merely a collection of decisions. On the other hand, etiquette without ethics can become corrupt and manipulative, taken up as a means to another end. But if ethics and etiquette are tied together and approached as part of the same thing, instrumentality is impossible; if the ethics are right, the etiquette that is shaped by it can never become a manipulative sales tactic.

The connections between ethics and etiquette are illustrated in the transplant coordinators' and nurses' action when opening the possibility of organ donation for a grieving family. The choice to donate or not to donate their loved-one's organs rests with

the family. Sometimes families who have just lost a loved one do not know they have this choice or what the choice means. It is often up to the transplant coordinator or ICU nurse to go to the family and offer the option of organ donation. How the transplant coordinator or nurse approaches the family involves ethics and etiquette that converge on points of timing and responding to the particular family.

Timing

The etiquette surrounding grief combined with the newer etiquette surrounding organ procurement prompts the nurse or transplant coordinator to approach the family in a particular way. The transplant coordinators' and nurses' concern with proper timing is related to their commitment to organ donation as a choice. The family must be free to say either yes or no, and poor timing can offend and alienate family members, make them angry and thus interfere with their choice. But there is also a tension in the practice; the transplant coordinators and nurses voice their commitment to providing the family with a free choice while showing a tendency toward manipulating the experience in favor of consent. The transplant coordinators and, to a lesser extent the ICU nurses, are in a conflicted position in regards to offering the donation option to families. On the one had, they are committed to organ procurement and transplantation as good things that improve the quality of life for many people and save the lives of many others. On the other hand, they are committed to the idea that donation ought to be a choice the potential donor's family freely exercises. Given these commitments, it is not surprising that the transplant coordinators want to offer donation simply as one option but at the same time present the

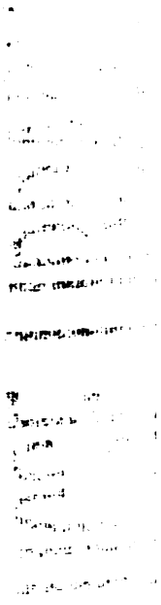


donation option in the best possible light. Timing can be seen as satisfying both of these commitments as illustrated in the following excerpt:

> 3A: The family's told about brain death and then given some time if that's what the family needs. Some families are ready. They've been given grave prognosis, brain death is just a formality that they're hearing and they're ready to make some decisions. But a lot of times these families are hearing, even though they've been given grave prognosis, they hear brain death and they need time to accept that. Because if they don't have time to accept that and you go in and mention donation, a lot of families are thinking you don't care. Or you just want him for his organs, or how can you say my loved one's dead and now you're asking for his organs. Things like that, so, we like, if that's what the families' needs are, they need to accept brain death before you can ever mention donation. Coming in, having a patient come into the ER and having organ donation mentioned in the ER before that family's ever seen their loved one is detrimental and consent rates are terrible. So giving that family time with their loved one, having them understand brain death, and then introducing the subject of donation. (3A1.int; 13; 569-583)

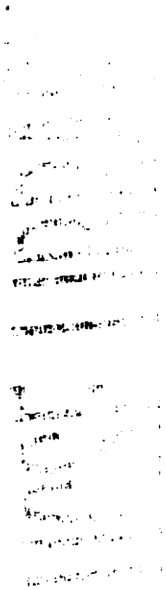
Based on this excerpt it seems clear that 3A does not want to violate the family's sensibilities by presenting organ donation before they are ready to hear it because to do so would preclude consent. This shades the issue of timing in terms of manipulation; in this view, 3A times her approach in order to create an atmosphere favorable to consent. At the same time, 3A, at other times in the interviews, has voiced her commitment to choice and her belief in the importance of finding out and supporting whatever is the right decision for the family, whether yes or no. These two commitments, to obtaining consent and to providing the family with a choice, pull the transplant coordinator in two directions and end up reconciling in a practice that points to the connections between etiquette and ethics.

In the previous excerpt, 3A's comments imply that the transplant coordinator has the power to produce consent or denial depending on how she approaches the family.



While to donate or not to donate is ultimately the family's decision, the decision will be based, at least in part, on the family's response to how and when the option is presented. The literature on organ procurement makes frequent reference to these ideas backing the theory up with research that shows lower or higher consent rates depending on what approach was used (Garrison et al., 1991; Stark, 1994; Shirley et al., 1994; Niles & Mattice, 1996; Gortmaker et al., 1998). The idea that how and when the family is approached impacts consent rates is common in many of the interviews with both transplant coordinators and nurses. This view of the process of presenting the donation option sets up consent as the desired outcome and suggests timing as a technique for obtaining it. Timing the approach so that the family first understands that full treatment was provided for their loved one's injury but that he or she did not survive is a technique that is instrumental to the task of obtaining consent. As a technique, timing should have the same effects and produce a predictable outcome when applied to similar situations.

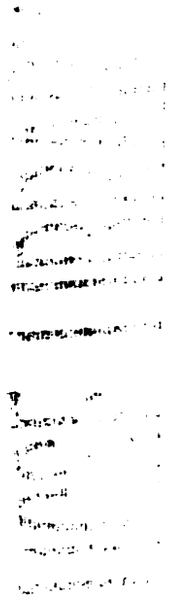
3A's conflict comes from her commitment to decisional ethics and the doctrine of informed consent, and the fact that she is operating within a close and intimate social space, in relationship with a family, in which she must act. Ethical action within the relationship is what is important to 3A but she tries to separate this from ethics and ends up talking about etiquette as if it is only a technique. This comes partly from the literature on organ procurement. By separating etiquette from ethics and treating it as a technique, it becomes possible to measure the success of the technique in terms of best return; a decoupled approach to offering the donation option improves consent rates; therefore a decoupled approach ought always to be used.



Nurses and transplant coordinators do take up timing as an important way to influence a family's decision. But they also appreciate the basic decency of it as evidenced in the following excerpts in which an ICU nurse describes her concern with timing the approach to the family.

> LD: So, what is your concern in mentioning it too soon? What would happen?
>
> 2A: I think families would probably be in, in shock, or I, I'm more afraid that they might get turned off by it, thinking that, you know, your interests are not in maintaining somebody alive, more so than your interest in maintaining, I mean, just trying to get them to consent to being an organ donor. Because I think they're, you know, they're, they still think that you're treating them as somebody who will, who will live, versus somebody who you know is just there because they're a potential donor...(2A1.int; 12; 456-470)
>
> 2A: [the family thinks that] the approach and the care of the, the particular patient is different. So, I think they would probably be angry. They would be very angry towards the staff. They would probably take their anger out on the staff. Them being, you know, them being, them listening, really. I don't think they're ready to listen to anything. So, I think you have to be very careful as to when you bring it up. Oh, sometimes doctors are terrible about it, you know, they just bluntly say, uh, you know, they're brain dead and, you know, you're, it's. But I think there's probably a more, that's probably why the donor network is, is really good about the approach. 'Cause I think once you turn off families, then, you know, to get them back to donating, it's just, I don't think that's gonna work.
>
> LD: What do you think they'd be angry about?
>
> 2A: Well, they would really be angry because the outcome is really poor. But they would be angry that, the approach is, that probably we're not gonna be aggressive enough.

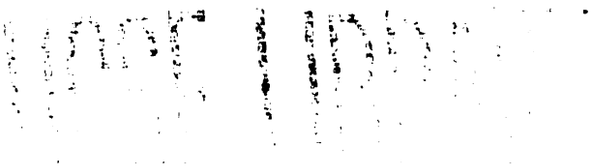
One risk of bringing donation up too soon is that the family will think the nurse or transplant coordinator does not care and that she is only interested in the patient and family because of the possibility of obtaining organs. This in itself is bad, but the



family's misperception of the nurses and transplant coordinators as being there only for the organs may cause the family to become angry and close off communication before they fully understand organ donation. This may result in the family refusing donation under a false understanding of the situation. If the family refuses under these circumstances, the transplant coordinators and nurses cannot be sure if their refusal was freely chosen or if it was unduly influenced toward the negative.

2A is worried that the family will be turned off if she mentions organ donation while they still have hope that the patient will survive. This is similar to 3A's concern and points to a distinction in forms of influence; making a bad impression on the family may influence the family's decision in a way that makes saying yes impossible for them. 3A, a transplant coordinator and 2A, an ICU nurse, both know they are not there solely in the interest of obtaining organs. Sensitivity to timing can let the family know and appreciate the transplant coordinators and nurses as care-givers first, and as first interested in the family's experience and only secondarily in obtaining organs. In this view, this is a good kind of influence because it provides freedom for the family to say yes or no and further illustrates the way etiquette provides the social space in which ethics can be acted upon.

Deciding on an appropriate time to talk to a family about donation depends on the situation and on the particular family. 3A gives a rule of thumb - the family needs to accept brain death before anyone mentions donation. This rule is referred to in the organ procurement literature as a decoupled approach discussed in Chapters 1 and 2. Providing the family with information about their loved one's condition and letting them assimilate



the information before moving into a discussion of organ donation seems intuitively proper. But proper timing demands sensitivity to the particular family's understanding of the situation. This sensitivity is important in a relational sense in that it both builds and requires a relationship between the family and the transplant coordinator or nurse. Each family is different and the timing of the organ donation discussion must reflect this as pointed out by the next excerpt.

> 2F: And I think it's important in being able to assess where the patients family is. You know, to be able to listen to that, you know, 'cause that's, I think that's my, my biggest thing, is you have to listen and hear what they're asking you. And if they're at a point where, you know, they're asking real inappropriate questions, you know, they're not ready. I mean, it, it, it's just, I think you're causing more problems than it's worth at that point. Instead you get to the point, you know, I, I try to be really honest with people, if they're asking me, oh, well, is he getting better or something like that, you know, I'll say no. He seems to be getting worse or he is the same. And this is what, you know, if they ask me, this is what I think, you know, where we're going here. And then, you know, they say, well, what happens then, you know, I might bring it up. Or, you know, if it's getting to the point where it's really close. I don't know, you, you just have got to treat each situation differently. There's no real stock answer. That I think it's a matter of identifying the people who it's really appropriate for and being able to feel out the family to see what they're able to deal with. And sometimes, I mean, it's perfectly fine to punt to the donor network. (2F2.int; 3; 111-126)

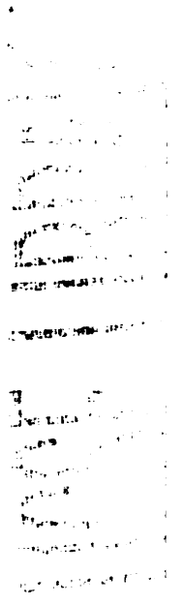
2F describes the need to tailor one's approach based on a read of the family. How the family responds to coaching on prognosis (discussed in Chapter 5) and what questions family members ask can help direct the nurses toward or away from a discussion on organ donation. This requires contact with, and attentiveness to, family members and the family as a whole. As discussed in Chapter 5, nurses spend time in the patient's room answering family members' questions at the bedside and determining their

readiness for information. This builds their relationship with the family and contributes to their determination of the proper timing for a discussion of organ donation.

Choosing when to bring the family into the discussion of organ donation involves attentiveness to the readiness of family members. As discussed in Chapter 5, coaching family members to understand and believe the patient's prognosis from brain injury to brain death can help prepare them for the organ donation discussion. But it is important to the nurses and transplant coordinators that the family be kept in the dark about donation until they are perceived as ready to hear it. It is common for the transplant coordinators to be in contact with the ICU without the family's knowledge.

> 2A: At least from what I've been, I remember being educated on by the, the donor, donor, um, coordinators as basically let us approach the family at the right time. So, I try not to even mention it to the family about organ donation until they come in...in fact I find myself being discreet about calling the organ donor network, and, you know, going to the other side of the station saying, oh, I've got a potential donor for you, because, you know, it's, it's still, for some, you know, for most families, it's still such a, you know, they're still going through the shock of losing somebody, you know, versus saying, they're already dead, they're already brain dead. So, you go to the other side of the station and just, kind of, make the call, and say, well, we've got somebody here. (2A1.int; 11; 420-429)

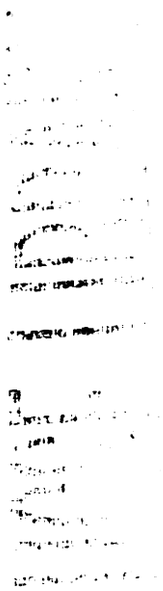
Like most ICU nurses, 2A calls the OPO early to alert them of a potential donor. But she is careful to keep her call a secret from the family in order to preserve the proper timing. During an observation with a transplant coordinator, the transplant coordinator arrived at the hospital to evaluate a potential donor who had not yet been declared brain dead. She spied on the room from an abandoned nurse's station around the corner so as not to be seen by the family before she thought they were ready. At one point we walked



casually past the door to the patient's room and glanced nonchalantly in to see if family was there. When the transplant coordinator saw a man she thought might be the patient's husband we kept walking without stopping and went back to the abandoned nurse's station.

This undercover work allows the transplant coordinator to begin evaluating the patient as a potential donor without involving the family prematurely. The transplant coordinators routinely review patients' charts before the family knows they are involved and before the family knows organ donation is a possibility. This practice is tied to the importance of timing and points to a distinction the transplant coordinators and nurses make in practice; the delay in confronting the family seems manipulative because it involves withholding information. Both 2A in the previous interview excerpt and the transplant coordinator in the observation seem to take up timing as a technique that may improve the chances of consent. In this view, timing is a way of manipulating the family or orchestrating the process of requesting donation in order to increase the chance of obtaining consent. But from the transplant coordinators' and nurses' perspective, keeping the family in the dark about the possibility of donation is in the interest of protecting the family's choice; to disregard the importance of timing and risk choosing an inappropriate time to approach the family risks offending the family and thus is influential in a way that may preclude consent. If a free choice is what is important, closing off the possibility of consent is as wrong as closing off the possibility of refusal.

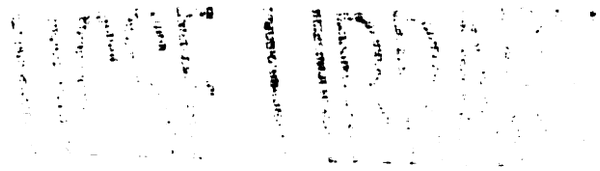
Regardless of the nurses' and transplant coordinators' intent, the use of timing is in some ways dangerously close to manipulation and illustrates what can happen when



etiquette becomes an instrumental technique that is disconnected from ethics. In some situations, the preservation of perfect timing ought to be let go in favor of respect for the family. The following excerpt clearly points to this possibility.

> 2B: But, um, I didn't feel good about asking the family yet I felt like it was something that probably sh [should?], y'know, when somebody comes in that we identify as an organ donor, we automatically call the organ team. Always, even in cases like this. And, um, in this case they came out, and, um, they waited hours before they went in and talked to the family and the family declined. I knew this family was going to decline. I did not approach the family about it. Um, just by talking to them, interacting with them, I knew that they were gonna decline so I, I let the organ team go in, um. I felt uncomfortable with this case, this woman I'm talking about because, um, again, because the organ team was there they wanted me to draw some lab work, and I felt really awkward about that, drawing lab work on a patient that, brain dead, and we're just waiting, family was there, we were just waiting for another organ team member to get there so that they could all talk to them together, and I needed, they needed to send off some serology, and I needed to wait until the family stepped out for a minute. And then I was afraid they were gonna walk back in and say what are you doing? It put me, that's what I told the organ team, I said you put me in a very awkward position.
>
> LD: I'm confused about which patient you're talking about.
>
> 2B: Not the one that went through. This other one, the or, the um, let's just say fer, the Asian family that, again, with this one, even though I knew they were gonna say no, and they did say no to organ donation. Um, yet I had to draw some blood work on them, and here I am drawing, and they knew that she was brain dead, family knew that, um, so therefore if they would walk in and say why are you drawing blood work? Well, because the doctor wants. I mean y'know? And I, I felt like I was in a position where I might have to lie to my family and I'm not going to do it. So it was very awkward, and, and I knew that they would say no. (2B2.int; 7-8; 280-304)

In this excerpt, 2B's description of the situation as awkward points to the difficulty with separating etiquette from ethics and using it as a technique to increase consent rates. 2B is put in the position of going behind the family's back to draw blood for a test related to organ donation that the transplant coordinators want to do before they



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approach the family for consent. She feels the wrongness of this; it makes no sense to draw blood once the patient is brain dead and she would be unable to justify this action to the family without their consent for organ donation. In this example it becomes clear that etiquette as technique is in conflict with ethical practice. Drawing the blood before presenting the organ donation option to the family violates 2B's ethics while preserving the technique of delaying the approach until the ideal consenter (the transplant coordinator) identifies the best possible moment as defined by a body of research that uses consent rates as its measure of success. Application of the technique may, in the long run, increase consent rates (although in this case the family ultimately declined) but 2B is unwilling to give up ethics in favor of increased organ procurement.

Responding to the Particular Family or Family Member

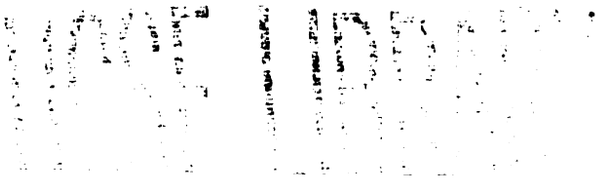
Once the transplant coordinator or nurse perceives the family as ready to talk about organ donation, they can begin to explore the option in detail. A good consent experience involves exploring what organ donation may mean to a family or to the individual family members and getting a feel for whether or not the family member feels free to say either yes or no to donation without he or she feeling inappropriately influenced, manipulated or coerced. The distinctions the transplant coordinators and nurses make between influence, manipulation and coercion show up in their narratives of practice situation that have stood out for them. In the following excerpt, a transplant coordinator talks about her experience with a brain dead three year old child whose mother was jailed for suspected child abuse and homicide. Her description of what made

this case memorable for her helps clarify how the transplant coordinators make these important distinctions in practice.

> 3B: Um, the most memorable case in the five and a half or so years that I've been doing this, close to six now, um, had to do with a child who was an infant. He was, um, about two years old and he had been brought to the, to a [name of hospital] after being, um, found by the police. And, um, the police were raiding a house in [name of city], uh, looking for, um, two men who had parole violations and their sister was there at the house. And, um, they had a search warrant because they were searching for the two men. And, uh, they went into the closet and in the closet they found this huge pile of like bedding and linens and they moved it because they though well, he could be underneath there. And they found this child wrapped in blankets. It was described as, um, like a burrito in the report. And, um, the child was, um, you know, barely breathing, um. He was taken to, uh, [name of hospital] and, um, within a day or two was brain dead. Um, this is kind of when I was called in [laughs] and, um, the report that I got from like social worker that had been working with the family was that the mother was at the jail accused of the murder of this child and the, um father. I ne-never actually met the father, but what I had heard was that, um, the security, um department at the hospital had been called multiple times to, um, take care of problems at the bed side, removing family members and arguments and fights and difficult situations, you know. And so, um, that was the situation that I was called to, um, try to obtain consent from the family. And, um, it's kind of interesting; I worked with the social worker there at the hospital who was very, um, wonderful woman who has worked with us in a lot of cases and they know also about the process and so it was very, very helpful to me. And, um, one of my first concerns was, you know, to evaluate the patient and the, the patient certainly seemed suitable to be an organ donor. But, um, there was no family there at the hospital, it was how to talk to them about donation. But he came to the phone and she said, well, y'know, and she talked with him for a while and then she said, you know, I-I need to ask you something and it's kind of a difficult question. And he said oh you mean about that donation? Sure, we want to give. [laughs] So we were all, like, oh, very shocked by this, you know. I never thought that they would ever have considered that. So, um, but the father, you know, was very angry with the mother, you know. They hadn't been together I don't think since the child's birth. It was kind of, they weren't married, you know, they hadn't really been together. But he was real angry about the situation and basically said that, you know, all I needed was his consent and, you know, she should have nothing to do with it. But I know legally that, you know, even in cases where the, um, the next of kin is the perpetrator or the cause of the murder, because I've had other cases like that, you still need to obtain consent because somebody is innocent until proven guilty.

So the mother still had legal rights in this. So, um, I, um, the social worker helped me again and we contacted the jail over in [name of city] and the arrangement for, for me to go there. I actually talked to the mother on the phone just briefly, but she was crying so that I, um, I said I can't really, you know, it wasn't like I felt comfortable, like I could talk to her. So I said I'll just, I'll just come over there and talk to you about it. And so she wanted me to do that and. And I went to the jail. I just remember I was so nervous, I was so, um, excited and nervous because I, you know, I didn't know how I would feel about the woman, you know, if she'd killed her child. I mean I didn't know if I was going to see a murderer or if I was going to see a grieving mother, you know. I was kind of like really torn on my way there, wondering how I would respond to her, you know. Because she was responsible for her child's death. And so, I just remember, I mean, getting frisked, and all my paperwork being looked at and waiting in different things for doors to unlock and then [laughs] my first experience at the jail! And then being taken into a room, um, with her and a, some sort of a worker from the, I don't know, it's just some social worker sort of person from the jail. And, um, she was, it was interesting 'cause she was clearly a grieving mother. She explained to me that, um, you know, in her own strange way, um, I don't think she in any way meant to kill the child. She said that, um, the child had an ear infection and was very irritable to sounds and, uh, she was trying to, to, uh, pad him or protect him from the noises. And, um, but she also admitted to shaking him before she put him in the closet because of her frustration. Then I also, you know, found out from her that she had, uh, she was 22 and she had two other children. This was the youngest and she had a, um, an older child and then the middle child was somehow mentally retarded, I don't know if he, what it, to what extent, but, had, had a lot of special needs. So here she was, 22 years old, with three children, no husband, lived at home with her parents and her brothers that were, you know, parole violators [laughs], or whatever, you know, criminal, uh. So I, you know, I, uh, but she wanted to donate. I felt she came from a very, um, loving place, to help other children. Um, she was, um, she understood. I said, um, it's very clear to her that, 'cause I had never done this and I thought that any decision that she makes regarding donation has nothing to do with what's going to happen to her in the future, with this, and, and she understood that. And, um, signed the consent. And, um, it was a, s-really, it was an experience I'll never forget, no, obviously.

In this narrative 3B does not hesitate to meet the child's mother even though the circumstances are unusual and the meeting takes a special effort to arrange. 3B is satisfied with telephone consent from the father who right away agrees to donate and whom she identifies as angry with the mother and as having been only minimally



involved in the child's life. Her main focus is on the mother, who is in jail accused of killing the child. Prior to meeting the mother, 3B does not know how she will respond to this woman accused of murdering her child but feels a face-to-face meeting with her will help her understand the woman's story. 3B's description of her trip to the jail demonstrates her concern with knowing the mother and understanding her motivations. If she were interested only in the legal requirements of informed consent 3B could have completed the process over the telephone. The rules of consent require that consent be informed and voluntary. Deciding how to ensure these requirements takes judgement. Telephone consent may have been adequate in terms of providing information to the mother and offering her the choice to donate or not to donate. But, in order to feel comfortable with the mother's response, 3B must be sure the mother feels free to say either yes or no to donation and that her decision is not based on some false hope of personal gain or on some other misunderstanding of what donation means. 3B pursues a face-to-face meeting because the situation demands a face to face meeting; 3B wants to spend time with the mother and get to know her story.

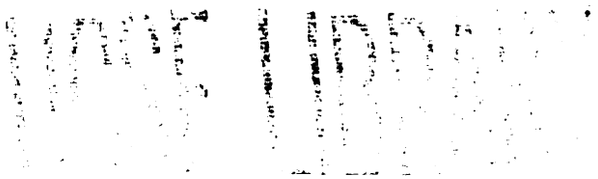
When 3B meets the mother she realizes the woman is grieving and is convinced her desire to donate her child's organs comes from her desire to help other children. Because she was able to form a relationship with the mother 3B felt comfortable that the mother had chosen organ donation freely from her own desire to help others. Getting to know the mother and understand her story helps 3B make distinctions between acceptable influence, manipulation and coercion. 3B already has an idea of what counts as manipulation and coercion and of how far she can go with influence without being



manipulative. But, through her efforts to understand the child's death from the mother's perspective, 3B can get a better feel for the boundaries of acceptable influence within the context of this relationship and the distinctions become more obvious. 3B finds that in this relationship, coercion might have shown up as offering to reduce the mother's jail time if she agreed to donate the child's organs. This tactic would be coercive because it implies the threat of more severe punishment (IE: longer jail time) if the mother refused to donate. It is manipulative because the transplant coordinator has no power over the courts and could not carry the promise through. The mother's response shows 3B that she had not been manipulative or coercive but had engaged the mother and formed a relationship with her that allowed the mother to feel safe in telling her story and sharing her motives. In the end 3B was sure the mother had felt free to say either yes or no to donation.

The importance of relationships in forming distinctions between influence, manipulation and coercion is explored further in the next excerpt from and interview with a transplant coordinator.

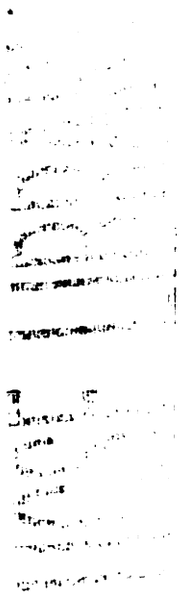
> 3A: I thought about it and there was a case three years ago on Thanksgiving. It was a 36 year old man who had been hit the day before by a drunk driver. And he was a married guy who had five kids and one child on the way. And one of my coordinators, one of my colleagues had been on site from about midnight til six or seven when I got there to relieve her. And a real difficult situation, he had finally herniated, they were starting to declare him and his wife, when I got there, his wife wasn't there at the time. Um, he had been very unstable, kind of turned around and was a little bit more stable for me, and I was relieving my colleague to get consent from the wife and just as kind of really start the whole process though we had been managing through the night. I was taking over management and to try and obtain consent from the wife. Um, I think around ten or so she came in and we did hold a family conference. It was a Mormon family, needless to say,



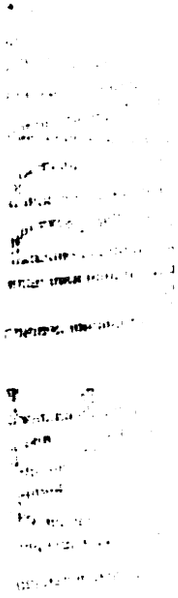
very distraught. She did not work, they were on a minimal income and she had all of these issues of not only was her spouse dead, she was pregnant and she had no financial way to support her children, um, and she was facing the most major loss of her life. And consent went back and forth for quite a while, or, you know, the issues about consent and talking to the family and having other members in there. They finally did agree that donation was what they would want to happen. And the family stayed on and off throughout the whole day. His brother and sister, his wife, his parents came in and out of the room, and because he was such a young man it was really such a difficult situation. And around the same age that I was, um. We finally did get all of everything placed and we set up an OR time of 11:30 at night. And the family stayed at the bedside until we went into the OR. And one of the main issues that happened with him is, he was pretty stable and we were placing liver, kidneys, and his heart, I don't know about, I don't remember. I think his pancreas also. Um, he had very active spinal reflexes and it was extremely confusing for that family and I kept going over and over and over about spinal reflexes and how it was different than a purposeful movement. But they were highly religious and it was a hard thing to grasp that he would move his leg. And we were there with the teams. The heart team got there first from [name of hospital]. We were there with the teams and one of the docs, it was to the point where the family was almost going to say that they couldn't donate because they were struggling so much about what was happening with the patient and the movement. And one of the heart doctors came in and re-explained to them about spinal reflexes and reinforced everything that I had said and spent probably a good twenty to thirty minutes with that family. And again, just reinforcing everything that the family had heard throughout the day. And at that point in time, the family could let him go. And, um, we did go in and recover organs on him. But it was, it was extremely difficult case, a long case, you know, a good more that 24 hours and, just emotional issues, hard not to relate your own personal life.

LD: So what you described as her struggle with whether he's dead or not, that came before she gave verbal consent?

3A: Mmm, it came afterwards. She gave consent and he did not really have active spinal reflexes. And then about ten o'clock at night, or actually I saw it even earlier, but the family hadn't been in the room, and I had explained about reflexes, but until you see them, they're pretty hard to really understand and when you see them it will freak you out. And you start to question yourself. Now I didn't because we had two brain death notes on the chart, I know the doctors well, I had done my own clinical exam, but I went in after seeing the spinal reflexes, I, and the family seeing the spinal reflexes, I went in and did a neuro examination in front of the family showing them almost all of the things that we would do, without becoming invasive, to check for response. And reassuring them that we would not be doing this if we were not positive that he had had, um, he had met

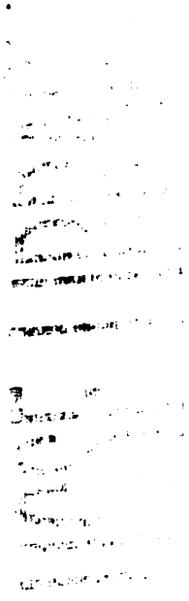


brain death criteria, you know. I looked in his pupils and I had them look in his pupil to see if they saw any reaction, um. I tested for deep pain, I suctioned him to see if there was a cough, I put a, a q-tip down his throat to see if there was a gag. We tested for corneal reflexes, and I even took him off the ventilator for about, oh, probably three minutes or four minutes to show them that his chest did not rise and fall. But he continued to have the reflexes, you know, movement without any stimulus. And it would, it's just a very hard thing to understand. And one of the analogies that I give is, um, or two analogies would be a chicken with it's head cut off, or a snake. You have to do those in a very delicate manner, but people that live out in the country can understand those a little bit more. Or a lizard that loses it's tail, the tail can continue to move because there's a kind of a spinal reflex there until it stops, um. So intellectually they understood that, but it disturbed them. And it disturbed them for, you know, until we went to surgery, until that physician came in and talked to them. [some text deleted] If this family had still struggled, at one point, during this process when they were struggling about these spinal reflexes, I had said to his wife maybe this isn't something you should do. Maybe this isn't the right decision. And that I support you in your decision because I want you to be comfortable and I want you to be sure. And if you are not sure, then I don't think you should do this. And she had been very sure until another family member came in and started putting questions into her mind about the spinal reflexes, about some other things. I can't, it was mainly about the spinal reflexes. She had been very sure. She understood that he was gone. He, he looked dead. Some patients don't look dead, but he had been a severe trauma and he had, you know, he had third spaced and he was swollen and he had, you know, massive head injury and was bloody and cut and so on and so forth. So he looked dead. But it wasn't until another family member came in and started questioning that she started questioning. And I did support her and tell her that she could change her mind and that it would be fine. And, I think, really what kind of turned her around was that physician coming in and talking to her. We were very lucky that we had an excellent physician that could come in and talk to her in a very down to earth manner and explain, re-explain all the things that was so reassuring for me. Because she, he came in and almost verbatim said the same things that I had said and thanked the family for considering donation. But again said that they needed to be comfortable with their decision. And in the end they had said yes. So, it was a heart-wrenching, draining situation in that sense. I couldn't believe that I had gotten to the point of having my teams arrive and that the family was gonna back out. I truly believed that donation was gonna help this family and it has. You know, in my follow-up it really has helped them. But at that point in time, I just couldn't believe that they were gonna decide not to do this. And, um the emotions, you know, I was to a point where there was nothing more I could say to that family. The nurses had supported me and, you know, kind of tried to sup-, and were supporting the family completely, but were trying to tell them about spinal reflexes, um. But they needed an authority figure more so than I was, I think to just reassure. But I was just, it had been a long day,



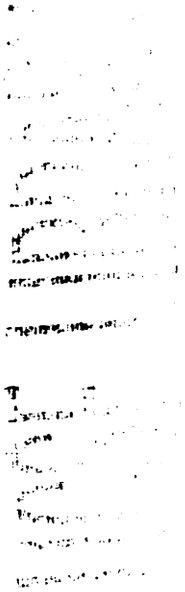
I was tired and I just was in shock that this was down to the wire and it wasn't gonna work. Here was a 36 year old man we had placed, as I remember, you know, four of his organs. And it wasn't gonna work out. And my teams were there. And I'm saying to this family, you know, you don't have to do this. Um, when they made their decision it is one of the most difficult things to have the family in the room and wheel that patient out of the room with all of us dressed in our OR gear. And that family following you to the doors of the OR. And, um, I'm a pretty emotional person, I cry a lot with the family and watching his wife say goodbye and she is seven months pregnant and struggling, knowing that this is the last time she's gonna see him warm, and see him with a heart beat. Um, it's, it's tough and I cried. I cried saying goodbye to them, I cried walking into the OR, um. One of the transplant coordinators that came for the heart came with a friend of mine. And thank goodness because she kind of, you know, I have a role once I get into the OR and I was a basket case. It took me, you know, 20 minutes to regroup, to try and, you know, be able to function again as in my role instead of as somebody in grief. I think that's one of the things that happens is, at least with me, you know, I said again, I believe that the patient is gone, I believe he's in a better space. But the family brings that patient alive to you or not alive, he, he's dead, but brings that patient real to you. And you learn about that member of the family and you learn about who he was and you can sympathize with the family. And it breaks your heart, and I grieve for these people. And then wheeling that patient out into the OR and watching them, you know, watch you, I just am a basket case. It doesn't happen every time, thank goodness, but there are those times that it's so difficult, you know. Your perfect scenario is if the family goes home early and you can kind of regroup and become a transplant coordinator again and look at the patient in a very clinical manner instead of looking at the patient as somebody's husband, somebody's father. I'll always consider them that, but I know they're gone. It's the family that makes them real. So, it's tough. (3A1.int; 6-8; 231-351)

3A: We got consent with his wife who was his legal next of kin. But included in the process was a sister and his parents. And his parents were elderly, elderly meaning, you know, probably in their seventies. Um, 'cause he was one of many children. I don't know where he fell in the chroni-chronological order, but, um... you know, and very religious upbringing, Mormon upbringing. [sighs]. And it was just, you know, a lot of explaining and reassurance and letting them know that their son would be treated with respect, that he would be taken care of, that there would not be any mutilation, that's a big issue, I don't use that word in the family conference, but I do reassure families that there's, their loved one will be treated with respect. And I think that that brings comfort. They were glad that he could help others because that was the kind of man that he was. He was just a very generous person, um. His wife did sign the consent, his parents did co-, sign the consent. There wasn't any issues of, you know, problems between the, those two entities, um. It just was a long process because they needed, you know, a lot



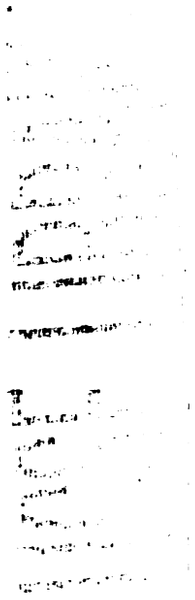
> of reassurance, they needed to know, you know, would this, how long would this take, and, just was he really gone and re-explaining brain death and even though they knew that he was, they needed to hear it again. And so not only the doctors have mentioned donation or mentioned brain death, but we go in and re-explain it and speaking of that, the doctor, one of the doctors is the one that brought up donation first. And we try to not have that be the scenario but very often at [name of hospital] they ha-, they feel the need to be the first ones to mention donation. And in this case it was a family that didn't freak out about it. They just needed to know that he was finally dead to finish that, um, and have closure before they really agreed upon it. The process of consent went on for, we had our initial meeting in the, his wife came back around ten in the morning. I introduced myself to her and then the whole family, his parents and his sister and his wife gathered again in the early afternoon and we sat and talked for quite a while. The wife wanted to go home and see her kids and then came back in the early evening. And she had given me verbal consent but the actual signing of the consent probably wasn't until five or six at night, when she was at a point to, to really sign the consent, um. So, you know, it's not a quick process. (3A1.int; 4-5; 161-227)

The transplant coordinators are committed to the idea that organ donation is not right for every family. What makes donation right or not right depends on the family and on the context. In 3A's story, organ donation seemed right for the wife because of the family's Mormon background and history of giving. But it also may have been not right because of the wife's interpretation of spinal reflexes as a sign that her husband was not dead. In contrast to the position that organ donation ought to be taken up as a family's duty to its community, the transplant coordinators make it clear, as illustrated in both 3B's and 3A's stories, that it is the individual family's decision to donate or not to donate, and that the family ought to make the decision free of influences outside itself. But the transplant coordinator 's respect for individual choice does not translate into abandonment. When the wife in 3A's story hesitates over her decision to donate her husband's organs, 3A does not walk away. She stays to help the wife understand brain death while always leaving open the option to decline donation. In this way 3A feels for



the boundaries of acceptable influence within the context of her relationship with the wife. 3A has concerns similar to 3B's in her story of the family man who died in a car crash. Like in 3B's story, the rules of consent can take 3A only so far. The wife, in collaboration with other family members, initially gave consent for organ donation then had second thoughts when the body began showing reflex movements. The situation prompts 3A to coach the wife with what seem to be crass analogies: a chicken or a snake with its head cut off, or a lizard's tail when it first detaches. These analogies could be characterizes as simply another way of providing more information. But 3A's discomfort and nervousness point to another, more difficult question: how can a transplant coordinator in this situation know when she has provided enough information and in the proper form? The transplant coordinator could make a rule: when a family still does not understand brain death after x number of explanations, move to the chicken-with-its-head-cut-off analogy. But when does more information or another explanation become manipulative?

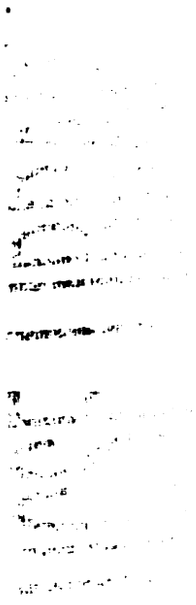
The answer to this question can only be provided contextually. General distinctions between influence and manipulation are helpful as a starting point, but the difference between a manipulative act and an act that helps the family or a family member clarify her position depends on the situation, the experience of the particular family and the relationship that exists between the family and the transplant coordinator. 3A spends time getting to know the family and it is this intimacy that helps 3A get a feel for the moral boundaries when she pushes the wife to understand the body's movement as a manifestation of meaningless reflexes. 3A feels for this boundary in this circumstance



and finds herself providing more of a particular kind of information. She brings in one of the transplant surgeons to go over the information again. But at the same time, 3A stays open to the idea that organ donation may not be possible for this family in this context; if the wife could not believe the movements she was seeing were reflexes and that despite the fact that the leg moved her husband was dead, she would not be able to freely agree to organ donation.

In the next excerpt, an ICU nurse is talking about a brain dead Filipino woman whose husband left the donation decision up to the patient's mother who had first said no to donation. The ICU nurse's response to the mother's refusal is in contrast to the transplant coordinators of the previous excerpts.

> 2C: I got, you, you observed me on that lady that's almost the same age as me and she's also a nurse. So, and she's also my nationality, so. Going in with the family knowing I can really relate to their beliefs. [Name of another nurse who might have taken care of the patient that night] right off said no, she's not going to go through that 'cause I think she went through another donation the night before. So that's the reason why she didn't, she's too overwhelmed. And I said if nobody wanted, then I'll, I'll go since I'm fresh, kinda from days off. But I didn't know it's gonna be that much for me. I, I thought it was, I can block myself. Sometimes you, you know, you kinda tend to just block your emotions, but it's hard. I talked to the family and the mom and the, uh, da-, the oldest daughter. She was so good and I, you know, she was saying to me, you know how we are, how, you know how we believe that you don't take any organs. And I said, I know, but do you know where you are right now? We are not back home. I know we believe that in the Phillippines. But when you come over to another country, their beliefs is a lot different than ours. But I think there is already dona-, donation going on in the Phillippines. It's just because of the, um, Catholic issue, you know. Roman Catholic and, it's the religion, actually. But I said, your grandchildren, her kids, I have to block myself, otherwise I cannot go through it. I just have to go to the, um, OK right now [laughs]. The practicality of what's going on and I said, you know, your grandkids is gonna be living here. How if, god forbid, they get sick and they might require some kind of organ. And right then, you realize you refused donation and then you wanted something, don't you



want, do, would you think that you'll feel guilty trying to get something and then not being able to, it's a give and take, you know. She said, oh I never thought of that. And then she kind of had a different direction, a kind of different view as far as that's concerned. I said, you know, your belief and their belief is completely different 'cause they're already born here.

LD: Oh, the grandchildren.

2C: The grandchildren. And they're gonna be living here. I know you're going back home and coming back . You're visiting and coming back home. I know you're gonna be the one that's gonna be deciding for her but, aren't you gonna think of them and what your daughter might think? Because I bet she will be thinking the way I think. She's also working here. But she said, how about you, if you get in an acc-, in an accident or something. I said hey, I'm giving everything. I told her. I told my husband that already. I said I've gone through that to him, with him and I've seen every possibility, patients might need it and some people that really needed it. But I told her if anybody wanted my, any of my organs and I am in a situation that I can give it, I am willing. [Your daughter]'sin the same field that I am and she knows everything what's going on and what people go through. And she [the mother] said I'll think about it and, couple minutes, she went out and she came back to me and she said OK. I think kidney, the kidney is OK.

LD: Kidney is okay.

2C: 'Cause she has, she has the family member that has been waiting for a kidney. But, you know, doesn't mean that her daughter has uh, the same, because they already have [noise], you know, for compatibility. It's not, they have asked everyb-, I said, well, does that give you something to think about? That's what, she turned around so easily after that, when I, when I made that question. And then later on we proceeded to the donation process. And she said OK, one kidney. I said, you remember, we have two kidneys? Oh, I didn't know that [the mother said]. I said, you know, we got two kidneys, two kidneys, one here and one there. That's why when one fails the other one can take over. We can still survive with one kidney. Oh, OK, two kidneys. I didn't realize we have two [the mother is saying]. So, there are some people that are ignorant to that we have to give them all this information to make a decision. I know it's hard to make. Sometimes people will say, you don't imply or tell them what, you know, to make the decision. You just give them all the information and then they can make the decision, that's it for me, I think.

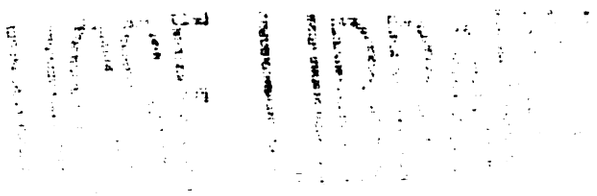
LD: Is that what?

2C: That woman didn't know as far as, you know, I figure, well, she has her own beliefs but let me say what my point of view, and she can make a decision. It's not I am telling her she has to, you know, I never do that. I ne-, you know, I know sometimes we have to make, because they are not in their ca-, capacity to just make a decision at that time because of all the anguish and all denials. We still go through that, the grieving process. But sometimes if you get just, lay down all the information and all the things they should know, even though sometimes it doesn't go through, and most of the time it doesn't, I tell you. Nothing that you tell them stays. They turn around and they ask you the same question over and over and over. But just be patient, just keep on saying, I always just keep on telling them. Anything they ask me I answer right away. Even if it's the same question they asked five minutes ago. And it will go through, one, one way or the other, it goes through anyway.

LD: Your information gets through.

2C: Yeah. That's the only thing I remember as far as that is concerned. Actually the donor, um, who is that, um, is it [name]? No, it's not [name], [another name], from donor network. She called me and thanked me for that. I said what did I do? I mean, I don't even remember what I did. She said well we thought we won't be able to get that patient and there's something you said that made them change their minds at the last minute. And I said, well, all I said is just put yourself in the situation at the other end, that's all I said. (2C1.int; 2-4; 38-125)

The ICU nurse in this excerpt used shared culture to influence the mother's decision. She focused the mother's attention on what the daughter would have wanted and made her see donation from the recipient's perspective. 2C's tactics seem harsh considering the woman has just lost her daughter. But 2C was able to help the mother see organ donation in a way she otherwise may not have. Her tactics are different from the transplant coordinators' in that they focus less on protecting the individual family's choice and more on helping the mother understand how communities work for all citizens. When the mother refused to donate, 2C reminded her of her obligations as a citizen who may some day be in need. This simple reminder opened the mother's eyes to her position as a member of a community who is dependant on, and obligated to, others.

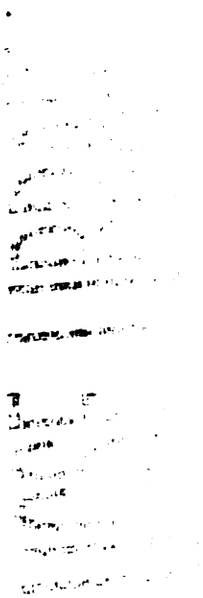


2C's approach is in contrast to both 3A's and 3B's. The transplant coordinators build their approach on the importance of individual choice free of manipulation. 2C clearly tries to change the mother's mind although in the end she does not recognize her conversation with the mother as influential. This disclaimer at the end of 2C's story illustrates the power of the free choice paradigm. Even though she encouraged the mother to go against her original choice and meet her community obligation, 2C still felt the need to play off the mother's final decision as freely chosen. The mother's final decision split the difference between her inclination not to donate and her feeling obligated to donate; she agreed to give one kidney and 2C negotiated for one more. Rather than push for kidneys, heart, lungs, pancreas, small bowel and various tissues, 2C felt the mother's boundaries and stopped there.

2C's story points to the importance of accounting for culture in approaching the family about organ donation. Because she shares a cultural background with the patient's mother but is also an American citizen, 2C is able to pull both cultures together for the mother in a way that makes sense to her. Most people brought up in Western culture find what 2C says to the mother too influential and manipulative, not to mention rude and inappropriate under the circumstances. Yet, 2C puts into words a sentiment about organ donation most of us could agree on: if you are not prepared to give, you should not be allowed to take. This adage has even been proposed as a policy for organ registries in the United States whereby priority for receiving an organ would go to those who have donated or, if a person does not register in advance as a potential donor (by, for example, indicating intent on the driver's license or some other public record), she or he cannot be

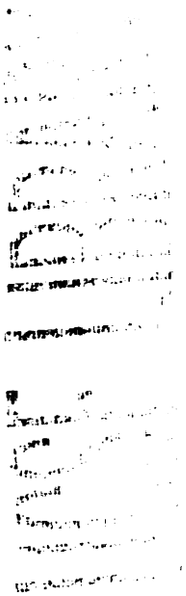
registered as a potential recipient (Prottas, 1994). This is one way to ensure the rights of citizens to decide not to donate while at the same time ensuring in one respect just distribution of organs. That 2C brings this idea up to the mother immediately after her daughter's death and uses the potential needs of the grandchildren as a leverage point to gain consent seems unsavory. But at the same time, 2C's honesty is refreshing; 2C speaks her mind as a citizen.

What all three of these stories illustrate is the need for a sentient connection and relationship in order to find the boundary of appropriate influence when approaching a particular family about organ donation. Each transplant coordinator or nurse got close to the family and was able to find the moral boundaries of influence in the particular context. This points to how the abstract concepts of influence, manipulation and coercion must be worked out in context and in relationship and dialogue with a particular family in order to gain full meaning. But the transplant coordinators and nurses do not form relationships with families as a means to realize these distinctions. Rather, in examples of the best practice, the transplant coordinator or nurse forms a relationship with the family as a good in itself or as a way of meeting the family. This meeting creates the possibility for distinctions (Benner, 1996; Stannard, 1997). The importance of relationship shows how the transplant coordinators and nurses identify with their practice and recognize their role in organ procurement as part of a larger practice with notions of good internal to it (MacIntyre, 1984). The transplant coordinators and the nurses in these examples take up organ procurement as nurses first in that they attend and respond to the



family as care-givers. This relational practice creates the social space that allows distinctions to show up (Benner, 1996).

As an example of clinical and practical knowledge, the skillful way these nurses approach the family with the option of organ donation illustrates what Aristotle called phronesis (Aristotle/Barnes, 1984). Phronesis is closely related to ethics and is necessary for ethical practice in that it is the way one gears oneself toward a situation and how one is then set up to respond to others in that situation (Dunne, 1993). Unlike techne, the other form of practical know-how that results in technique and uses technique to obtain a predetermined end, phronesis is concerned with action and conduct, with means rather than product. Phronesis does not result in a durable product but in the proper conduct of one's life or practice where practicing well is its own reward. Because phronesis is an expression of self in action, and because the agent is always already acting from a store of developed habits, phronesis can never be purely instrumental (Dunne, 1993). This is similar to how MacIntyre (1984) defines practice as having goods internal to it. Nurses have a practice in which certain ways of being are related to good practice and nothing else. For example, forming relationships with patients and families and being attentive and responsive are caring practices that nurses engage in not in order to produce a result but because of who they are as nurses (Benner, Tanner & Chesla, 1996). The fact that such practices do result in good outcomes in terms of healing shows the power of engaged caring practice. But good practice itself is an end in itself and not instrumental to another goal.



Nursing practice as illustrated by the two transplant coordinators and nurse in the previous examples shows phronesis. The nurses do not apply a set of predefined techniques to approach the family but stay flexible and respond to what the situation demands. They do not approach the family with the goal of gaining consent but stay open and ready to respond to whatever response the family gives.

Disruptions in the Consent Process

There are many places where the process of approaching the family about organ donation can break down. In the stories involving a disruption of the process or breakdown, the concerns of the transplant coordinators and nurses and the nature of the process can be further clarified. Three kinds of breakdown were observed: family misunderstanding the transplant coordinators' and/or nurses' position, dissent among family members, and the family being rushed into a decision.

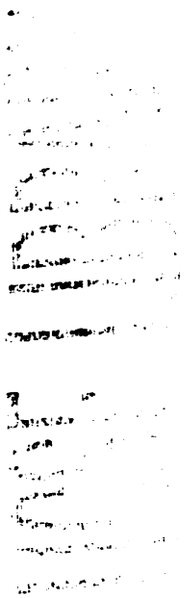
Misunderstanding the Nurses' or Transplant Coordinators' Position

The ICU nurses and transplant coordinators take up the work of organ procurement with a certain sense of what that work means and how they relate to that meaning. Certain values are crucially important to their interpretation of themselves as nurses and this influences how they orient themselves toward organ procurement. For example, a belief articulated by all the participants is that the ICU nurses and transplant coordinators are there to support the potential donor's family and offer them the option of organ donation. The work of organ procurement is secondary to this goal; if the family wants to donate, the transplant coordinator and the nurse facilitate the process of procurement.

Breakdown in the consent process can occur if the potential donor's family misconstrues the transplant coordinator's and/or the nurse's intentions as illustrated in the following excerpt from an interview with a transplant coordinator. The story involves a five-year-old child who was dying. The transplant coordinator had been called in to evaluate the child as a potential donor but the family had not yet been informed of the child's condition or that she was being considered as a potential donor.

> 3B: It was an African-American family and, um, you know, it was one of those situations where you couldn't help but having to step in because it was like nobody there to help this family to understand what was happening with the little girl and she was getting brain dead and all this stuff and I was, had quite a bit of contact and we got... I, I think that they just assumed that I was with the hospital or something like that. And actually, it came down to the mother came to me and said, um, well, it's, if she really is dead then we'd like to donate. OK, so then I said well, you know, I. Then I thought well, I should let them know who I am, you know, so if they have other questions or want, you know. So I gave her my card and she was fine, she was fine with it. But the grandmother who had been there quite a bit was not fine with it and she was chasing me around the [pediatric] ICU yelling, you just wanted her organs. That's all you wanted. That was the only reason that you were talking to us. I was, it was, I was quite new at the time. I don't think I'd been more than six months or so and I just remember sitting in the ICU just crying. I was so upset, you know, that, um, because it wasn't my intention, nothing she said was true, but it was still really painful, you know. And so after that it was like, I'm not gonna get so involved with anybody again to where they would try to, you know, they might see it that way. (3B1.int; 13; 573-592)

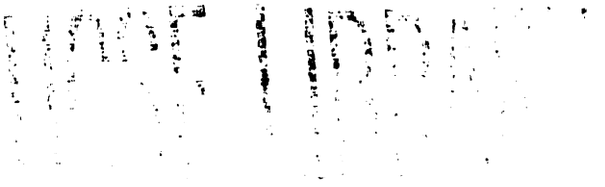
This transplant coordinator's conflict with the child's grandmother points out the power of the transplant coordinator's self-understanding and the tension it creates with the organ procurement situation. 3B steps in in response to the family's need for information. The family had no one to let them know what was going on with their dying child. 3B filled this need by providing information and helping the child's mother



understand that the child was dead. 3B begins to form a relationship with the family and the mother mentions organ donation as something the family wants. But when the grandmother responds by berating 3B for only wanting the organs, the consent process breaks down. 3B sits in the ICU crying over the grandmother's misunderstanding of her intentions.

In 3B's story, the grandmother's accusation is hurtful even though it is untrue. It implies manipulation on 3B's part and suggests that the support she offered the family was only in the interest of obtaining the child's organs. 3B explains her response as partly related to her newness as a transplant coordinator. In the next excerpt from an interview with an ICU nurse, the nurse responds differently to a similar situation. In the next story, 1A, who is an ICU nurse functioning in this situation as a transplant coordinator, is speaking to the family of a 16-year old boy who was killed in a drive-by shooting at his high school. A few years earlier, the boy's father had died in an accidental shooting while he was cleaning his gun. The boy's mother had been leaning toward donating his organs but his uncle, his father's brother, was angry.

> 1A: I went, at eleven o'clock I spoke to everyone then I came out, I said, 'Please come in, talk to him, touch him, and if there's anything we can do to help you with this process, let us know.' And [the uncle] never came back in, so I thought, well if he's not coming in, let me go to him. And I went out, and by this time the nurse, bedside nurse, had gone into the [waiting] room and [the uncle] was in there talking and she said, 'Are you okay?' And there was a lot of loud voices and things like that, and he said, [imitates angry voice of the uncle], 'Well I don't know why he's hanging around looking for organs.' And she said, 'Who?' And he said, [angry voice] 'That guy who spoke to us, that nurse.' So [the nurse] came up to me and she said, 'They're really angry and they're really angry, you know, 'cause they say that you're still hanging around.' So I thought let me go and speak to them. And I went and I spoke directly at [the uncle], I looked



> directly at him when I spoke, and I said, 'Is there anything that you need clarified?' And he said, 'No, everything's been clarified.' So I said you know you've got a right to, I spoke to the children first, that were there, and then I spoke to him and I said, you've got a right, I said, you lost your brother through a horrible accident, and now you lost your nephew, I said, you've got a right to be angry, and I said this is a very natural thing. And I said he was a beautiful child and a good child, I said, it's not fair. And [the uncle] just never spoke. Instead of looking a me he just looked down and kept looking down. And I went on to reinforce that family at this time, such a tragedy, that mom needed family to be strong for her, but it was alright to cry, it was alright to be angry. In this situation the family needed to stick together and they needed to support one another and [the uncle] was very, at that time her was like there was a moat around him, he was very angry and very insulated in that room full of people. (1A1.int; 13-14; 463-505)

1A's response to the uncle's anger is in contrast to 3B's response to the grandmother in the previous excerpt. Instead of backing away as 3B did, 1A confronts the uncle and forces his point. Even though the uncle has made it clear he has nothing more to say and that he is uncomfortable with 1A being there, 1A pursues his own agenda. He must reinforce his intent as to offer organ donation as an option, not to obtain organs as the uncle thinks. If 1A were only interested in organ procurement, he would do better to focus his efforts on the patient's mother who was already leaning towards donation. Instead, 1A is drawn to the uncle because the uncle is angry and because he has questions about 1A's identity that 1A wants to clear up.

These two stories demonstrate one way the process of offering organ donation to a family can go wrong. The breakdown is related to the relationships between the transplant coordinator and the patient's grandmother in the first excerpt and the nurse and the patient's uncle in the second excerpt. Because they perceive the transplant coordinator or nurse's presence as instrumental to the goal of obtaining organs, these

family members undermine the transplant coordinator's and nurse's practice in a way that cannot be repaired. By questioning 3B's self understanding at a vulnerable time in her career as a transplant coordinator, the patient's grandmother disrupts 3B's ability to pursue the organ donation discussion. 3B is certain now that she is there to support the family and that obtaining consent for donation and then obtaining organs for transplant are secondary goals. But when the grandmother responds with anger, 3B cannot recapture the rapport necessary to make the distinctions important to providing the family a true choice. This breakdown in trust and 3B's inability to redirect her relationship with the grandmother may have been related to 3B's newness as a transplant coordinator. But, given the grandmother's anger and her understanding of the situation, even the most experienced transplant coordinator may not have been able to rebuild a trusting connection.

Similarly, the uncle's anger prevents 1A from forming a meaningful relationship with the family. The uncle's anger and misunderstanding of his intentions puts 1A on the defensive and instead of responding to the family he lectures them on what it is alright to feel. In this way he reinforces his own concerns with supporting the family; for him, too, organ donation is a secondary concern and he wants the family to understand this. However, 1A pursues this end to the detriment of his relationship with the uncle whose anger seems to worsen as 1A repeatedly intrudes on his grief and attempts to regain lost credibility as a source of support.

These two stories are examples of breakdown in the organ donation discussion not because the encounters end in the family choosing not to donate. In the first story it is

never clear whether the situation ended in donation or not. What these stories point out are two similar situations of breakdown in the process and relationship leading to the family's decision. In both cases the disruption occurred because a family member misunderstood the nurse or transplant coordinator's intentions. 3B's and 1A's responses illustrate how important it is to them that the family perceive their role and responses as that of caregivers rather than as only instrumental to obtaining organs. These are the boundaries that make relationship possible and that provide the context for both positive and negative freedom. When a family member perceives the transplant coordinator or nurse as only interested in the organs it becomes impossible for the family to feel supported and cared for and impossible for then to say yes or no to donation on their own terms.

Dissent among Family Members

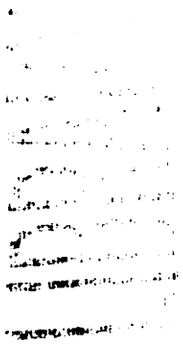
Sometimes family members disagree over whether or not to donate their loved one's organs. The decision to donate or not to donate takes place at a very stressful time in a family's life and each family member may respond to the pressures and possibilities differently. Often the death of a family member brings in distant relatives who normally may be only peripherally involved in family decisions but for whom the organ donation decision is very important. Whether disagreement within the family leads to breakdown in the consent process or not depends on the nurse's or transplant coordinator's response as illustrated by the following two stories from an interview with a transplant coordinator.

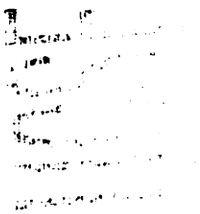
> 3B: I, one time I, I had a mother, it was just like that, a mother who was the dissenter. And the, and, um, but it was like the, the husband and the two sons, they all wanted to donate. But her mother was like, and she was Hispanic, and

she had these concerns, you know, I think it was more a cultural thing. But the boys and the father were standing strong on that they really thought it was the right thing to do and she would have wanted it. So I asked the mother, um, so if you were to step outside and not be involved with this at all, will that make you feel better? And she said yes. It was her husband and children wanted to donate and her mother didn't want them to. But, you know, and, um the thing is that sometimes if you can't necessarily bring them all together, I didn't see ability to bring her in to wanting it. So therefore I asked her would she be more comfortable if she weren't involved in this decision. And she said she would be and she left. So that's another alternative. The thing is, is, you know, when you've got a husband and two children who really want to donate, you don't want to take away from them that. You know, so, so it's, um, it's weird. Every case...(3B1.int; 11; 498-517)

3B: There was another case at [name of hospital] where it was a Filipino family. And it was a big family but the husband and two sisters of this woman came forward and said that the rest of the family doesn't agree with it but we really believe that donation is the right thing and we want to proceed with it. And, so we had a conversation and it did exclude, but it did include the next of kin which was the husband, but it excluded all the other people. And I was, you know, I don't like that, and, I did make it very clear to them that, um, you know, this could be, you know, this decision could be difficult later on. There was a lot of other people out there that weren't gonna know. You know, I told them this could be a very dec-, difficult for you to keep this kind of a secret and this decision later on. This has come up before for other coordinators and, you know, it's always difficult, but at the same time. So I, you know, I talked to them for quite a while and they were sure they wanted to do it and, you know. One of the sisters had a really hard time and she called me and, you know, I actually helped her by getting a priest, there's a priest in the outreach program from [name of hospital], to go to her home and to help her. She had a tremendous amount of guilt because she lived with her daughter who did not know. So it was like every day she had to live with that she had this huge secret from her own daughter who she lived with. Even though I had told her at the time, you know, this could be a really big decision not to share this information, but they were sure they wanted to do it. I think I would be, next time this situation, I think I would be more emphatic even about what that meant. That, their decision as they were making it, what that could mean to them in the future. Because she was really, really bothered by it. She was having trouble sleeping. (3B1.int; 11-12; 520-543)

In the first story, the transplant coordinator finds a creative answer to the disagreement between the patient's mother and her husband and children. Because the





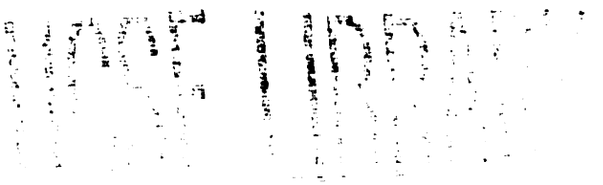
husband and children want to donate and think the patient herself would agree, but the mother cannot agree, the transplant coordinator offers the mother the opportunity to step aside and neither consent to nor prevent the donation. The transplant coordinator excludes the mother by first getting her consent to be excluded. The second excerpt contrasts with this one in that family members were excluded from the decision without their consent. The patient's husband and two sisters agree to organ donation but decide to keep the donation a secret from other family members. Even though this option allowed organ procurement to take place when some family members were not in favor of it, the transplant coordinator in this example recognizes the difficulties it caused for the family later.

These two stories illustrate different approaches to gaining family consent and a contrast between good practice and questionable practice around issues that go beyond a simple reading of informed consent. In both stories the transplant coordinator met the obligations of informed consent: she obtained informed and voluntary written consent from the legal next-of-kin. The first worked out well because the transplant coordinator was able to come to an understanding with the mother who, when asked, chose not to be involved in the decision to donate or not to donate. Ultimately, it was the mother's choice not to be involved and by excluding her the transplant coordinator was able to find a comfortable fit between the whole family and donation. In the second excerpt, the exclusion strategy did not work because it involved deception and because it split the family in a way that proved difficult for a prolonged period. The transplant coordinator, along with the patient's husband and sisters, did not find a fit so much as force a fit by

questionable means. Because the husband and sisters wanted to donate and the transplant coordinator did not want to deny them the opportunity to donate, they crossed the boundary of acceptable consent practices and deceived other family members who were important to the decision but not legally responsible for signing the consent. The transplant coordinator recognized this at the time and she felt uncomfortable with the family's decision to keep the donation a secret. But the mistake became more clear over time when the secret became more and more difficult for one of the sisters to live with.

It is usually the transplant coordinators who approach the family about organ donation and the ICU nurses often rely on the transplant coordinator s to solve problems of family disagreement. The following excerpts are from an interview with a staff nurse who is telling the story of a patient she took care of, a 21 year old African-American man who crashed his car. The man's father and mother, who were divorced, had both agreed to donation. Before they signed the consent, a minister came in and convinced the mother and her sisters that the patient might recover. The nurse thinks the mother is being manipulated by the minister and also by her sisters but when the mother then refuses donation the transplant coordinator does not pursue it.

> LD: So you had the inexperienced donor nurse. Um, what stopped you from stepping in and sort of taking over with the family on that issue?
>
> 2F: Um, well, like I said, the fact that I really hadn't established a strong relationship with the mom. Probably part of the fact too, it was like, probably ten o'clock at night, you know, it was getting toward the end of my shift and it was like, if it had been at the beginning of the shift it probably would have been a little bit different. Um, and [the transplant coordinator] didn't ask for my help at all. I mean she was just like tying up in a bow and saying OK. She wasn't looking for help. Um, she just kind of wanted to, you know, get out of there I think, pretty much. So, and, you know, it's, I, I don't really like to step on people's toes. And



at that point I think, you know, if, um, the [preacher] had gotten everybody whipped into a frenzy at that point it might have been really difficult to, you know, de-escalate it, or whatever. You know, probably, I think, you know, still, I think, there, there, it could have been done, possibly. But, um, like I said, I didn't have the energy in me to, you know, and she really wasn't looking at that point. You know, so it was like, you know, and I kinda feeling she was, you know, I didn't really want to step on her toes that much either. You know, it's like, well, I was a little upset about it, but it's like, well, you know, at this point, I just didn't have it in me to try and, I didn't want, like I said, I didn't want to step on her toes, you know.

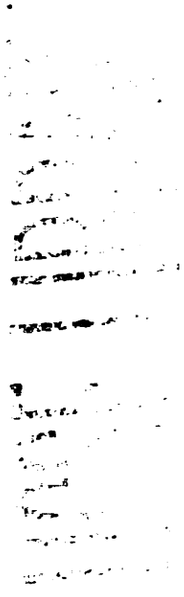
LD: So when she came back and said, the family said no, she was ready to pack up and go.

2F: Um-hm. Yep.

LD: And you said?

2F: I said, you're kidding! And she says no. She says I think, I said, wow. I said, well did you try to talk to them? And she said no. They had made up their minds. I was like, well, you know. What can I say? I mean, I didn't want to say, I don't know. I don't, uh, believe in trashing people. You know, [I didn't want to say] what the hell's your problem? [laughs] Did you really try? You know, 'cause I could see, she just didn't.

In this story, the ICU nurse defers to the transplant coordinator's judgement not to pursue organ donation further even though she believes the transplant coordinator is inexperienced and did not really try to talk to the mother about her decision. The nurse is aware of her own limited relationship with the mother and the strong influence of others. It is not clear what the nurse expected the transplant coordinator to do but she does think the situation could have resolved differently had the transplant coordinator been more willing to intervene. What the nurse seems to be concerned about is that she cannot be sure the mother made her decision free of undue influence. When she reproaches the

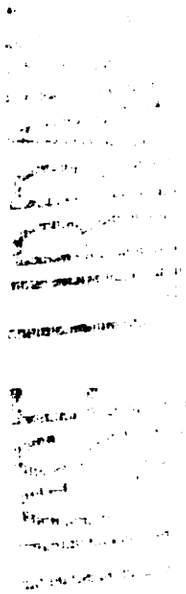


transplant coordinator for not trying to talk to the family she wants to be clear about the mother's decision.

This story points to the ambiguities that are possible in the consent process and how the process can break down without resolution of the ambiguities. The nurse will never be sure whether the mother was free to consent to donation and freely chose not to partly because she did not form a strong relationship with the mother and so does not know the mother on any intimate level. The nurse does not know if not donating would have been better for the mother than donating and has a feeling that the minister exerted inappropriate influence on the mother. For this reason the consent process was less than satisfying for the nurse and she describes it as a bad experience.

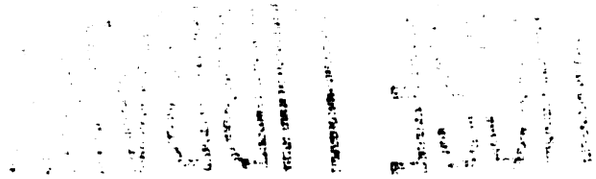
Rushing the Decision

Often family members are confronted with organ donation before they have thought about it and before they have had time to discuss it. Ideally, a family will talk about issues of death and dying, including organ donation, before a crisis occurs. In this case, the nurse or transplant coordinator need only remind the family they have the option of donation and the family knows what to do right away because they have discussed the issue with the patient under better circumstances. It is the hope of OPOs and health care providers all over the world that prior discussion will become the standard. In the absence of an understanding of the patient's known wishes, the health care team, including transplant coordinators and ICU nurses, must ask the family to make their best guess as to what the patient would want. Sometimes the family is able to immediately grasp that organ donation is the right thing to do. Other times the family agonizes over



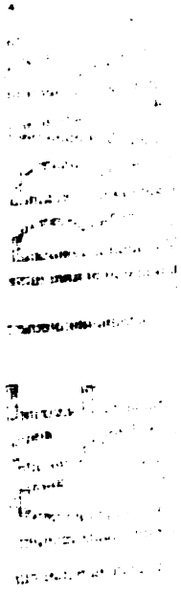
the decision and cannot come to a conclusion. In the following excerpt from an interview with a transplant coordinator, the patient's two daughters are forced to make a quick decision.

> 3B: Hm, [long pause], hm, well, there was a, there was a case where, um, it was two daughters who were consenting for the mother. And, uh, it was at a, it was over in [name of city] at [name of hospital] and, you know, uh, these trauma centers, you know these big hospitals and they get busy and they need the patients out. And that patient was dead. What happened was that they were talked to about it, and donation and they just were unsure and they were, they were fairly young, in their early 20's, and they just were real unsure. And the doctor said to them, well, you know, you don't have to make this decision right now. We couldn't, you know, we can readdress it in the morning. So they liked that [laughs], or no, in fact I think he said in a couple of days [laughs]. Well, you know, and this is some nice, young resident, and I walked up and go, [whispers] I don't know if that can, you know, if we can do that, you know, I'm, what, if you could do that. It's not up to me. It has to do with the hospital. He went out, he went out and mentioned to the charge nurse that they were gonna take a day or two to think about it. She just hit the ceiling. [The charge nurse said], 'You go back in there right now and tell them they have to don-, they have to make their decision right now.' And, um, I mean, I didn't like it but I knew I didn't really have control of the situation. I mean they can't have the patient, the patient's dead, they can't wait. I mean that was not reasonable. He should never have said that. I would have said well we can give you an hour or something [laughs], you know what I mean. You just, you know it's the reality of things so, anyway. So he went back and said I'm sorry you have to decide right now [laughs]. Anyway, so now, these two girls were just really confused, really confused. And, um, and a little bit angry too, you know. You just told me I had days and now I have minutes, you know. And what is this, and I can't make this decision now, and I, I told them that I, I think that it's, you know, being the time frame and everything. It was practically like there was a patient waiting for the bed, you know, it was just like, I said, you know. Being the time frame and how confused and difficult this is I, I just don't think this would be the right thing for you to do. You know, I, I didn't feel like they could come to a decision necessarily. So, you know, I told them, I, I think that we should, you know, not worry about the donation issue, you know. Your mom's gonna be taken off [the ventilator]. And they, they got all that. But they couldn't make the decision any way, so I said OK, well then they decided , oh, no, we're gonna donate. We want to donate, we want to donate. One of the daughters had a horrible time after the donation. With nightmares and she became, this is when I had just started, I mean a horrible time, concerned about her being cut up and all this. Was she really dead and all this



> kinda stuff and it all came down to that five minutes, you know, that they were, or had to make their decision. And I think I had a good sense at the time that maybe we shouldn't do this, but they convinced me through. And in the end, you know, I mean, she came around, she sent me Christmas cards and pictures of her new baby two years later, you know, and it was all like, you know, and she was really OK with it. But I had to help her get psychiatric services and they were really poor all these people and, you know, but. It was, um, you know, my, my gut said this was not probably a good thing for them to do in five minutes was right. But after they came back and said, oh no, we really want to do it, we really want to do it, what was I supposed to do? No, no, I'm sorry, I don't want it. You know, I mean, I, you know, what are you supposed to do? You know, so we went ahead and she did have a lot of trouble with it. Just as I thought she might. But it, it, you know, it took a while, but, it all worked out in the end, but it was difficult because she was so pushed to make that decision before she was ready.

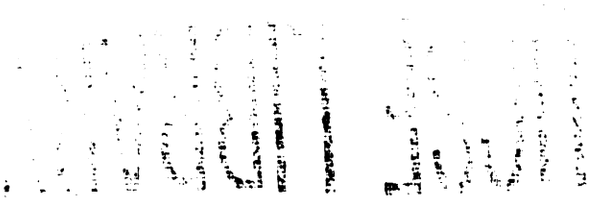
In this story, the transplant coordinator felt uncomfortable with the daughters' decision to donate their mother's organs. The situation demanded a quick decision: the mother was brain dead and the ICU was busy. The physician tells the daughters they can take a few days, but the transplant coordinator realizes this is unrealistic given the fact that the patient is brain dead and the charge nurse is demanding justification for taking up an ICU bed with a dead body. The family's consent to donate organs would provide this justification since brain dead donors are supported in the ICU for many hours while the organs are tested and placed with recipients. But the daughters need more time to make their decision about organ donation. When they finally do come to the conclusion that they want to donate, the transplant coordinator is not comfortable with their decision but she also feels rushed. She does not have time to explore the daughters' feelings but feels compelled to proceed with procurement even though she has a feeling it is the wrong thing to do.



This story illustrates a very difficult position for the transplant coordinator. Her relationship with the family is bounded by time. She does not have forever to analyze and interpret the family but only a few hours in one day. And those few hours must produce an important decision the family will have to live with forever.

The transplant coordinator is concerned that the family has made the wrong choice and tries to talk them out of donating. 3B's feeling proves true in the end; one daughter begins having doubts that her mother may not have been dead when the organs were taken. This suggests the idea that the daughters may have been using organ donation as a way to delay the removal of the ventilator, but it is not clear in this story how the daughters weighed their alternatives. By agreeing to donation, full support of their mother's physiologic function continued for possibly up to 24 hours. This could have given them the time they needed to think about donation and make a less hurried decision. It is also not clear in this story whether the daughters knew they could withdraw their consent for donation at any time. But if withdrawing consent for donation was at all connected in their minds to withdrawing life support it may have been difficult if not impossible for them to do it.

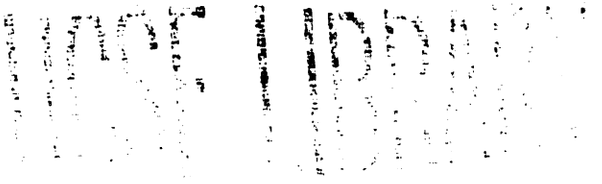
This story points to a dangerous double standard of care that can be abusive and also abused. The daughters in this excerpt were pressured into a decision on organ donation in large part because of the status of their mother as brain dead. Brain death, as discussed in chapter 2, is a somewhat problematical concept but is still the only clear case of medical futility in which the decision to withdraw support will be made unilaterally. Because the medical standard equates brain death with death, many physicians find



continuing physiologic support of a brain dead body abusive and disrespectful of the dead (W. Smith, personal communication, July 8, 1999). In this excerpt, the charge nurse wanted to move the body out of the ICU as soon as it was declared dead. The daughters were not asked if they wanted to continue life support; the patient would have been taken off the ventilator without the daughters' consent if the daughters had declined organ donation. This sets up a coercive situation: the withdrawal of support from a brain dead body is absolute unless the family agrees to organ donation in which case they are rewarded (if the family takes it up this way) with continued support in the ICU possibly for many more hours. To put this another way, families who refuse donation are punished with immediate removal of the body. This problem will be explored further in Chapter 7.

Summary

The ideal consent experience is one in which the transplant coordinator or the nurse can get close enough to the family to know whether or not donation is right for them. Whether the family gives their consent or not is beside the point. The transplant coordinators and nurses only want to offer donation as a possibility and help the family discover their own feelings about it. This is in keeping with the Western ideal of individual freedom; free choice is the basis of the nurses' and transplant coordinators' approach to consent. The theme of free choice comes up time and again in the interviews as nurses and transplant coordinators refer to organ donation as a choice the family must make on their own in keeping with their own beliefs. What I am calling a good consent

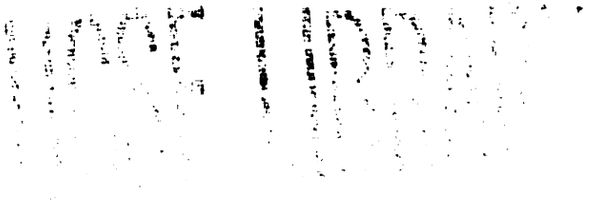


experience may not end in consent but must end in harmony with the family's sense of what is right and good in the particular situation.

Transplant coordinators and nurses go to great lengths to discover the family's feelings about donation and to help family members find a fit between their self understanding and organ donation. The transplant coordinators and nurses make efforts to know the family as part of their practice as nurses and also as part of the process of consent; they must know a family before they can know if donation is right or wrong for that family. Ideally the transplant coordinators and nurses have time to spend with family members to find out their story and get a feel for how far to push the idea of organ donation.

Sometimes the consent process is disrupted and there are many areas for breakdown to occur. The areas described here are the ones most evident in this data set. Other areas that have been touched on but not fully developed include cultural and language barriers and mistrust of the health care system on the part of the family. These factors can contribute to a bad experience in that the transplant coordinator or nurse can never get close enough to the family members to be satisfied that organ donation is or is not right for them. When the process of offering the option of donation is disrupted, the outcome is ambiguous in that the transplant coordinator or nurse is not sure if the family's decision is right for them. This could mean the family decides against donation when it might have been better for them to donate or that the family decides to donate when it might have been better for them not to donate. Many factors or combinations of factors may be involved in disruption or breakdown in approaching the family.

Examining stories of breakdown can further our understanding of the good consent experience by offering a contrast. Good consent requires the transplant coordinator or nurse to present themselves in a way that promotes the family's understanding of their position, and prevents misunderstanding of their intentions. It also requires that the family as a whole be comfortable with whatever decision any individual family member makes and that the transplant coordinator or nurse and family have time to fully explore what organ donation may mean to this family in this situation.



Chapter 7

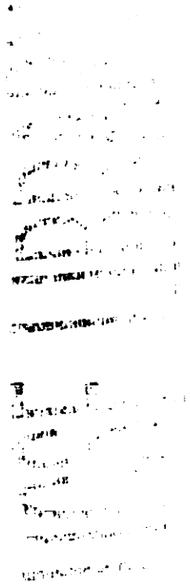
Death without Donation

Losing a Donor

Preparing the Family

When the ICU nurses and transplant coordinators begin to pursue organ procurement, they do not know what will happen. Even though they do everything they can to bring the donor to the OR and recover as many organs as possible, several obstacles stand in the way. The donor may be rejected based on the results of blood tests. Various organs may be rejected based on evaluation of their function. The OPO may not be able to find a suitable recipient for some of the organs. Any of these reasons alone or in combination may result in what one transplant coordinator called a wash: a donor situation where no organs are recovered.

A wash can be traumatic for the family as well as the nurses. As one nurse pointed out in an interview, the family may be as committed to organ recovery as the transplant teams are. In this case, the family saw organ donation as something good coming out of their son's death. This added commitment compounds the tragedy when the donor is lost before organ procurement can be accomplished. It is for this reason that transplant coordinators hesitate to offer the donation option to the family before they review the patient's chart and evaluate his or her suitability as a donor. If the patient can be ruled out as a donor based on information obtained from a review of the chart, the coordinator can save the family the burden of deciding whether or not to donate and prevent them from latching on to a hope that will prove impossible to fulfill. For



example, if the transplant coordinator finds the patient has a history of lung cancer, information the transplant coordinator can get from the patient's chart or by talking to the physicians in charge of his treatment, she will right away rule him out as a potential donor without ever having to meet the family.

If possible, the transplant coordinator will rule out an unsuitable donor early, before the family is even approached about donation. Sometimes it is not possible to rule a patient out as a donor before obtaining family consent. After the family consents, the OPO can test the potential donor for communicable diseases like hepatitis, venereal disease or human immunodeficiency virus (HIV), and decide based on these results whether the patient can donate organs. If it turns out, for example, that the patient is positive for HIV, he or she will be ruled out as a donor. Because it is traumatic for the family to consent to organ donation and then have organ donation turn out to be impossible, the transplant coordinators prepare the family for this possibility during the consent process by presenting organ donation in terms of uncertainty. The next excerpt from an interview with a transplant coordinator illustrates this point.

LD: You said that he, um, ended up that he couldn't donate his lungs.

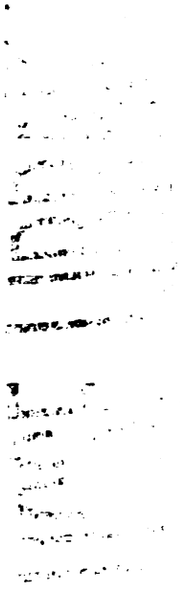
3A: Because of the pulmonary edema and his blood gases. His blood gases weren't very good. They were OK for heart parameters, but for lung parameters, he had terrible congestion. And, um, it puts too much risk for a potential lung donor. You know, the, the lungs have to be pretty much pristine. They could have chest tubes in, they could have had a little atelectasis. Most of the lung guys will come in and bronch the patient. But because of his pulmonary edema and all the fluids that he had gotten, there was just no way we could turn him around, and his blood gases were not great. And we need pretty great blood gases to have these things happen.
LD: Did you find out about that early on?

> 3A: Yeah, I suspected it because his blood gases had been pretty off. So I wasn't real surprised. And when you're in consent and you're talking to the family, you kind of let them know perhaps because of age he can't be a pancreas donor, or because of his smoking history, it might be a problem of placing his lungs. Or because of a drinking history, I'm not sure about his liver, we'd still like to evaluate it. I don't want to rule it out, but I'm just letting you know that not everything might be able to be recovered. (3A1.int; 11; 497-514)

3A feels the need to warn the family of the possibility that some organs may be unsuitable for donation. Later in the interview she describes this as a way of protecting the family; for donor families organ donation is an exciting possibility. If their loved one's organs turn out to be unsuitable, the family may be disappointed. 3A protects the family from disappointment by warning them early that donation of certain organs may be impossible.

> 3A: I think these families get really excited that all these things can be donated and then when they find out that the patient's only a liver-kidney donor they get extremely disappointed. And especially with the heart. People, um, view the heart kind of differently than other organs, kind of where the heart is the soul or the, you know, the make up of the person. And so, I hear a lot of times, oh, she had such a good heart. She was such a good hearted person, I'm really disappointed that somebody else couldn't get her heart. So I'm trying to prevent them from disappointment. (3A1.int; 12; 527-534)

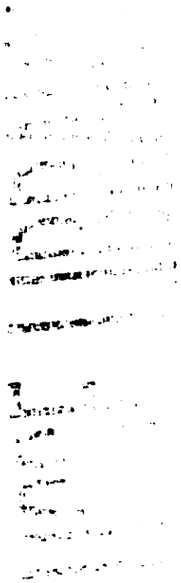
In the midst of the tragedy of losing a loved one, the family gets excited about the possibility of organ donation. For whatever reason, the family finds comfort in the idea of giving the organs, and the transplant coordinator does not want to disappoint them. So she builds into her consent the warning that some organs may be unsuitable.



Losing the Donor after Consent

Managing the unstable donor can be emotionally as well as physically challenging. Working for many hours to stabilize the body can bring a nurse to the emotional edge as shown in the previous chapter. If the body goes on to cardiac arrest, the emotional burden is compounded as pointed out in the next excerpt from an interview with an ICU nurse. 1B had been caring for a patient who had sustained a gunshot wound to the head and had been stable. The patient suddenly became unstable to the point of cardiac arrest from which 1B could not resuscitate him.

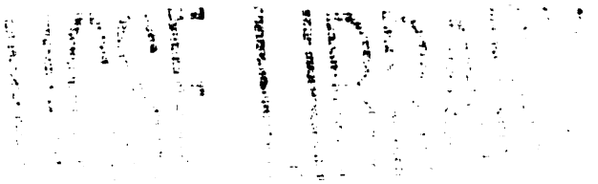
> 1B: Actually that case of the 16-year old, that was very, very sad because we, you know, it's sad when there's a family that said there's ah, you know, if anything good can come out of this, this is something, donation would be good. And when, actually they were at the bedside when he crashed and, um, you know, that was such an obviously stressful situation and, you know, the adrenaline is flowing for everybody. And, then all of a sudden he crashed, I mean, it was just, it was totally devastating and left you just totally hanging there, you know, it was horrible. One of the worst experiences I've had with a donor, you know, nothing's worse than that.
>
> LD: Can you describe that any more about the, I mean when he crashed, that feeling of hanging there?
>
> 1B: Um, it just feels so empty, and you feel as though um, you feel, you feel as though the family were cheated, as if you cheated them, if it wasn't bad enough, with you know, with them losing their son and then you mention organ donation and it's almost like something that they hang on to. You know, they're OK, if anything good can come out of this, you know, that this is what we want. At least we can save other peoples's lives. And that's definitely how they were feeling. And, um, then all of a sudden he crashes and you don't even get that. And, you know, you're working hard toward actually getting there and I don't think you actually deal, necessarily, I don't think you can actually totally let yourself go and, and um, think about how horrific the whole situation is; and all of a sudden you lose him like that, and all of a sudden it comes back to you, you know, you fall right into the moment. And, um, then it all dawns on you, you know, how terrible it is.



The scene 1B describes is not a common occurrence. Usually even the unstable donor makes it to the OR and something can be salvaged as described in the last chapter. The loss of a donor to physiologic instability is especially traumatic perhaps because of its rarity. The disappointment and horror 1B describes in this story gives a feel for the emotional pitch of donor care. The nurse had been working toward organ procurement and thought he had a stable donor that would require minimal maintenance. The parents had consented and were very positive about donation as the only good that could come out of their son's death. 1B had geared himself toward this situation as one of organ procurement when the patient sustained an irreversible cardiac arrest. Family members were present for the arrest. 1B describes this as a stressful situation where 'adrenaline is flowing' as they try to stabilize the rapidly deteriorating body. But the pull of the story is toward the emotional burden of losing the donor rather than toward the physical management of the crashing body. When the heart stopped and 1B's struggle toward organ recovery ended, 1B experienced the loss of the person; the unexpectedness of the arrest forced 1B to abruptly confront the tragedy of the patient's death, what he called falling into the moment.

When Families Choose Not to Donate

Loss of a donor after consent can be shocking, traumatic and disappointing. When families choose not to donate, the loss of the potential organ donor is tempered by the ICU nurses' and transplant coordinators' commitment to personal choice. Because they approach donation as an option the family ought to be free to take or not take, the ICU nurses and transplant coordinators are ready to give up donation if the family

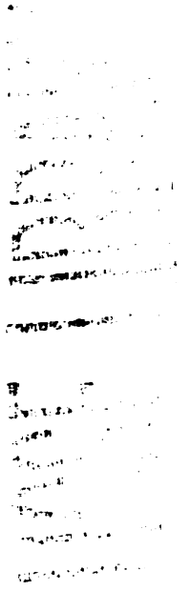


declines. But even with an understanding of donation as a choice, the nurses still express disappointment when a family declines donation.

> 2D: You, you, later you go out and you think, oh, he was so young and so healthy, he had nothing wrong [laughs], the human part of you, but basically it's their gift that they're giving if they decide to do it. That's my philosophy and, you know, yes, somebody could be very blessed but, you know, it's the family's, the family's decision. (2D2.int; 5: 192-196)

> 2D: But, um, but, yeah there is part of me that was regretting, yeah. 'Cause I felt he would have been a great, you know, person to have a lot of things to give, and very healthy, and had no problem during the night with anything. Lungs, heart, nothing, you know, every-, all systems were working real well. So, yeah, part of me did feel regret, yeah. (2D2.int; 9; 406-411)

> 2E: Well, a good outcome is if the family feels comfortable with how things ended up, I mean not that they're happy that the person died, but that they feel comfortable with the fact that you did everything you could do. And they made the best decisions they could make and they're comfortable with those decisions. Um, that's a good outcome. A better outcome is that they donate, for us, for me. But if they don't, if they feel good about what they did and the care the patient got and they're comfortable that we did all we could and were happy with that, that's a good outcome. And you feel good about that too, it's just, it would have been so nice, you know, if you could have had that little extra, but you didn't 'cause somebody else could've maybe had a good outcome. [pause] A lot of, a lot of your work is supporting the family so if, if they feel good about what's happened, then you've done your job well, and that's a good outcome. And that does feel positive, even though they don't donate. (2E2.int; 15; 573-585)



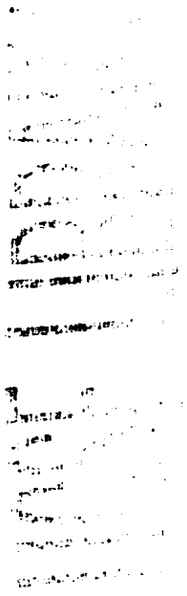
LD: So what happens for you, how do you feel, and you've said a little bit about this already but if you could just say a little bit more, when families say no to donation?

2B: Well, it's disappointing. Y'know, especially when it's, y'know, and we talk about it at work, it's like, oh my god can you believe this? Especially when it's y'know like a young person that you know, a young person that has not had any history of any kind of illnesses, no drug abuse, no alcohol use. Y'know, just someone that could offer so much to so many people. 'Cause you know they'd probably be a heart recipient, maybe even a heart lung, and heart, lung, liver, I mean you know they could probably take everything. And so you're very, very disappointed. I mean it's just a sadness. But then again, y'know you have to realize where the family's coming from is that it has to be okay. And I don't know that I could do that for my child. I mean I hope I would if something like that happened, but I don't know. I mean you never know until you get put into that situation. And you hope to god you don't have to. So you, so there's no anger, y'know, there's no, at least for me, there's, there's disappointment. I never let the family know that. (2B2.int; 19; 802-818)

These excerpts illustrate the nurses' commitment to organ donation as a good thing but also as a choice the family must be free to make. If they commit completely to organ donation as a good outcome they risk influencing the family too much; if they let the family see their disappointment when the family declines to donate, they risk making the family feel guilty. But, in the interviews, the nurses freely admit their own disappointment with the family's refusal. In practice, they keep these feelings to themselves while showing the family support for whatever decision they make.

Withdrawing Support from the Brain Dead Body

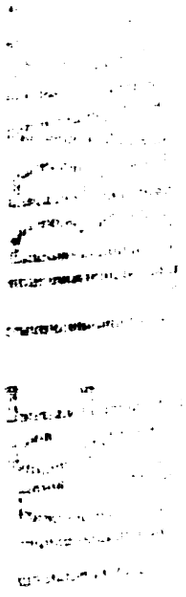
As pointed out in chapter six, once the family makes the decision not to donate, the only option left is to discontinue the ventilator and other support such as intravenous vasopressors. Since the brain dead body by definition is apneic, discontinuing the ventilator alone will result in cardiac arrest within minutes with or without vasopressor



support. This fact makes withdrawing support from the brain dead body dramatic; the body changes from pink and perfused to dusky and cold within minutes. Often the timing of withdrawal is important to the family because they want all family members to see the body while it is still ventilated and perfused. This can lead to conflict in the ICU as illustrated by the following excerpt from an interview with an ICU nurse.

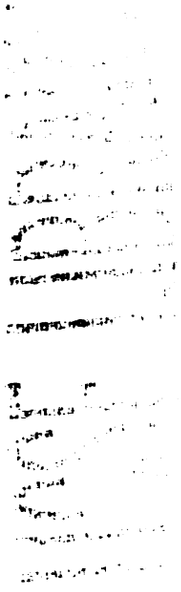
> 2F: So, the patient was indeed declared brain dead because of the results of the nuclear medicine study. So, the family calls and, um, I tell them the results, she's brain dead. And, uh, I said to them, 'cause the donor people were there, I said, look. I said, you know, um, there are some people here from the [OPO] that, you know, maybe in the morning you can come and talk to them about the possibility of, you know, whether you are interested in donating or not. I said this is, there's no reason to make up your mind now, you know. But, um, in the morning you might, you know, just talk to them about some of your options. And it's entirely up to you. So the guy goes, oh, we're not gonna donate. It's like, excuse me? But I said you don't have to make up your mind. [He] said, you know, no, we're not going to donate. And I felt, oh shit. The patient's brain dead, they don't want to donate. So what do you gotta do? You gotta take the patient off the ventilator. These people are going, well, I said, well, OK, well, you know, then we'll need to take her off the ventilator. [The family member said], 'What do you have to do that for?' Well, you know, she, she's dead. And I said, we, we can't just keep her here. Well, cousin Luigi is coming in from New York, or someone, I don't know who it was. And I said, well, I'm sorry, you know, um, you know. And I didn't want to say well, if you'll say you might donate, you know, we'll keep her, 'cause they would have. And, you know, so, he was furious and all bent out of shape. [text deleted] So I've got the supervisor there now, I'm going, what do we do? They said no, they don't want to donate. The patient's dead, you know. And, um, we ended up taking the patient off the ventilator, but I, the family member did end up calling me back and [he] said why are you doing this? And I was like so upset, I said, you know, I, I don't know what to tell you except, I said, one day, you know, it's like the insurance company is not gonna pay to have a dead body in ICU overnight. And I said, you know, that sounds really cold, but, and he can't tie up a critical care bed with a dead person. And my heart went out to him, I felt horrible. It was just like the worst thing. (2F1.int; 2; 42-69)

The nurse in this excerpt is in a difficult position. Problems arise, as pointed out in chapter six, when health care institutions set up a double standard of care for donors



and non-donors. As illustrated by 2F's story, if the family had agreed to organ donation, or even just pretended to be thinking about organ donation, the hospital probably would not have thought twice about keeping the dead body in the ICU overnight. This is, of course, bounded by resource availability. If the ICU had no beds available, or if, as happened during one observation with a transplant coordinator, there is no staff available to maintain the body, the nurses and physicians would have to set shorter limits on the time allowed for the family to make a decision. But in the absence of short resources, a dead body can take up space in the ICU if that body has even the potential to donate organs. As discussed in chapter 6 and illustrated by 2F's story here, this is not true of the dead body whose family has firmly declined the option to donate organs.

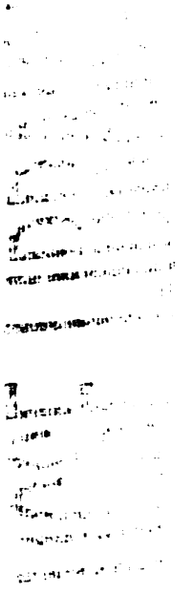
It is hard to see how the work of organ procurement could take place without this double standard of care. One of the most important things that makes organ donation possible at this point in history is the fact that physicians and courts accept brain death as real death. Since the ICU is generally not in the business, as 2B says, of keeping dead people going, it makes sense to transfer the body out of the ICU as soon as it is declared dead. But what of the potential organ donor that is dead but also in need of intensive physiologic support? These bodies are cared for in the ICU, and while the family cannot be present when the ventilator is turned off in the OR, the family usually has continued access to their loved one until the body is taken to the OR which could be construed as a benefit of organ donation that cannot be offered to those families who choose not to donate.



Nurses seem uncomfortable with this double standard of care and yet are committed to brain death as death. This is illustrated in 2F's dilemma: she wants to give the family time to come back to the hospital to see their loved one again but she is also aware of the problems of keeping a dead body overnight in the ICU. Because the patient has been declared dead, the situation is not simply one of withdrawing life support. In cases of withdrawing life support from dying patients, the family is given maximum flexibility in terms of timing. No one wants to be accused of rushing the family into withdrawing life support. In the case of a brain dead patient, the ventilator no longer represents life support since the patient is dead by legal and by common medical definitions. Yet the transition from brain death to cardiac arrest also has meaning. The nurse in this excerpt points to this when she describes her feelings about having to discontinue the ventilator before the family is ready.

Discontinuing the ventilator on a brain dead patient can be as significant for the family as discontinuing life support on a dying patient. The nurses and transplant coordinators appreciate this and try to accommodate the family as much as possible. Sometimes this means waiting a few hours or even a day for the whole family to gather. But there are limits as illustrated in the previous and following excerpts.

> 2B: The thing that you have to make sure is that these people realize, that these families realize that this person is dead. You know and you obviously say that in a very nice way, but, um, this person is dead and you've chosen not to donate so we're gonna turn the ventilator off. You know, and you make sure that if they want all their family to be there, what's a good ti, y'know, have all the family there, if you wanna be in the room, that's fine. And just make it as comfortable for them as you can. And, um, again that's their choice. I mean, the patient's dead, there's nothing we can do about that, and, um, this is what we're going to



> do because we do not keep dead people going. If there's an out of town family member, um, most often we try to wait, if somebody, if they say well so-and-so, I mean if it's three days form now, if they're coming from y'know, out of the country, we don't. I mean there's no way. But, um, we'll wait, we'll wait 24 hours. If it's, if somebody needs to get there. And that gives them a lot of, I mean that's good, good feelings too. I can't think of the word I wanna say, but um, you know, so that they can get their family members there to be with this person. Or to be with them when they d/c [discontinue] the ventilator, when we d/c the ventilator. (2B2.int; 7-8; 839-855)

The nurse in this excerpt talks about discontinuing the ventilator on a brain dead patient as if it is not optional but also as if it is significant. She wants to wait for the family to gather and is willing to wait as long as 24 hours, longer than 2F in the previous excerpt. Twenty-four hours is a long time to wait with a brain dead body and it will take a fair amount of effort to sustain the body for that long. Her description points to the ambiguous space the brain dead body occupies. She wants to be sure the family understands that the patient is dead and that the ICU is not a place where they 'keep dead people going.' But, even though she recognizes and makes a commitment to brain death as death, this nurse still wants to make an effort to get the family together to be with the person before she turns off the ventilator. Both 2F and 2B recognize the significance of turning off the ventilator and both of them want the family to be present for it. In both stories it is not the decision to discontinue the ventilator that is important; that the machine will be turned off is a given after brain death is declared. It is the act of disconnecting and turning off the machine that is significant, and timing this event is important.

Chapter 8

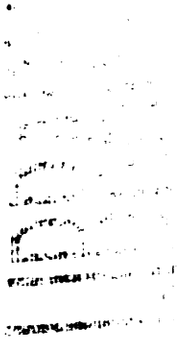
The Process of Organ Recovery

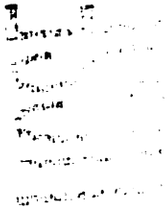
The process of supporting a potential donor from brain death until the body is taken to the operating room for organ recovery can be long and harrowing. Maintaining the donor body is hard and busy work that requires careful timing and rigorous intervention. This work is directed and carried out primarily by transplant coordinators and ICU nurses. The path of organ procurement includes two sets of concerns: those involving testing and placing the organs and those involved in maintaining the donor body in stable condition. In order to explicate the practice, I describe these two concerns separately. In practice they are happening at the same time and the interventions done for each sometimes overlap. In general, the testing and placement of organs concerns mainly the transplant coordinator although the ICU nurses are also involved. Stabilizing and maintaining the body is more of a joint effort in which the transplant coordinator and ICU nurse work together to bring the donor to the OR.

Managing the Donor

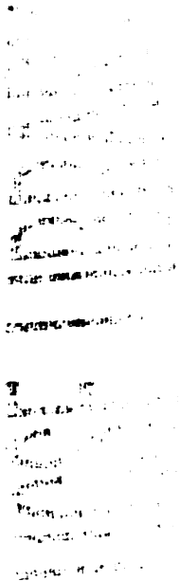
The Transplant Coordinators' Perspective

The transplant coordinators are responsible for keeping the donor stable and for testing and placing the organs. This takes place in the ICU, after the family has consented to donation and before the organs are harvested. The following excerpt is from an interview with a transplant coordinator who is describing the work of donor management, and organ testing and placement.



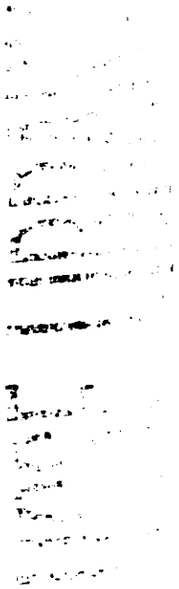


3A: Um, you're never idle. All the information that we gather is throughout the whole day, you know. We do [every] six hour lab work and sometimes [more]. So any updates I then would...we have this twelve page flow sheet that we fill out. And all that information is filled out and then faxed on to our office, who then runs a national list and we, starts to place the organs. We could not actually start placing the organs until I got formal consent. But I had filled out my worksheets and I had faxed most of it in. And then when I got consent around five, I faxed, you know, any updates, and. So, you know, there's always lab work. We keep, we watch the vital signs, we write all the vital signs down every hour, urine output, what was the, um, fluid intake, what were the blood gases, are they needing to change the ventilator, are we needing to adjust the dopamine, can we come down, were the antibiotics given, um, what's the, the lab work, what's his H & H, do we need to give blood, do we not need to give blood, um. We send off, um, blood for serology testing for HLA [human leukocyte associated antigens], or not HLA, but hepatitis, HIV [human immunodeficiency virus], VDRLs [venereal diseases], a lot of things, that takes time. All of those things you try and get done early, um. An echocardiogram, we had to make arrangements to get an echocardiogram done on Thanksgiving and a tech came in in the early afternoon after their meal and did the echo. So, you know, you're looking at the kindness of a lot of people because some people would refuse to come in, um. Not always, but sometimes that does happen. So you're constant evaluation and constant changes and upgrading and so on and even though he was pretty stable, you know, his potassium's two. We need to replace the potassium, making sure that the nurses are following the orders, making sure that the orders are written, that the orders are sent, um, that, um, you know, I'm keeping in touch with the placement coordinator to know what's happening with consent. And then when we do get consent, faxing everything in and they start their, their phone calls for the organ placement. And then once all the organs are placed, making arrangements with the OR for an OR time. We call the OR very early to let them know about these cases. We need to get a lot of saline cooled off so we stick liters of pourable saline on ice for during the surgery to cool the organs down. There's, you know, lots of little chores. We copy the chart, we make a, a copy of the chart for each organ that goes. So we kill a lot of trees. Not always the whole chart. Now the coroner, we co-, um, we copy the whole chart for, but there's certain things, progress notes, um, what was the pre-hospital, what's the lab work, we need two verifications of his ABO, um, his serologies, um, blood gases, you know. So there is a lot of things. If the patient's only been in there a couple of days it's not too bad. But you go to a teaching institution where everybody writes in the chart, only been a couple of days, you're doing reams of copying, um. And then there is some waiting time, you know. If the patient remains stable, you know, I'll flip through a magazine or kind of chit chat with the nurses a little bit, um. Always kind of re-evaluating, we turn, suction, everything like any...You know, we're suctioning that patient every hour. And we're sending sputum cultures and gram stains and then, not only do we send these things, did we get



> our results back. Did we get somebody to read the chest X-ray. On a holiday it's very difficult to get somebody to come in. Not, now they are a trauma center, but, you know, do they have a physician on staff that can read your chest X-ray? If not can you bring it down to an ER physician, or is there somebody, a cardiologist, to read your echo? Making all of those arrangements are very time consuming. People think that the process of organ donation, well, you sign the consent and the patient will be out of here in two hours. The normal process takes 24 hours from start to finish and sometimes more. If the OR's busy, say on a regular schedule day, we very seldom get into the OR during day shift hours or even PM shift hours. Because they're so, the OR's are so busy. We have to wait 'til there's a clearing. In a trauma center we have to wait. If a trauma comes in and we haven't gone to surgery yet, we're gonna be the ones to get bumped unless our donor is extremely unstable. Otherwise, we have to wait. We're not the priority. We've got basically a dead patient. Yes, he's going to help five or six people survive, but we've got a dead patient. So, um, you know, it's just a time consuming, data gathering, sometimes hair raising wait. In this case, this gentleman had evened out for me. The coordinator that had been prior to me had really done an excellent job of, you know, giving him a lot of blood products, giving him a lot of fluids just to keep his blood pressure up. And, yes, we had played around quite a bit, but by the time we had gone, no, he had calmed down quite a bit. So there was, there was some down time for me where I could go and enjoy the staff's company a little bit and chit chat with them and enjoy the turkey that they brought in and so on and so forth. So,...(3A1.int; 11-12; 428-496)

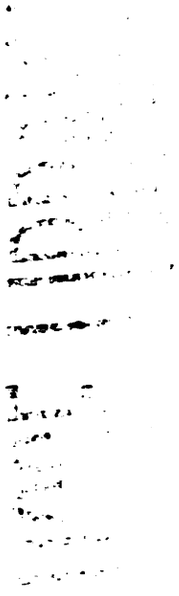
This story illustrates the shift in responsibility that occurs after brain death. As described in Chapter 4, care and treatment of the brain injured patient is managed by a team that includes neurologists, neurosurgeons, trauma surgeons and ICU nurses. This team works together to plan and implement a course of treatment intended to help the patient recover. Once the patient's recovery is doubtful, the team may begin more seriously to consider organ procurement as a possible outcome and may begin to make treatment decisions that take into consideration salvaging the organs within the context of treating the brain injury. But once the patient dies, once the physician declares the patient dead based on brain criteria, the responsibility for treatment shifts. The physician who had been in charge of treatment turns over treatment to the OPO and from that point



on, all treatment decisions are the responsibility of the transplant coordinator. The physicians who had been treating the patient's brain injury withdraw from the scene and the maintenance of the brain dead organ donor becomes the responsibility of nurses.

This transfer of responsibility provides an important transition point both for the physicians and for the transplant coordinators. The transplant coordinators stay distant before brain death. They may review the patient's chart to determine suitability for donation but they make no treatment decisions until after brain death. This prevents a conflict of interest; if the group responsible for organ recovery makes treatment decisions before the donor is dead, they risk acting on, or at least being accused of acting on, motives other than the patient's best interest. Similarly, if the physicians in charge of treating the patient's brain injury continue to be involved in managing the organs after death, their treatment decisions before death may come into question. The physician's official handing off of responsibility prevents these questions; before brain death, the physician in charge of treating the patient's brain injury writes all the treatment orders. After brain death, if the family agrees to organ donation, the physician writes one last order to transfer care to the OPO and from that point on, the transplant coordinator writes all the treatment orders.

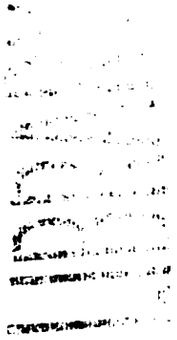
The transfer of care is somewhat symbolic in that the neurologists and neurosurgeons involved in treating the brain injury sometimes stay involved in maintaining the organs in an unofficial way. The transplant coordinators sometimes consult with them on treatment decisions and the physicians often check on the progress of organ procurement. But what is most interesting is that the ICU nurses do not even

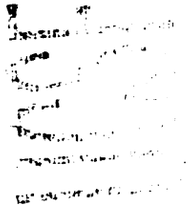


make a symbolic break in their care of the brain injured patient who becomes an organ donor. As described in chapter four, the same nurse may care for the brain injured patient before, during and after brain death all the way to the point of organ harvesting. Individual nurses show evidence of concern for conflict of interest and some make attempts to distance themselves from organ procurement while caring for the brain injured patient. But once brain death is declared, the same ICU nurse who was caring for the brain injured patient makes the transition to donor care without pause. Some ICUs are set up so that the same nurse may care for both organ donors and organ recipients. This kind of cross over in care delivery is not tolerated in medicine.

Several factors may contribute to the ICU nurses' ability to provide care to both the brain injured patient and the organ donor without the same concerns as the physicians and transplant coordinators. The ICU nurses interviewed in this study seemed to stay focused on providing care to the donor and the donor's family as a way to honor the patient's last wishes and as a way to distract themselves from the reality of the patient's death. In this way, donor care becomes an extension of patient care and there is no conflict. Also, as noted above, the transfer of responsibility from physician to transplant coordinator is partly symbolic and is partly done to make the family and the general public more comfortable. Since nurses generally have a much less obvious public image than do brain surgeons and organ procurement organizations they may find no need for such symbolic displays.

3A's description of donor management in the last excerpt gives a good sense of the organization and skills it takes to do this job. In this case, 3A is concerned about





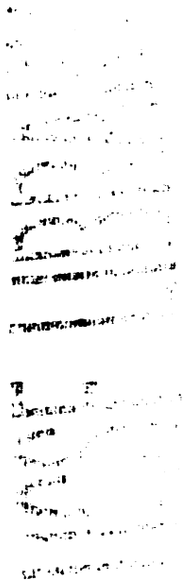
many related tasks. She describes donor management as time consuming data gathering and as involving many little chores. She must order labs and medications and make sure they are sent and given, and make sure the lab results are reported and acted upon. She must constantly evaluate the donor's changing condition and not only decide on treatments like blood transfusions, ventilator changes and the dose of vasoactive medications, but also report this information in writing and over the telephone to a placement coordinator at the OPO who will work toward placing the organs with appropriate recipients. In addition to all the evaluative and donor management tasks done by the nurses at the bedside, the transplant coordinator must arrange for more tests to be done and read by specially trained physicians and technologists, arrange for an OR time and arrange for special supplies for the surgery. The case 3A describes here took place on Thanksgiving day which she feared could further limit OR times and delay test results.

Despite all the many problems that came up and the many arrangements she had to make, 3A still had time to sit down to a turkey dinner and enjoy the company of the ICU staff. As evidenced in field observations, the tasks 3A catalogues here are often done all at once and, at the same time, the transplant coordinator and nurses are diagnosing actual and potential problems. For example, while titrating the dopamine, the coordinator may be making ventilator changes, ordering a dose of antibiotic and sending to the blood bank for a unit of packed cells, all based on ongoing assessments of the donor's condition. Meanwhile, the ICU nurse is suctioning the patient and a technologist may be setting up to get an echocardiogram.

3A points out the importance of keeping ahead on the paperwork and labs; she already had the 12-page flow sheet filled out and ready to fax before she got final consent from the family. She also tries to get the serology testing done early. Catching up on tasks allows 3A to finally characterize donor management as just a long wait. She had finished all the tasks long before the OR was ready. With the donor 3A describes, the wait was long but not hair-raising because the body stayed stable thanks to the efforts of the coordinators and nurses.

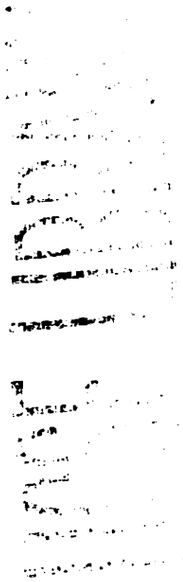
A large part of the transplant coordinator's job is information management. As 3A says, the transplant coordinators go through a lot of paper and kill a lot of trees. The coordinators copy vital signs and lab values from the donor's ICU flow sheet onto the OPO's own forms. Then they make a photocopy of the progress notes and other parts of the chart, and fax all of this information to the OPO office. The following excerpt is from a field observation with a transplant coordinator.

> 1630 - 3A (a transplant coordinator) is back from a short break and begins right away to catch up on her paperwork. This involves copying vital signs from the hospital flow sheets onto the OPO's data collection sheets. The nurse tells her the chest x-ray and EKG have been done and another transplant coordinator called the operating room to warn them the patient will be coming for organ harvesting. 3A wants to weigh the patient but there is a problem with the traction. His left femur is in a splint traction device that may interfere with getting an accurate weight from the bed scale. 3A wants to hold the traction frame up while the nurse hits the weight button on the bed. It takes two of us to hold the leg up and 3A is still not happy. She wants to take him out of traction. I visualize his femoral artery lacerated on bone fragments but say nothing. 3A decides to list his weight as '98.8 kg with full leg skin traction and a right arm splint.' If that doesn't work, meaning if this does not satisfy the OPO placement coordinator who must try to place the organs based partly on their size estimated by the patient's weight, we'll have to do it another way. She takes out a tape measure and measures his height; 72 inches.



> 1650 - The nurse discovers the ventilator is still set at 100% FIO2. It was supposed to be set back to 40% after a blood gas was drawn on 100%. 3A decides to leave it at 100%; the patient's PaO2 on this setting is 393. 3A would like to see it greater than 400. This says something about the function of the lungs, how high the PaO2 gets when pure oxygen is delivered. 'We're not going to be making offers anytime soon,' 3A says. She will be 'camping out forever.' She's at the computer looking up more flow sheet information.
>
> 1700 - 3A wants to get an echocardiogram and pages the cardiology fellow. He calls back as we are preparing to move to patient to another room. The room he's in is shared with another patient and 3A prefers a private room so as not to disturb another patient. She once had a donor's room mate think he was the one going for organ harvesting. 3A tells the cardiology fellow she needs the echo in order to decide to go for a cardiac cath or not. If the heart looks bad on the echo there's no reason to spend time or money on the cath. If the heart looks good on the echo, they have to do a cath to make sure all the vessels are patent. It takes six people to move the patient and all the equipment - bed with a traction frame, 4 IV pumps, ventilator, and warming blanket - down the hall to a private room. (FN book 3, #3)

This excerpt shows the cooperative efforts of the ICU nurse and transplant coordinator. In order for transplantation to be successful, the donor body must be maintained in a stable, well-perfused state, and the organs must be offered and accepted by transplant surgeons on behalf of potential recipients. Since this donor's physiologic function was stable, 3A's main concern was to test organ function and collect information important in the process of placing the organs. 3A scheduled an echocardiogram to evaluate the function of the heart muscle. She anticipated needing a cardiac catheterization to evaluate heart perfusion. She set the ventilator to deliver 100% oxygen to roughly evaluate lung function. She weighed and measured the body in order to estimate organ size. She wrote this information on a data collection sheet and faxed it to



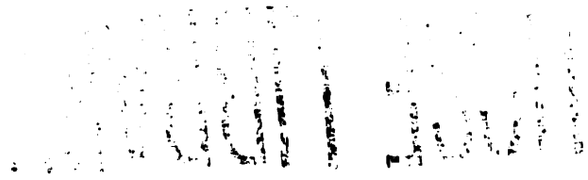
the OPO main office where a placement coordinator passed it on to the transplant surgeons to whom the organs were offered.

In the end, the organs are evaluated by a team of transplant surgeons who decide whether or not to take them. Because the surgeon's evaluation is based on information gathered by the transplant coordinator, the transplant coordinator must do her best to obtain accurate information and the transplant coordinators feel responsible for matching the organ to the recipient. Organ size and sometimes tissue type, as well as donor blood type, all go into determining each organ's suitability as a replacement for each potential recipient. One transplant coordinator told a story about taking a donor to the OR for recovery of the heart. The cardiac transplant team had accepted the heart and had a recipient ready for it. But when the surgeons saw the donor they realized they had been given inaccurate information on the weight and so had inaccurately estimated the size of the heart. The recipient they had lined up needed a bigger heart than the donor could provide and it was too late to offer the heart to any other potential recipient. Although the potential recipient had no been prepped for surgery, and not physical harm came to him, the organ was, in this transplant coordinator's harsh opinion, wasted because she had not double checked the donor's weight.

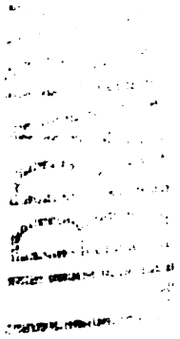
In addition to information used in matching donor to recipient, the transplant coordinator must also provide information used to evaluate the organs' function. This information is more difficult to obtain and the results of functional testing sometimes require more interpretation than the information on the match between donor and recipient. Interpretation of organ function is important; the transplant coordinators and

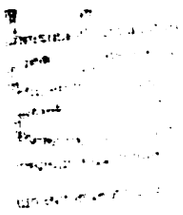
the OPO may rule out a donor based on their interpretation of test results. This is partly a matter of finance; the OPO takes over payment after the family consents to organ donation. The recipient or the recipient's insurance eventually pays the OPO an organ finding fee to cover the cost of donor maintenance. If the organs are not accepted for transplant, or if they are accepted but found to be unsuitable, the OPO suffers the financial consequences. Because of the financial burden, the transplant coordinators are under some pressure to avoid unnecessary tests and treatments and it is up to them to determine what those may be. For example, if the transplant coordinator can rule out the heart based on the results of an echocardiogram, there is no need to spend the money on a cardiac catheterization (cath). But if the echo results are good or inconclusive, the transplant coordinator may opt to get the cath. If the cath results are poor, the OPO will not be able to recover the costs of either test since the heart will not be offered.

Interpreting the evaluative tests can be tricky and fraught with uncertainty. Blood tests to determine liver and kidney function seem easy to read but may also be inconclusive. One transplant coordinator told me the liver function tests done on the blood can look great but the surgeons may still reject the liver based on what it looks like in the OR. What this means to the transplant coordinator is that she can spend more than 24 hours testing and supporting the donor organs, get the body to the OR, and end up only harvesting two kidneys or possibly even nothing. This can be a frustrating and disappointing experience. The transplant coordinators seem to try to anticipate the outcome early on in order to protect themselves and the donor family from disappointment. In another observation with a transplant coordinator 3B, after reading



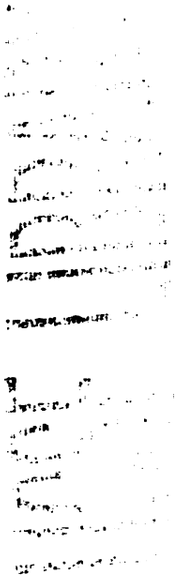
the chart, thought the donor would not have many suitable organs. She anticipated recovering only kidneys because the donor's liver function tests were up and down, she had a high blood sugar, had been in pulmonary edema and had evidence of a myocardial infarction, all of which might have ruled out the liver, lungs, pancreas and heart. Based partly on this evaluation, she told me she would approach the family 'softly;' that is, rather than spend time trying to understand the family and understand why they consent or do not consent to donation, she may right away guide them away from donation if she gets any indication that they are hesitating. This soft approach to the family was partly to defend against disappointment if all of the organs were ruled out for transplant. Later, the neurosurgeons who were signing off the case said the donor had definitely had a myocardial infarction evidenced by an elevated serum troponin, and septal wall dyskinesia on the echocardiogram. 3B said that these could all be signs of stunned myocardium, a temporary syndrome common in donors, rather than a myocardial infarction, and that the heart may still be good for transplant; she only knew this because she had seen so many donors. 3B and another transplant coordinator looked at the original echocardiogram and said it looked just like a normal donor heart despite the apparent muscle weakness evident in the septal wall. Based on this evaluation, the coordinators decided to get a repeat echocardiogram which showed normal function. The tests of liver, pancreas and lung function had also improved. As it turned out with this particular donor, the family consented right away and 3B managed a seven organ recovery, the most organs possible from one donor.





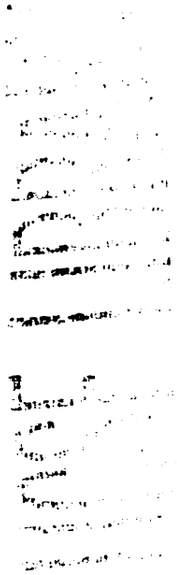
3B's experience with this donor shows the under determined nature of the procurement situation. When the coordinators first come to the site they only have access to the chart and others' interpretations. As they become more involved with the donor and the donor's family, they begin to make their own interpretations of organ function. As with the donor 3B described, the original interpretation was that the donor had had a myocardial infarction and that her liver, lungs and pancreas were also malfunctioning. Based on information gained from the chart and from discussions with the medical team, 3B was almost ready to rule the patient out as a donor. But, after evaluating the organs first hand, after looking at the echo herself and re-testing other organ functions, 3B was able to turn the situation from what she called a 'wash,' where no organs are recovered, into a very successful organ recovery.

While working toward organ maintenance and placement, the transplant coordinators also take up the job of continued family support. They often spend a great deal of time with the family after consent. If the family says good-bye to the patient and leaves soon after consent, the transplant coordinators feel free to focus on the technical aspects of the donor and organ recovery rather than on the emotional aspects of family support. For some this is a relief; for others, care of the family is the primary concern and focusing exclusively on the donor is boring. No matter what their ideal situation, the coordinators are always ready and available to continue family support throughout the organ recovery process and always offer the family the option of staying until the body goes to OR.



Another concern of the transplant coordinators is in getting the transplant teams together and scheduling an OR time. The transplant teams are groups of surgeons who come from the hospital where the organs will be transplanted. There is usually one team for the heart, one for the lungs and one for the abdominal organs. While an organ donor can come from any hospital, and organ recovery is generally done at the hospital where the donor has been maintained, the surgeries done to implant the organs into recipients are only done at a few large medical centers, the so-called transplant centers. The organs are usually recovered wherever the donor happens to be then transported to the receiving medical center. Part of the transplant coordinator's job is to arrange for the arrival of the transplant teams and to schedule an OR time to coordinate with the teams' arrival. The timing involved in this can be anxiety-provoking as illustrated in the following excerpt from an interview with a transplant coordinator. 3A describes her feelings in a situation where she has already arranged the OR and the transplant teams are on their way when the donor's wife has second thoughts.

> 3A: Um, because we were going to surgery, the teams were there and the family was on the edge. They weren't comfortable, they were concerned about these reflexes. They were having doubts about whether he was dead or alive and, you know, you feel pressure about are we going to go to surgery or am I going to have to turn these teams around and say no. What I do say to the family is that maybe if they aren't comfortable with this process and they aren't sure, that they need to say no. But being the liaison between the family, the donor, the, um, surgeons that have come, you feel, you know responsible and you feel guilty that all these people have come and maybe they're gonna have to turn away. So I'm trying to coordinate everything and right before you go to surgery there's a lot of things to do, getting the patient prepared, especially if there's family still there. The family's having to say their last goodbyes. It's a very emotional time when they know that this is the final goodbye. A lot of tears and, I'm an emotional person anyway so I get caught up in that. And then just trying to have the patient all prepared to go to surgery. So, yeah, could say I was frazzled, emotionally and

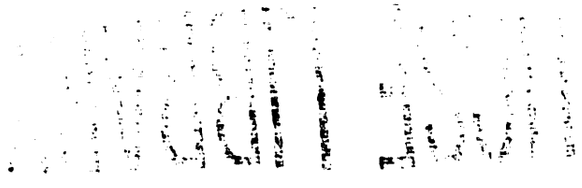


> feeling a little bit of pressure to get things done, so if it did go, that everything would be OK. (3A2.int; 1-2; 34-50)

This in between position of the transplant coordinator, as liaison between the family/donor and the transplant teams, causes the coordinators anxiety. Arranging the organ recovery is not easy. The transplant teams may come from different hospitals and OR time is always scarce. Having the wife threaten to back out after 3A had scheduled the OR time and after the teams had already arrived caused 3A discomfort and guilt. 3A says later in the same interview that if the family was not comfortable, she would cancel the surgery. This illustrates once again the coordinators' commitment to ensuring a fit between donation and the potential donor's family even at the risk of inconveniencing the transplant surgeons and OR.

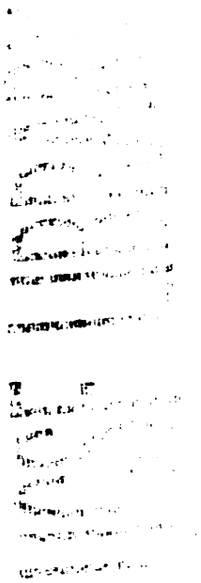
The ICU Nurses' Perspective

The process of testing and placing organs can take a long time, sometimes longer than 24 hours. 3A expected the case in the previous field note excerpt to take long enough that she might have to camp out at the hospital. The transplant coordinators at this OPO work 24 hour shifts and in this excerpt, 3A had been at the hospital since 0700 that morning. While gathering the information needed to place the organs, the transplant coordinator must also keep the body physiologically stable. After brain death, the physicians in charge of treating the patient's brain injury sign off the case and, if the patient's family consents to organ donation, turn over all treatment of the body to the OPO. It becomes the transplant coordinator's responsibility to deliver the organs to the transplant surgeons in the best condition possible. The body without a brainstem needs



technologic interventions to maintain basic vegetative functions including ventilatory and blood pressure support, fluid and electrolyte replacement, and temperature regulation. Supporting these functions requires constant surveillance and minute by minute intervention. The ICU nurses and transplant coordinators are always vigilant as they make sure the body is supported adequately with the least amount of intervention. The nurses' primary concerns in providing support to the brain dead organ donor are fluid and electrolyte status, perfusion, and pulmonary function. While the transplant coordinators manage the treatment of the brain dead body, it is primarily the ICU nurses who carry out the interventions as illustrated in the following excerpt from an interview with an ICU nurse.

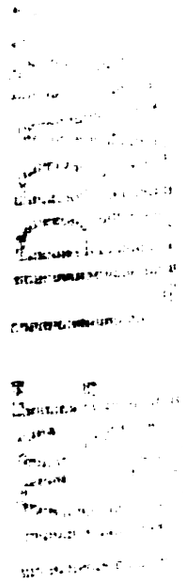
> 2B: You know he's dead, he's pronounced dead, um, my, our goal is to get this body now in good shape to OR, and that, that's what my goal was, was just to maintain, um, luckily, like I said he was stable. Others haven't been stable, you know, you, they've got no blood pressure, they're tachycardiac and so you're working really hard to get all that stable. His lab work was fine, his, um, like I said his blood pressure and his, his temp and his heart rate, all those things were, were normal. I mean obviously he, if he had been hypothermic I would have warmed him up, or, you know, low output, I would have given him more fluids. In all, all directed by the transplant coordinator, whatever I saw, I went and reported to them because no longer was the doctor involved in the care. It was the transplant coordinator and I doing, doing what we needed to do to maintain, main, maintaining was, was my goal. To get him to surgery. And initially, I, I, the first day, the second day, basically, but the, and the first day obviously initially getting the lines in place, and getting the lab work off, making sure that all those things, um were being done, because it's, it's our hospital, I mean, the transplant coordinator is a guest there so they don't do all the calling, you know. You, you are doing all that for them, getting the doctors to put in the certain lines and then just making their job easier by providing them with information, you know, when the lab comes in, getting it for 'em, and, and, um, you know the phones, the phone's a big thing for them, they're on the phone a lot, you know. And so you're with the patient and just keeping them updated on what's going on with the patient so that we can support 'em. (2b1.int; 14; 616-637)



In order to stabilize the brain dead body and keep the organs in good shape for the OR, the ICU nurse follows a set of standard orders given by the transplant coordinator. The orders include full blood chemistry, cardiac enzyme and liver function tests, hematology and coagulation panels, blood gases, blood, urine and sputum cultures, and blood typing and cross matching. The orders also call for up to two different intravenous antibiotics, maintenance intravenous fluids at a specified rate, settings for the ventilator, a calculated dose of solumedrol, and potassium, calcium, desmopressin and insulin given according to need based on blood electrolyte and glucose values and urine output. If the body becomes hemodynamically unstable, the orders call for extra doses of colloid fluids including hetastarch and/or 5% albumin, and dopamine titrated to keep the systolic blood pressure above 90 mmHg.

To provide these interventions, the nurses must monitor the body closely; the orders require vital signs including heart rate, blood pressure (systolic, diastolic and mean), temperature, central venous pressure and oxygen saturation be watched continuously. The orders ask the nurses to measure and record the urine output every hour and blood sugar every four hours. If the body temperature falls below 36 degrees centigrade, the orders request the application of a warming blanket. The nurses are asked to turn the body, hand ventilate with an ambu-bag and suction the endotracheal tube every hour.

These orders reflect the complex nature of brainstem replacement. When the body loses all function of the entire brain including the brainstem (the definition of brain death), it becomes apneic and vasoactively unstable. Hemodynamic function may



stabilize over time, but in the initial few hours the body requires constant intervention to prevent cardiac arrest. As illustrated by the previous interview excerpt, the ICU nurses work closely with the transplant coordinators and report any significant changes. In this excerpt 2B described some of the technical work of donor maintenance. Working with physicians to get central and arterial lines placed, keeping the blood pressure, heart rate and temperature within acceptable limits, and sending lab work are all priorities in donor maintenance. The nurse does not share the details of this work but describes the patient as stable. Despite what the nurses and transplant coordinators say in the interviews, the newly brain dead body is usually unstable. The reason it seems stable to them is because they are working to make it so.

The transplant coordinators stay close to the bedside and stay in communication with the ICU nurse. If needed, the transplant coordinator will lend a hand with maintenance care such as suctioning the endotracheal tube, turning, or drawing blood, but these tasks are most often left to the ICU nurses while the coordinator spends time on the telephone arranging organ recovery and placement. The interaction between the ICU nurse and the transplant coordinator depends on the experience and level of comfort of each. As 2B pointed out in the interview excerpt, the transplant coordinators are visitors at the hospital; they must rely on the ICU nurses to show them the standards for the particular unit especially if the transplant coordinator is new to the job. This is illustrated in the following excerpt from an observation with 2F, an ICU nurse. In this observation, 2F was working with a new transplant coordinator who had been off orientation for four months.

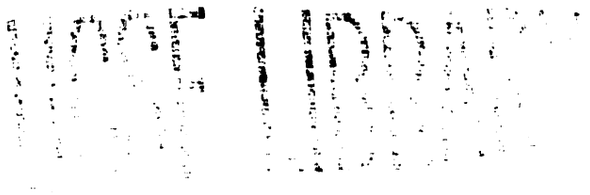
1545: 2F listens to his chest and abdomen then covers him back up. She's concerned about the family, doesn't want them to see him looking a mess. She goes out to the nurses' station and confers with the transplant coordinator. 2F picks up a copy of the standing orders the transplant coordinator has filled out. She asks about the ventilator orders and the transplant coordinator says 60% oxygen is okay after 2F says his sats are 97%. The transplant coordinator has a bunch of meds in a plastic bag and offers to mix them but doesn't know what the policy is at this hospital. She and 2F agree she, the transplant coordinator, will mix the meds but 2F will administer them. The transplant coordinator wants to wait for the father to arrive before she talks to the family. 2F encourages her to just go introduce herself to the mother and at least initiate contact. The transplant coordinator goes out to talk to the mother. 2F starts setting up to measure the CVP (central venous pressure). She looks again at the standing orders. 'This is a pretty general thing,' she says, referring to the standing orders she got from the transplant coordinator. The page seems to include every blood test available plus a huge list of meds.
1615: A lab technician shows up to collect some specimens. 2F draws 30 mL of blood from the arterial line and divides it into red, blue and purple-topped blood tubes. The transplant coordinator is back and says she needs some other tubes as well. 2F and the transplant coordinator go over the list with the lab tech. The transplant coordinator wants an ABG and a sputum and urine culture sent. 2F connects the sputum specimine trap to the in-line suction catheter then leaves it to draw the ABG from the arterial line. Then she suctions some bloody secretion into the trap. Next she collects a urine specimen. She is concerned about his urine output being high; he's put out 750mL for the past hour. She thinks he probably needs some ddavp (desmopressin, antidiuretic hormone). She goes out to discuss this with the transplant coordinator . They confer over the correct dose; 2F does not know how much to give and finally the transplant coordinator goes to her bag and brings out a calculator. She writes an order for the ddavp and 2F gives it. (FN book 2, 2F)

This excerpt shows the interaction between the ICU nurse and the transplant coordinator. In this case, the ICU nurse believed she had more experience with donor care than the transplant coordinator and felt like she had to guide the transplant coordinator to do the right thing. For example, 2F encouraged the transplant coordinator to talk to the family and advised her to give the desmopressin (ddavp). But they also worked together to decide what lab specimens to send and how much ddavp to give.

While the ICU nurse was better informed of the donor's condition, like the high urine output, it was still the transplant coordinator's job, in discussion with the ICU nurse, to decide on the intervention. This give and take of information and consultation between the ICU nurses and transplant coordinators is part of the atmosphere in many ICUs. It was especially evident in my observation of trauma centers where the ICU nurses are very familiar with organ donation and organ donor support.

Team Work

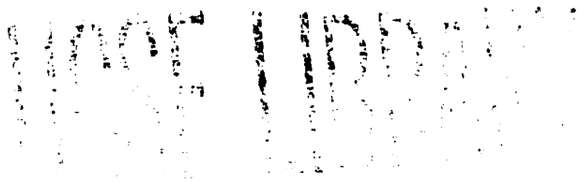
Evaluating and supporting the organs is a team effort that involves more than just transplant coordinators and ICU nurses. The transplant coordinators on site consult administrators and placement coordinators in the office with questions about what tests to do or not to do, and whether or not to rule out certain organs. Sometimes there is more than one coordinator at a site either working on the same donor or working on another donor. In one observation I did, two transplant coordinators and a hospital development coordinator were at the same site managing two different donors. The transplant coordinators support each other and there is a sense of comradery when more than one is present. Even though the hospital staff is part of the procurement team, and the coordinators work with the ICU nurses, there is a sense of loneliness when the transplant coordinator is at a hospital alone. The transplant coordinators are visitors at the hospital; they have no real home but do their work on the road, so to speak. In order to make their work bearable, the transplant coordinators must form good working relationships with a huge number of staff members at many different hospitals. The transplant coordinator's I observed were very good at this. They became part of the team wherever they were but



were always wary of potential conflict and always aware of their tenuous position; if they offend the staff this time the next time may be more difficult.

The transplant coordinator's are in a difficult social position. They are the experts in donor management and yet they sometimes must defer to the hospital staff in the interest of maintaining good relationships. In another observation, the transplant coordinator had helped the ICU nurses to turn a brain injured patient who was actually brain dead but who had not yet been declared brain dead and whose family had indicated an interest in organ donation. After turning, the patient's systolic blood pressure dropped to 70. The transplant coordinator, who had much experience in donor management, thought the BP would come back up on its own and told the nurses she was not worried. When the neurosurgery resident came in and saw the low blood pressure, she angrily wrote an order not to turn the patient and to give a 500 mL IV fluid bolus. The transplant coordinator spent the rest of the day apologizing to the nurses for getting them into trouble and this theme became an ongoing joke throughout the day that helped the transplant coordinator and the nurses work together. This points to the transplant coordinator's attention to her relationships with the staff.

The social negotiation required in this role is evident in another observation; a transplant coordinator gave a donor IV calcium chloride at the recommendation of the ICU nurse she was working with, not because she thought the patient needed it, but because she thought it would make working with the nurse more difficult if she did not give it. Giving up certain decisions is one way the transplant coordinators maintain their relationships with hospital staff. The transplant coordinators are also always careful in



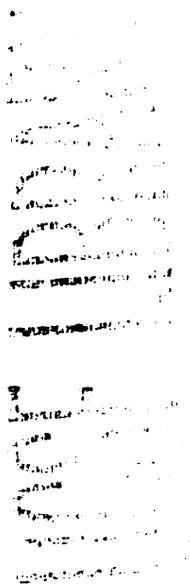
their interactions with staff and often want to make sure the nurses feel involved in the donor maintenence decisions.

The field note excerpt from 2F showed the way ICU nurses and transplant coordinators support each others' practice around donor maintenance. Examples of this support have also come up in the interviews although the transplant coordinators are much more concerned about collaborative practice than are the ICU nurses. The transplant coordinators talk about how they try to help with the physical work of supporting the donor as much as possible and about how they often seek the ICU nurses' advice on treatments. Most of the ICU nurses talk about how donor maintenance is the responsibility of the transplant coordinator and say that they follow the transplant coordinator's orders for all treatments. The ICU nurses' willingness to turn over treatment decisions to the transplant coordinator contributes to the nurses' feeling, described by 2B in another interview, 'off the hook.' This means that the ICU nurse no longer feels the same responsibility toward the donor as she did before the patient became a donor. But even though the responsibility is not the same, the ICU nurses still have a stake in donor maintenance. Perhaps the difference is that, with a donor, not as much rests on the ICU nurses' judgement; the transplant coordinator shoulders most of this burden.

That the burden of responsibility for donor management falls to the transplant coordinator makes sense. As previously discussed, after brain death, the responsibility for donor management shifts from the neurologist, neurosurgeon or trauma surgeon to the OPO and transplant coordinators. This shift allows the transplant coordinators to focus

exclusively on donor management and the physiology of brain death. The transplant coordinators have gleaned their clinical knowledge from many experiences with many different donors. Whereas an ICU nurse, even one who works in a trauma center, may see one donor for eight to twelve hours once per month, each transplant coordinator at this OPO spends ten 24-hour shifts on call per month. When she or he is on call, the transplant coordinator may be called to any hospital within so many miles radius to evaluate and manage a donor. This means the transplant coordinators have spent a great deal more time managing donors than have the physicians or nurses with whom they work.

Because they spend much of their time managing brain dead donors, transplant coordinators have developed clinical wisdom in this area (Benner, Hooper & Stannard, 1999). This is experiential knowledge that comes from thinking through the donor situation time and again and learning from each new donor experience. The ICU nurse's willingness to give up responsibility and let the transplant coordinator make all the final treatment decisions shows respect for the transplant coordinator's knowledge and experience and acknowledges that the ICU nurse's expertise lies elsewhere. At times the nurse or physician is less willing to relinquish responsibility. This can prove frustrating to the transplant coordinator as it was when the transplant coordinator agreed to give the calcium chloride to apease the nurse or when the transplant coordinator was chastised by the neurosurgery resident for turning the unstable donor. It can also be frustrating for the ICU nurse to work with a transplant coordinator she does not trust or who does not seem to have enough experience.

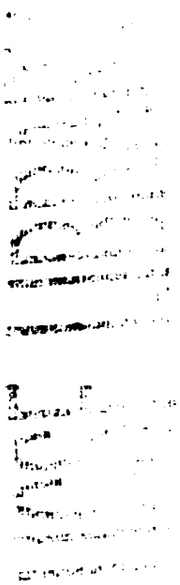


The Unstable Donor

For the ICU nurses and the transplant coordinators, donor maintenance can be routine work; the donors are often stable and require little intervention. Yet, as evidenced in the field observations, maintenance of even the most stable donor does require a great deal of highly technical intervention and surveilance. Donors can also be very unstable and the path from consent to the OR can be fraught with physiologic obstacles that require constant attention.

> 3B: Each patient is different it seems like, they just always, and then there's similarities, I don't know it's like, it can be real, y'know it depends, y'know you get these big trauma patients, you know, they can be really hairy. And y'know, so we do often guide the management of the patient even before consent sometimes. Just to assist the hospital. When the hospital and the doctors know that the patient's herniating and is not gonna survive often they will turn to us for guidance, not necessarily for us to do it, but some of the times for us to do it too. But to help with the fluid resuscitation and all of that. And it can be real interesting, it, it, it, y'know, some patients are real challenging and others are, like I said, almost boring. They are so routine. Yeah. I, the most memorable case, of a really interesting probably donor was a guy who had fallen off of a ladder over at [name of hospital] and he was um, he had a huge, huge retroperitoneal bleed. And they had done an excellent job with fluid resuscitating him during the night. He had had 18 units of blood, and 12 of FFP, and 45 of platelets or whatever, I don't know, but he was, he was a normal size man who looked like he was 9 months pregnant, he was like this, bleeding was so huge. But all his numbers looked fine and his wife consented right away. But I didn't know he had a CVP of 35. And he had, um, he was a tall man, but he had, y'know, on his x-ray you could see his diaphragm's way up here and he had these little tiny lungs 'cause there was so much pressure and I was so nervous (laughs), I was nervous, about, y'know, what we can do, and I told them hurry up and get here, just hurry up and get here, 'cause I don't know if we can hold this one off and one of the other coordinators came to join me because on a rare occasion when it's that difficult, y'know, you can ask for some other help, and, and, um, 'cause I was mainly worried about the operating room, I thought when they open this poor man that's gonna be like. Actually he did fine. (3B1.int; 20-21; 882-907)

Handling an unstable donor can be difficult and labor intensive.



In this excerpt, the transplant coordinator describes the donor as so unstable managing him took the efforts of two coordinators. While the description is vague as to the source and manifestations of the instability, the excerpt gives a sense of the pressure the coordinator felt. She tells the transplant teams to hurry up and get here because she is not sure how long she can keep the organs systems going as the body continues to bleed and accumulate blood behind the lungs. There is so much blood accumulating that it is pressing on the lungs, decreasing their capacity and compromising oxygenation. 3B ends this story by saying all went well in the OR. This transplant coordinator told me in another interview how important it is for her to project confidence as she manages the donor. Her downplaying the details of this case may be her attempt to maintain her image of confident coordinator, always in control although she did admit to feeling nervous.

The idea that every donor is different points to the ambiguity of donor management. Like the brain injured patient, the nurses and transplant coordinators never know what a donor may do, how the brain dead body may respond to any given intervention. Experience with donors gives them a place to start, but how the management will go over the course of the 16-24 hours it takes is unpredictable. 3A's experience of each donor being different is echoed by an ICU nurse:

> 1B: You know, mostly it's fluids and dopamine and if they're in DI [diabetes insipidus] then you're giving them ddavp. Um, what else is there? In general, you know, you know more than anybody else, you know what to do. And if not, then you refer to the manual [a book of organ donor protocols available in this ICU]. And if, if not, then you refer to other nurses that ususlly look after [organ donors]. And it's funny, it's like all situations are so different, you know, they really are. And actually everyone, it never ceases to amaze me, even thoughI've been doing this for, been on the donor committee for four, five years, it's, it's,

> there's always something, some little something that's just so different it really catches you out. (1B1.int; 8; 213-224)

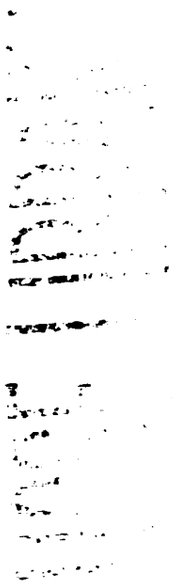
1B has had 5 years' experience in donor management. He knows what to expect in a general sense and usually he knows what to do. If not, he can refer to a manual on donor maintenance or he can consult with other nurses who also have experience in the area. But despite all his knowledge and resources, he still finds something unusual with every donor.

Providing support to a donor is both like and unlike treating an unstable critically ill patient. The physiology of brain death is sometimes very different from that of other organ failure. Often brain dead donors have no other pathology and it is difficult to sort out the causes of instability. One donor I managed had gone into DI overnight and had not been treated because the neurosurgery team thought she was going to die anyway. When I took her over as a patient, her sodium was up over 200 and the neurologist in charge didn't feel comfortable declaring her dead with a sodium that high. The family wanted to donate and we all knew the patient was probably brain dead but we spent the whole day battling her fluid balance, pouring in water, half normal saline or normal saline depending on her sodium level. Her CVP ran about 12-15 all day and her oxygenation was good. Once we corrected the sodium, we did an apnea test and the neurologists declared her dead. By that time her blood pressure had dropped to 70/40. I hand ventilated her for a few minutes thinking the hypotension might be related to the high pCO2 after the apnea test. I noticed her lungs felt really stiff and it was really hard to get any air in. The blood pressure was not coming up, it stayed around 70-80 systolic. The

transplant coordinator and the two neurologists decided they wanted more fluids. As I forced air into the ambu bag, sticky clear liquid was blowing out her nose very violently; I told everyone to stand back or they might get splashed. Her face was swollen and grotesque; I was glad the family had not come back in. I finally put her back on the ventilator, stood at the head of the bed and started pumping normal saline into the central line with a pressure bag. Her BP would come up temporarily as long as I kept forcing in the fluid. But if the IV bag went dry, the BP would drop again.

The picture described above is one of fluid overload and third-spacing to the point of pulmonary restriction. The neurologist and transplant coordinators responded by adding more fluids which seems in hindsight to be counterproductive. But with the blood pressure low, we could not ensure organ perfusion and the only thing that would bring the BP up was the fluid. This response was unexpected; the donor was young and healthy with no injuries except those internal to the brain. The donor in this case became so unstable the team had to rush her to the OR and quickly take the liver and kndneys before the rest of the organs could be placed. Once they took the body to the OR and made the abdominal incision, the extra fluid escaped from the gut, the diaphragmatic pressure was relieved and the physiology stabilized. The rush to get to the OR with a donor is described in the next excerpt taken from an interview with an ICU nurse:

> 1C: I was taking care of, it was dreadful where um, it was a matter of time. We finally got placement of the organs; I don't remember the details, I just remember that the next thing you know this patient was arresting in the unit and the donor network team says let's get him to the OR now. And I was doing CPR on the patient, I was doing the chest compressions while we were pushing the gurney into the operating room and they said don't stop compressions, keep going. And I did compressions and the next thing you know they went and they just did the big old incision and they went ahead and took the kidneys like that quick while I was



> doing CPR because there was no way they would get the heart back and they felt that they still could get the kidneys [laughs]. And I, it just totally blew me away, 'cause I was not prepared for that. And, um after they did the first incision, thank goodness the anesthesiologist said would you like me to take over, and I said would you please? Because I had blood all over me because an IV blood bag just blew up on transport. It was one of the messiest scenes that I've ever experienced as a nurse. Um, but that was fine, it was great because you know they felt that they could actually get a couple of kidneys. And so that was good.

In this story, 1C describes rushing an unstable donor to the OR as dreadful and messy but in the end good. The hurriedness of it surprised him because he was not prepared for it. Usually organ procurement takes place under very controlled circumstances; the donor is brought to the OR much like any other surgical patient. The unstable donor in 1C's story did not match his prior experience with donors. Despite the unpleasantness of the experience, the fact that it yeilded two kidneys makes the nurse finally characterize the action as a good thing.

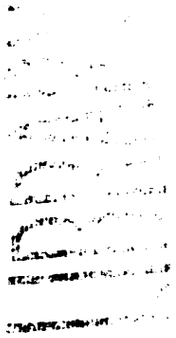
In all the stories of unstable donors, the ICU nurses and transplant coordinators make huge efforts to salvage the organs. They fight to stabilize the body with all the technology in their grasp and often are able to recover at least one or two kidneys. More important than the efforts of the ICU nurse and transplant coordinator to save the organs is what the body goes through. 3B described the donor as looking nine months pregnant. By the time the body got to the OR, the donor in the second story was completely unrecognizeable and the transplant coordinator recommended the family not consider an open casket funeral. 1C described the surgeons making a 'big old incision' that shocked even an experienced ICU nurse. At the same time, the transplant coordinators reassure families during the consent process that their loved one's body will not be mutilated, that

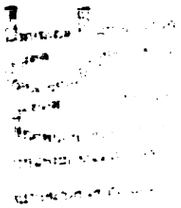
the organ recovery process is a controlled surgical procedure that treats the body with the utmost respect. What is missing from this description and perhaps ought to be included is the time spent before the OR tuning the body up and waiting for organ placement. This is the time when the body takes the most punnishment and often respect for the body must take a back seat to proceedures needed to salvage the organs.

Most health care professionals agree that informed consent cannot and should not try to include the details of every possible contingency. Organ procurement takes place in a world of contingencies. That the transplant coordinators leave out some of the details of organ procurement may indicate the complexity of the situation rather than their desire to mislead the family. The transplant coordinators do not know what will happen to the donor but can only speculate based on experience what is likely to happen. In the excerpts illustrating the care of the unstable donor, the donor's instability takes each nurse and transplant coordinator by surprise. In each story the procurement process is rushed and the transplant coordinator and nurse are busy and distracted with keeping the physiology stable. The whole team becomes caught up in the goal of salvaging organs and the situation goes out of control before anyone recognizes the treatment of the body as lacking respect. This scene is not unusual in the ICU. In a context where the goal is to save the patient's life, treatment often goes beyond what the family would objectively consider respectful before anyone identifies the intervention as improper.

The Operating Room and Organ Recovery

Going the OR with a donor is glamorized by the ICU nurses and generally dreaded by the transplant coordinators. Because the ICU nurses almost never get to see





the actual organ procurement, many of them mystisize the process. One student nurse, after attending her first procurement surgery described the experience as awesome. A new transplant coordinator described her decision to apply for a transplant coordinator's job as based heavily on one OR observation; as an ICU nurse she had an opportunity to attend a procurement surgery and when the surgeons removed the heart and lungs, held the mass of organs up and inflated the lungs one last time, the nurse immediately knew she wanted to become a transplant coordinator. In contrast, the more experienced transplant coordinators do not have any special affinity for the OR or for the procurement procedure.

> 2B: And once they get out the organ I don't know if it's the heart, well they start at the top and go down, but, you know once they don't need that blood supply anymore and everything, and they take out the heart, then everything else they just work quickly and go, and you don't need them being ventilated. So that's what people say, that's what my co-workers have said is th, the, it's kinda eerie because then there's just quiet. Y'know, normally in OR it isn't just quiet it's normally the vent, y'know the anesthesiologist is over there doing his thing, and the machines are goin' and the, they said it's just eerie once that ventilator gets turned off.
>
> LD: And, is it just curiosity?
>
> 2B: Um, no actually, yeah, curiosity to see surgery. More than anything else. And also to follow it through to the end. That would be kind of a very good feeling. Is to actually see them, you know you've started out and you've dealt with the family and the patient, and then to see them go to OR. It's kinda awkward just pushin' 'em in and then it's over for you. That would be maybe a, um, y'know, a, a, a completion. You know that you would feel yeah, yeah. Yeah, finishing what you started. 'Cause there's always that, even when you start something and the patient goes to organ, you know they donate and it ends up being the middle of the night or on a different shift, you don't feel that completion either, you know. You feel like, you feel good about it because the patient was able to go, but it's always nicer to send them off, you know, 'cause you've worked so hard. (2B2.int; 12; 497-517)

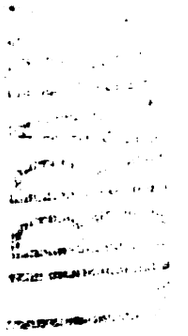
> 2B: the nice thing too with him and with the other one is we were able to send students to the OR to to um see the procurement. Because it's totally di, and I, I've never been able to go, that was the, one was going, 'Well, I don't know if I should or not, I don't know if my instructor,' and it was like, no, no, no, no, you don't understand [laughs], you may never get the chance to see this again. Because **we** haven't, you know I've been an intensive care nurse for 17 years and have never been able to go because you're working, I mean I sent my patient up to surgery, but I had another patient coming in the door, you know, within an hour. So I could, I didn't have the luxury to go over and witness, y'know, the procurement, 'cause I really think that would be something interesting to see. So and actually the fellow that did, was able to see that one I saw him yesterday at work, he stopped back into the unit and he just, he said it was just awesome, just amazing. (2B1.int; 10; 424-435)

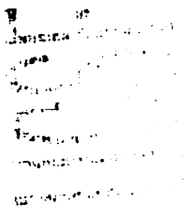
In these excerpts, 2B, an ICU nurse, describes witnessing the procurement process as something she never has the luxury of doing. She thinks going to the OR with a donor may provide closure for her but she is also just curious about what the procedure involves. She imagines the teams going from head to toe harvesting first the heart and lungs, then moving down quickly to take the abdominal organs once the heart has been stopped and the body is no longer perfused. She has heard stories about what the OR feels like after the ventilator is turned off and everything is quiet. The description seems shrouded in mystery; 2B really does not know what it is like in the OR. In addition to satisfying her curiosity and providing a sense of closure, going to the OR would be a luxury for 2B because she would be an observer there and have no role or responsibility, and going there would mean leaving the ICU; it would mean she did not have another patient on the way.

In contrast to the mystery described by 2B, the following excerpt is from an interview with a transplant coordinator who has been to the OR for organ procurement a number of times.

3B: it can be very stressful depending on the hospital you're at, you know. They've never done this before or they've only done it once or twice and everybody's all nervous. Or else, um, oh and it's notorious for some problem with the transplant surgeons getting into an argument with the scrub nurse, or the transplant surgeons arguing between each other over the patient or, you know. It just seems like, you know. And you get some smooth ones, but it's always like, I don't know. I mean, the operation, I've seen it hundreds of times, it's not very interesting, you know what I mean, it's just like, I don't know. It's just not very interesting. And then maybe it's a let down. You know, it's all done. You take the body to the morgue, you know. If it's not the middle of the night, you call the family, but. I don't know. It's just, it's lengthy and it's um. I feel like a technician could do it. You know, I feel like I have, um, expertise that, you know, in terms of families and donor management and stuff, clinically, you could have anybody in the OR there writing down the numbers and trying to keep the teams from getting into it [laughs]. And we've discussed that even. Yeah, well, I don't know, if that's exactly, it seems like it is. Um, I think that it, we've discussed it, and some organ procurement agencies do use recovery teams. So the coordinator is not in the operating room doing that. It's just very lengthy. It can be very, very lengthy, and like I said, it's kind of more of a technician job. Besides that I have no surgical experience. I don't feel that comfortable in the OR, I'm always like, the first thing I say to the scrub nurse is, I mean the circulating nurse is I'd be happy to help, I'm not an OR nurse, but. Y'know, let me know if I can help because I don't want 'em to start giving me jobs that are over my head at the same time. Could you scrub in over here? No. So, yeah, I don't know, it's not just me, there's others too who find it...(3B1.int; 19; 854-878)

The contrast between the transplant coordinator's experience and the ICU nurse's imagination is interesting. The ICU nurse imagines witnessing the procurement will provide closure; the transplant coordinator describes post-operative post-mortem care as a let down. The ICU nurse imagines a quiet and serious OR where a team cooperates to recover the organs. The transplant coordinator has experienced fights among surgeons and between surgeons and nurses and she recognizes preventing conflict between surgical teams as part of her job. It is clear from these descriptions that organ procurement is a procedure clouded in mystery for the uninitiated. While the idea of taking living organs

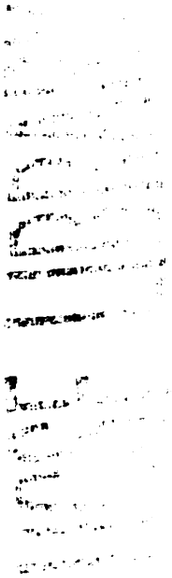




from a dead body may remain awesome, the actual fact of the surgery is enough to distract an experienced coordinator from appreciating this aspect.

The transplant coordinator's job in the OR is to keep track of the procedure, to support and offer help to the circulating nurse and scrub technologists, and to provide post-mortem care which involves preparing the body for the morgue after the surgery. As 3B pointed out in the excerpt, the transplant coordinators have ICU experience but no OR experience so they can offer only limited help during the surgery. There are three transplant surgery teams, one for the heart, one for the lungs, and one for the abdomen. The teams may be from the same or from different transplant hospitals, and they may be in their own OR, if that is where the donor happens to be, or in any number of hospitals in or out of the geographical area. There may be as many as 25 people who may or may not know each other or the facility in the room to recover seven organs. In this crowded and highly tense atmosphere, interactions among staff can be difficult; the coordinator acts as facilitator. Sometimes the OR runs smoothly as described in the following field note excerpt from an observation wiht 3B.

> 1430: They estimate the finish time as 1630. There is only one surgery team here to take the liver and two kidneys. The rest of the organs have been ruled out. 3B is glad about this because it means she'll be able to get home before her son goes to bed. Two techs are on the floor pounding bags of frozen lactated ringers with steel mallets. They are making 'sterile slush,' 3B calls it. They will pour the sterile slush into the abdominal cavity to cool the organs after cross-clamping. I'm not sure what cross clamping is but I think it marks an important transition for the donor. 3B and I sit on stools near the door, away from the OR table where the surgeons are making the first incisions. From here we are too far away to touch the patient. There is an anesthesiologist sitting at the donor's head managing ventilation and perfusion; there is no anesthesia involved.



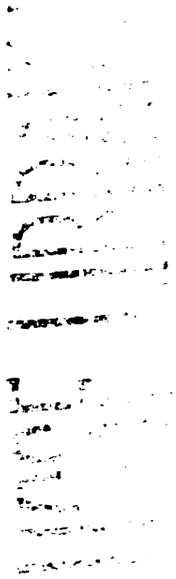
1500: I'm really tired and thirsty. I've gotten off my stool to watch the surgeons mucking around with the small bowel, pushing it out of the way to get to the liver. The intestine is grey and shiny and looks like the anatomy book pictures with the mesentery attached. The body is open from the top of the chest to the pubis even though they will only take the liver and kidneys. I wonder how they will get to the kidneys without a flank incision.
1510: one of the surgeons asks 3B to please check the urine output. She reports it to her then stands at the foot of the table talking to the circulating nurse. Everyone is very polite. The team is from a medical center in town and everyone seems to know everyone else.
1515: there is very little blood despite the huge incision. One surgeon asks for 'aortic cross clamps.' 3B comes back to the side of the table and stands next to me. Once the cross clamps are applied, the donor's blood pressure drops to zero and the anesthesiologist turns off the cardiac monitor and the ventilator and exits without saying anything. This is the end of circulation for the donor and where the risk of warm ischemia can threaten organ viability. The team scoops the sterile slush, which has been poured into a bowl, into the body cavity. The surgeons think the liver looks a little yellow and that it will need to be biopsied before they make a final decision about taking it. They're still flushing the cavity, mushing the ice around. They dissect some fat off the small bowel.
1520: back to out stools where 3B fills in more forms. The surgeons are still working in the cavity; the organs are not out yet. 3B is trying to figure out what meds the anesthesiologist gave during the case. The surgeons are flushing the aorta and portal vein with iced fluid.

This field note describes a smooth OR experience. The limited procurement and the experience of the OR staff and transplant team all contributed to making the procurement easy. The only hitch was the biopsy which delayed recovery of the liver by about 45 minutes. The biopsy revealed a healthy liver and procurement proceeded apace. The transplant coordinator's role in the OR was minimal in terms of the actual harvesting. During the surgery, 3B sat back and finished up her paperwork and wandered around the OR chatting with the staff, catching up on personal news from people she had not seen in a while. At the end she said it had been a good experience, a relaxed and unhurried procurement that allowed her time to finish the paperwork before she had to

step in and prepare the body for the morgue. From my perspective, the OR did not seem any different than for other surgeries I have witnessed other than the anesthesiologist's premature departure. There was casual conversation among the surgeons and other staff and the atmosphere was not the least bit heavy. No one discussed the donor in terms other than the quality of his organs and no one mentioned his family.

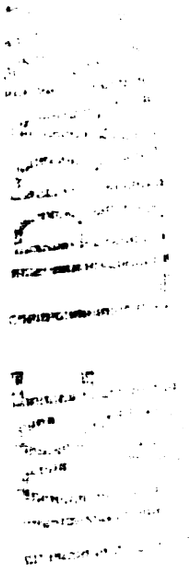
Summary

All in all, the process of recovering organs after the family consents to organ donation involves supporting the physiologic function of the body while waiting for the organs to be evaluated by the OPO and offered and accepted by a recipient. The transplant coordinators and the ICU nurses as two separate groups take up the work of donor maintenance differently because their responsibilities throughout the process differ. The transplant coordinators' primary concerns include evaluating and placing the organs and managing donor maintenance. This involves a lot of telephone work as they consult with the OPO staff and transplant surgeons. The transplant coordinators' management of the donor is more of a hands off advising although they also provide physical care when needed. The ICU nurses, on the other hand, have a very hands on job; under the supervision of the transplant coordiantor they provide the actual physical care and treatment to the donor. Sometimes the transplant coordinator and ICU nurses' roles are confused. The ICU nurse looks to the transplant coordinator to be the expert in donor management. When the transplant coordinator fails in this capacity, it is frustrating to the ICU nurse who must then step in and advise the transplant coordinator.



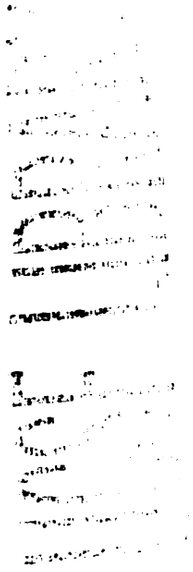
Aristotle's distinctions between phronesis and techne can help frame the process of organ procurement as it did the process of approaching the family to offer the option of organ donation (Chapter 6). If the work of consenting the family can be described in terms of phronesis as I argued in Chapter 6, the work of donor maintenance falls more toward techne in that the process is directed toward a durable product that requires skill to obtain. After consent, the transplant coordinator's goal is to deliver the organs in good condition to a recipient. The transplant coordinator is an organ craftsman, so to speak, whose work produces organs ready to be transferred to another body. The work differs from craft in that the transplant coordinator does not make the organs but only applies her techniques to supporting them when their intrinsic supports (ie: the brain and brainstem) are no longer functioning. But unlike the products of techne, donor organs cannot be manufactured. Each donor body is different and the transplant coordinators and nurses must always be attentive and responsive to what the particular body demands. In this way, donor maintenance is phronetic because it requires attunement to the particular rather than a general technique, template or theory that can be applied to all cases (Dunne, 1993).

The transplant coordinators have developed a body of knowledge around donor maintenance that no one else can claim as solidly. The shift in responsibility that occurs after brain death and after the family consents to organ donation makes it possible for the transplant coordinators to develope expertise in this area. But the transplant coordinators also appreciate that they cannot do the work alone. The transplant coordinator's and ICU nurses work together to provide the best possible support to the donor with the goal



of transporting a stable donor to the OR and recovering as many organs as possible. The organ recovery team also includes many other players in the ICU and in the OR. Technicians and technologists run special tests on the organs; specialist physicians offer their interpretation of the test results; OR personnel prepare the donor and complete the organ recovery. The organ recovery process requires that the team work together toward a common goal. Because the transplant coordinators often act as team leaders in hospitals at which they are visitors, they rely on excellent communication skills and the kindness of strangers to make the procurement process run smoothly. If the donor becomes unstable, the procurement process does not run smoothly. In this case, the transplant coordinators and the ICU nurses are willing to give their all to salvage what organs they can.

Once the organs are evaluated and placed, the transplant coordinator, along with a team of transplant surgeons, takes the body to the OR for organ recovery. To the experienced transplant coordinators the OR is tedious and anticlimactic. They have seen the surgery enough times that it is no longer interesting to them and taking a donor to the OR represents the most boring part of their job. To the ICU nurses, the OR is a mysterious and awesome place perhaps only because they have never been there and have never witnessed an organ recovery.



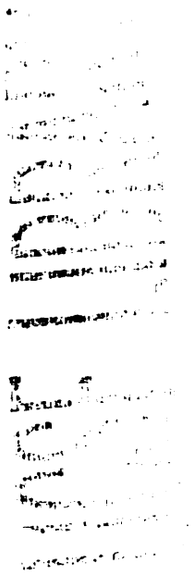
Chapter 9

Conclusions and Implications for Practice, Administration, Education and Future Research

This study has begun to explore nursing's role in organ donation and procurement by examining the practice as it is lived by the participants. By interviewing and observing the practice of ICU nurses and transplant coordinators, nursing practice and concerns have been articulated throughout the process of identification and support of potential organ donors. Identification of the potential donor, declaration of brain death, coaching the patient's family, approaching the family with the donation option, maintaining the donor and recovering the organs or supporting the family and patient while support is withdrawn are areas that have been developed in this study. As the clinical situation unfolds and the brain injured patient is identified as a potential organ donor, the nurses and transplant coordinators draw on etiquette, relational ethics, and phronesis as they open a moral space in which organ donation and procurement can exist.

Phronesis and Relationship in Organ Procurement

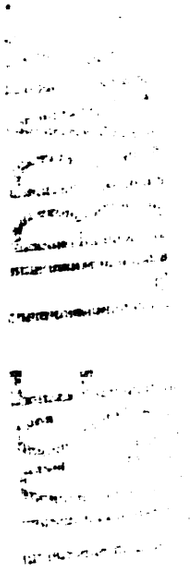
Phronesis is evident in many aspects of the organ procurement process. Aristotle described phronesis as practical wisdom involving ethical rather than productive activity that provides and ability to be responsive to the particular in any given situation (Dunne, 1993). Phronesis is evident in the way nurses identify potential organ donors, in how nurses and transplant coordinators approach a family to offer the option of organ donation, and in how nurses and transplant coordinators work together to maintain the brain dead donor's organs. The nurses' and transplant coordinators' actions may be influenced by certain theories like Kantian or deontological ethics, the idea of



decoupling, or physiologic theories of brain death, but because the actions involved in organ procurement require responsiveness to the particular, it is impossible to work strictly from a theory or template to produce the same outcome in every situation.

The ambiguity of the brain injured patient's prognosis precludes certainty when identifying a potential donor. The nurses involved in this process must stay open to the idea that the patient may recover while also keeping organ donation open as a possibility if the patient does not survive. Ethical practice requires the nurse never treat a person as a mere means (Kant/Patton, 1956). This means the nurses hold both concern for the brain injured person and his recovery, and the possibility of organ procurement as open possibilities while never treating the person as a means to another end, for example, as a receptacle for transplantable organs. This requires an openness to the ambiguity of the situation and an ability to respond to many different possibilities. It also requires the nurse to respond in the right way, or in a way that is in keeping with the ethics of his or her larger practice. These ethical demands describe the need for phronesis and also point to the importance of relationship in this area of nursing practice.

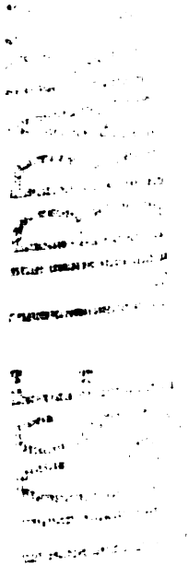
The process of identification of the potential donor and holding open the tentative possibility of organ procurement illustrates the practical difficulties of the early referral of potential donors to the OPO spoken of in the literature. Early referral implies a commitment to organ procurement the nurses may hesitate to make because of the risk to their relationship with the brain injured patient. While organ procurement may be in the back of the nurse's mind whenever a severely brain injured patient is admitted to the ICU, it is a different step to bring in the OPO to evaluate the patient as a potential donor.



The involvement of the OPO may be perceived as distracting and in conflict with the nurse's dedication to treating the patient's brain injury to the fullest. Perhaps bringing in the transplant coordinator while the patient is still alive prematurely tips the nurse's balance between the tentative commitment to organ procurement and the treatment of the patient's brain injury in favor of organ procurement.

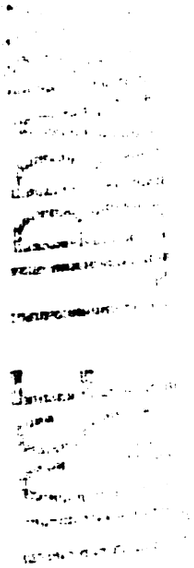
For some nurses, even categorizing a living person as a potential organ donor seems wrong. For this reason, brain death is important as a clear demarcation point, the point at which the person becomes an object or body. Brain death makes organ procurement ethical in that after death, the body is an object without personhood and can be treated as a means to another end. It is interesting that, despite the debates in the bioethics literature, the nurses did not seem to have any concerns about whether brain death reflects a good definition of death or not. They did, however, recognize brain death as a clinical diagnosis that marks an important point of transition in their relationship with the patient. Because the field of organ procurement and the idea of brain death are relatively new, ICU nurses are still working out the moral boundaries of this practice. The nurses' relationship with the brain dead body is different than her relationship with the brain injured person although it is not always clear how since the nurses often offer the same care in both cases and act similarly toward both.

Phronesis and the importance of relationship are further illustrated in the ways nurses and transplant coordinators present the family with the option of organ donation and maintain the donor body after brain death. The necessity of consent speaks to the theory of ethics upon which the organ procurement project rests. That donation should



be freely chosen or declined by the patient and his or her family assumes a process of consent that avoids manipulation, coercion and undue influence, or influence of the wrong kind, concepts which are emphasized in principle-based ethics (Beauchamp & Childress, 1994). But these concepts take the nurses and transplant coordinators only as far as recognition of the need for consent, or an understanding that consent is an important and necessary part of the organ procurement process. The actual consent process, or process by which the nurses or transplant coordinators present the family with the option of organ donation, arises in a rapidly evolving context in which the practitioners must act. The distinctions between manipulation and coercion, and between the right kind of influence and the wrong kind of influence must be worked out as a response to what the situation demands based on a relationship with a particular family. This speaks to both phronesis, in that the particular appropriate response cannot be predicted by theory but is embedded in a particular context and time, and to relational ethics in that the appropriate response is shaped by the nurse's or transplant coordinator's relationship with the family.

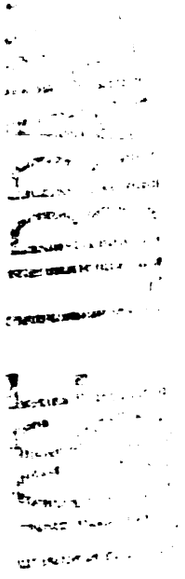
Once the family consents to organ donation, and once the patient is declared dead based on brain criteria, the maintenance of the organs becomes the responsibility of nurses. The brain dead body can be unstable and require a great deal of support. Like in the case of the brain injured patient, the brain dead body is unpredictable and providing the support necessary to bring the body to the OR for organ harvesting is also a phronetic practice. While the transplant coordinators and nurses draw on theories of the physiology of brain death to guide their treatment to a certain extent, the theories are not always



reliable predictors of the body's response. Rather than predict and control the physiology, the nurses and transplant coordinators must stay open to various possibilities and respond to the physiologic situation as it unfolds.

Etiquette

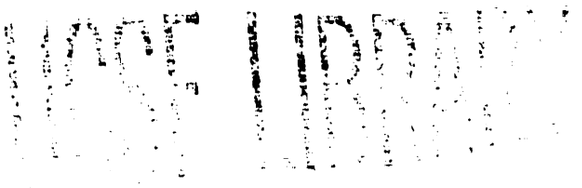
Another important phenomenon developed in the research is the distinction between making an ethical decision and acting on that decision. This is most evident in the practices surrounding approaching a family with the option of organ donation. The decision to obtain informed consent for organ donation from the next of kin is a broad concept of decisional ethics based in theories of deontology and moral principles (Beauchamp & Childress, 1994). The decision-making involved in ethics organizes much of what we think of as bioethics. Consequently, making ethical decisions is often equated with ethical practice. But decisional ethics lays the groundwork for a reflective approach to practice that does not have much to say about action. This leaves open the question: once an ethical decision is made, how should it be acted upon? In the case of organ donation and procurement, once the decision is made to obtain informed, voluntary consent, and once the concepts of informed and voluntary are defined, how can one actually approach the family in a way that ensures their consent or refusal will be informed and voluntary? This question is especially important given the temporal context in which the nurses and transplant coordinators act, a context in which they are always acting. The ethical comportment and skilled know-how it takes to put informed consent into action and open the social space in which the action involved in organ donation and procurement become ethical possibilities rely on etiquette.



Etiquette has always been an important dimension of ethical practice. As articulated by the nurses' and transplant coordinators' stories, the etiquette involved in approaching a grieving family can be a very important step in setting up the possibility of choice. The consent process can be corrupted or can break down if the nurse's initial approach to the family neglects etiquette, or uses etiquette as a technical means to gain consent. Etiquette opens the social space in which a relationship becomes possible. Without a way to open the social space in which consent can be presented and appreciated as an option rather than as an impossibility or as a requirement, informed consent is meaningless theory. On the other hand, if etiquette is taken up as a manipulative technique intended to trick the family into consent, that is, if etiquette is used unethically, informed consent again becomes meaningless. In this way, the interactions between ethics and etiquette become more clear: ethics must inform etiquette while etiquette makes ethical practice possible.

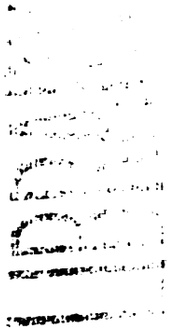
Implications for Education

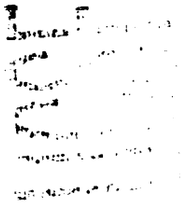
Nursing practice in the area of organ procurement has come a long way since the first cadaver donors. It is now becoming popular to include organ donation in nursing school curricula, and organ donation is a popular topic for continuing education courses and seminars. The state of the research in the field recommends teaching nurses how their behavior can best influence donation rates. Nurses can learn how decoupling and involving the OPO representative can improve the rate of consent for donation at their institution. What is missing from accounts such as these is a context-based approach to implementation. This study has shown that ICU nurses are prepared and motivated to



identify potential organ donors and participate in approaching the family to offer the donation option but that these practices are embedded in a relational ethics that relies on knowing the particular patient and family. In this way, this project sought to recontextualize the procurement experience and bring back all the ambiguity and contradiction it involves.

The ICU nurse participants in this study reported having had little or no formal education in the area of organ procurement. They learned their approach to organ donation and procurement issues by practicing and their stories reflect this. This research can contribute to a thinking-in-action approach to teaching nursing (Benner, Hooper-Kyriakidis & Stannard, 1999). Because the data are contextual, the stories from practice can offer nurses who are new to organ procurement a way into the practice that exposes the concerns as they come up in a constantly changing situation. This type of learning can be beneficial in that it does not offer a static behavior modification approach to organ procurement that blames the nurses for poor consent rates, but helps everyone involved understand the complexities and questions that can come up in a real situation involving the possibility of organ donation as it unfolds. Similarly, these stories from practice can help new transplant coordinators understand the ethics of their practice and how to balance their desire to increase donation rates with their commitment to organ donation as a choice each family must make for themselves. By incorporating contextual examples into their education, nurses and transplant coordinators can better learn and get a feel for the moral boundaries of their practice in this area.

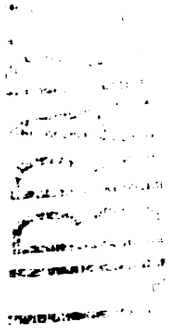


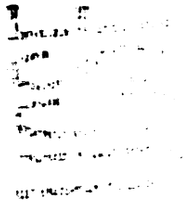


Implications for Health Care Administration

This study sought to understand and articulate the nursing practice and concerns involved in care of the brain-injured patient identified as a potential organ donor as the practice is lived. A study of nursing practice as it is lived must take into account the context in which the nurses are immersed. Nurses in the ICU and nurses employed as transplant coordinators make organ donation and transplantation possible. Nurses have participated with others in the field of transplant to build the social space necessary for ethical organ procurement to take place. This opening of social and moral space has been motivated at least in part by a transplant industry that seeks to transform organ failure into a failure of organ replacement and convey the message that, were it not for the organ shortage, many thousands of people could lead healthy, active lives. The ICU nurses and transplant coordinator participants did take up the work of organ procurement as a drive to end the organ shortage and indirectly continue their work of saving lives even when the life at hand was beyond saving. This was evident in their commitment to organ procurement as part of their professional responsibility and in the disappointment they expressed when the potential donor died without donating.

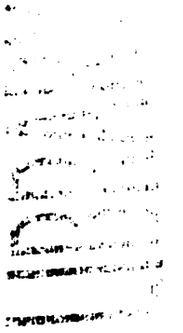
However, opening the moral space that makes organ donation and procurement possible involves more than a desire to increase consent rates. Organ procurement takes place in a world of contingencies formed by a context and by the nurses' relationships with particular families. The judgement involved in the identification of the potential donor, the nurses' concern with providing the best care to the brain injured patient while at the same time keeping the donation option open for the family, the etiquette of

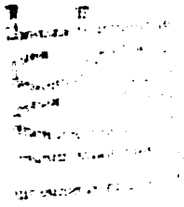




presenting organ donation to the family, and the continued care and support the nurses and transplant coordinators provide the family regardless of the final outcome point to the complexities involved in the procurement process. How nurses and transplant coordinators handle these complexities contribute to consent rates; some responses may increase the likelihood that the family will agree to donate while other responses may decrease this likelihood. But, more importantly, the nurses' and transplant coordinators' care and concern for the brain-injured patient and his or her family contributes to ethical practice in an area of nursing practice that is still being worked out.

The first cadaver donor heart was harvested in 1967. Since then, nurses in ICUs and organ procurement organizations, and others involved in transplantation have been building a practice around organ procurement that stays within agreed upon moral boundaries while holding open the possibility of donation. This study articulates some of these new practices and points to the ambiguities with which these nurses live. This research was not intended to improve donation rates or increase the pool of available organs. It is interesting that the literature on nurses and organ procurement justifies itself in terms of its contribution to solving the organ shortage. The present study of nurses' practices and concerns was intended to further the understanding of this difficult area of practice and allow us to better understand what the statistics on organ donation mean. Given the complexity of relationship, ethics and etiquette involved in offering a family the option of organ donation, it could be that the actual rate of organ donation and procurement cannot be evaluated in terms of the potential rate. This supports the OPO's





current emphasis on obtaining the most from those who do agree to donate rather than trying to increase the number of donors.

Many US States have passed laws regulating organ procurement. Required request and routine referral laws are becoming more and more popular as each State looks for ways to ensure all families of potential organ donors are offered the chance to donate. How these laws translate into health care administration at the institutional level varies from hospital to hospital. This research helps articulate the nurses' and transplant coordinators' role in organ procurement and offers a basis upon which to build hospital policies. It becomes clear when reading the participants' stories that the best practice related to organ procurement is not a rule-following practice but a response-based practice that takes into account the situation and the needs of the particular family. Nurses make practical judgements as to what the family is ready for and when. While rules that outline proper behaviors in the general organ procurement situation can be helpful to the beginner, such rules ultimately limit nursing practice possibilities and are less helpful to the more advanced practitioner who must read and respond to the particular situation as it unfolds (Benner, 1984; Benner, Tanner & Chesla, 1996).

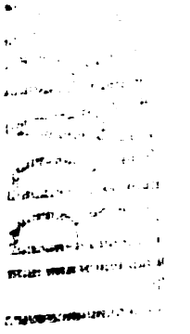
As more laws are made concerning organ procurement, hospital administrators seeking to comply with legal requirements would do best to issue broad recommendations for nursing that reinforce and encourage the creativity necessary for this expert practice to continue to develop. Plans to develop each hospital's potential for organ procurement must take into account the complex social and moral space in which organ donation exists, and must include ICU nurses and transplant coordinators as equal

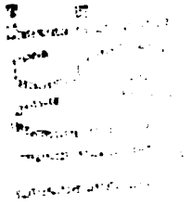
participants in the organ procurement effort. As this research has begun to point out, the nurses involved in organ procurement recognize the complexities and respond differently depending on the situation. This may mean abandoning organ procurement when it is not appropriate. Because of the flexibility required in end-of-life and family care, measuring the success of a hospital development plan by organ procurement rates may not be ideal. As we learn more about the ways nurses practice in this setting, it may become more clear how success should be measured.

Directions for Future Research

This work has pointed to several areas that can be further developed. This study focused mainly on nursing care of the patient identified as a potential organ donor. Expanding the study to include the family's experience and determining how the nurses' and families' experiences interact and overlap would be valuable in more fully articulating the meaning of organ procurement. The nurses in this study felt care of the family to be a priority and believed that they provided the best care and support possible while at the same time holding open the donation option. Interviewing family members on their experience would complete this picture. Similarly, it would broaden the dialogue on organ procurement to articulate the physicians' and other health care workers' experiences.

Brain death is a complicated and philosophically interesting problem that is frequently discussed in the bioethics and medical literature. The nurse and transplant coordinator participants in this study were not interested in discussing whether brain death is an adequate definition of death. They did express concern over when it is



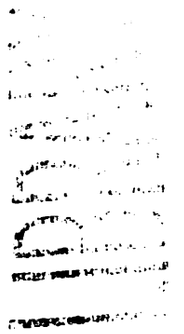


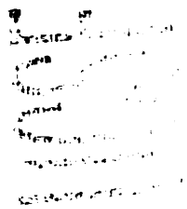
appropriate to begin treating the brain injured patient as a potential or actual organ donor; is it acceptable to begin treatments to preserve the organs before brain death and, if so, how soon before? An interesting area for future research could be focused more closely on how and when nursing care and concerns change as the status of the brain injured patient evolves, however it evolves.

Final Comments

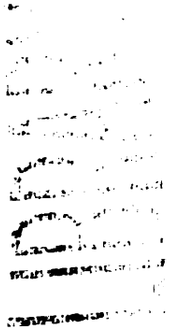
This research has attempted to bring back context to the organ procurement discussion. Although it has not been guided by a desire to solve the organ shortage, this research cannot help but stay in dialogue with this issue given the state of the current literature and the prevalence of references to an organ shortage contained therein. The nurses and transplant coordinators involved in this study were also aware of and in dialogue with the organ shortage, but concern with the particular permeates nursing practice and the practice surrounding organ procurement is no exception. The ICU nurse and transplant coordinator participants are primarily concerned with flexibility, and attentiveness and responsiveness to the particular family of the potential organ donor rather than with a set of techniques intended to increase donation rates. Ethical organ procurement is embedded in these practices and in these concerns.

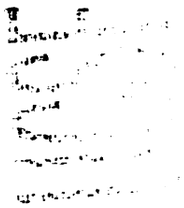
Ethical organ procurement is a practice that is still being worked out. Organ procurement organizations and organ banks that push for efficiency and strive to cut costs while at the same time striving to increase the donor pool should be cautious. The etiquette and relationship necessary to support the organ procurement project develops over time and requires skilled know-how rather than rule-following. Replacing engaged





phronetic practice with the efficiency of technique poses a threat to the relational ethics required for organ procurement to continue at all.





References

Ad Hoc Committee of the Harvard Medical School. (1968). A definition of irreversible coma. Journal of the American Medical Association, 205(2), 337-340.

Albert, P. L. (1994). Overview of the organ donation process. Critical Care Nursing Clinics of North America, 6(3), 553-565.

Aristotle. (1953). J. A. K. Thomson (Translator), The nicomachean ethics . London: Penguine classics.

Arnold, R. M., & Youngner, S. J. (1993). The dead donor rule: Should we stretch it, bend it, or abandon it? Kennedy Institute of Ethics Journal, 3(2), 263-278.

Barnard, C. (1967). A human cardiac transplant: An interim report of a successful operation performed at Groote Schuur Hospital, Cape Town. South African Medical Journal, 41(48), 1271-1274.

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

Bayertz, K. (1992). Technothanatology: Moral consequences of introducing brain criteria for death. Journal of Medicine and Philosophy, 17(4), 407-417.

Beasley, C. L., Capossela, L., Brigham, L. E., Gunderson, S., Weber, P., & Gortmaker, S. L. (1997). The impact of a comprehensive, hospital-focused intervention to increase organ donation. Journal of Transplant Coordination, 7(1), 6-13.

Beauchamp, T. L., & Childress, J. F. (1994). Principles of biomedical ethics (4th ed.). Oxford: Oxford University Press.

Benner, P., Tanner, C., & Chesla, C. (1996). Expertise in nursing practice: Caring, clinical judgement, and ethics. New York: Springer.

Benner, P., & Wrubel, J. (1989). The primacy of caring: Stress and coping in health and illness. Menlo Park, California: Addison-Wesley.

Benner, P. (1997). A dialogue between virtue ethics and care ethics. Theoretical Medicine, 18(1-2), 47-61.

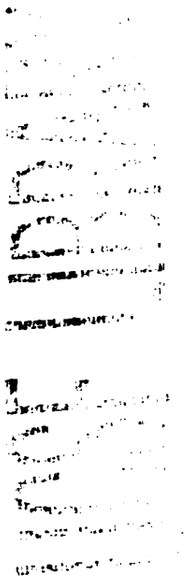
Benner, P. (1984). From novice to expert. Menlo Park, CA: Addison-Wesley.

Benner, P. (Editor)Interpretive phenomenology: Embodiment, caring, and ethics in health and illness . Thousand Oaks: Sage Publications.

Benner, P., Hooper-Kyriakidis, P., & Stannard, D. (1999). Clinical wisdom and interventions in critical care: A thinking-in-action approach. Philadelphia: Saunders.

Bidigare, S. A., & Oermann, M. H. (1991). Attitudes and knowledge of nurses regarding organ procurement. Heart & Lung, 20(1), 20-24.

Borozny, M. (1990). The experience of intensive care unit nurses providing care to the brain-dead patient. Axon, 18-22.



Capron, A. M. (1988). The report of the President's Commission on the uniform determination of death act. R. M. Zaner (Editor), Death: Beyond whole brain criteria (pp. 147-170). Boston: Kluwer Academic Publishers.

Chesla, C.A. & Stannard, D. (1997). Breakdown in the nursing care of families in the ICU. American Journal of Critical Care. 6(1):64-71.

Coolican, M. B. (1994). Families facing the sudden death of a loved one. Critical Care Nursing Clinics of North America, 6(3), 607-612.

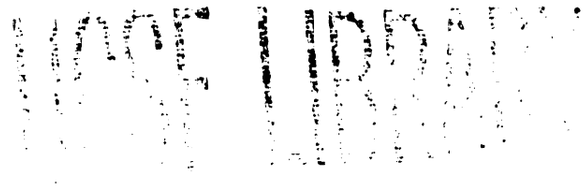
Corr, C. A., & Doka, K. J. (1994). Current models of death, dying, and bereavement. Critical Care Nursing Clinics of North America, 6(3), 545-552.

Couch, N. P. (1966). Supply and demand in kidney and liver transplantation: a statistical survey. Transplantation, 4(5), 587-682.

Cranford, R. E., & Smith, D. R. (1988). Consciousness: The most critical moral (constitutional) standard for human personhood. American Journal of Law and Medicine, 13(2), 233-248.

Devettere, R. J. (1990). Neocortical death and human death. Law, Medicine and Health Care, 18(1-2), 96-104.

Dunn, S. M., & McBride, V. T. (1994). Collaboration, consultation, and care: Developing an effective donor program. Critical Care Nursing Clinics of North America, 6(3), 599-605.



Dunne, J. (1993). Back to the rough ground. Notre Dame, Indiana: University of Notre Dame Press.

Eisenhart, K. (1994). New perspectives in the management of adults with severe head injury. Critical Care Nursing Quarterly, 17(2), 1-12.

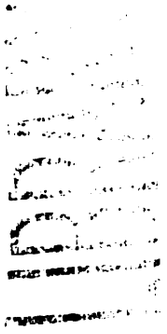
Evanisko, M. J., Beasley, C. L., Brigham, L. E., Capossela, C., Cosgrove, G., Light, J., Mellor, S., Poretsky, A., & McNamara, P. (1998). Readiness of critical care physicians and nurses to handle requests for organ donation. American Journal of Critical Care, 7(1), 4-23.

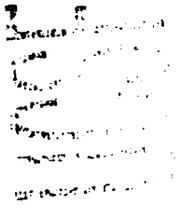
Fox, R. C., & Swazey, J. P. (1974). The courage to fail: A social view of organ transplants and dialysis. Chicago: University of Chicago Press.

Fox, R. C., & Swazey, J. P. (1992). Spare parts: Organ replacement in American society. New York: Oxford University Press.

Fulton, J., Fulton, R., & Simmons, R. G. (1987). The cadaver donor and the gift of life. R. G. Simmons, S. K. Marine, & R. L. Simmons (Editor), Gift of life: the effect of organ transplantation on individual, family, and societal dynamics (pp. 338-376). New Brunswick: Transaction Books.

Gaber, A. O., Hall, G., Phillips, D. C., Tolley, E. A., & Britt, L. G. (1990). Survey of attitudes of health care professionals toward organ donation. Transplantation Proceedings, 22(2), 313-315.





Garrison, R. N., Bentley, F. R., Raque, G. H., Polk, H. C., Sladek, L. C., Evanisko, M. J., & Lucka, B. A. (1991). There is an answer to the shortage of organ donors. Surgery, Gynecology & Obstetrics, 173, 391-396.

Gervais, K. G. (1986). Redefining death. New Haven: Yale University Press.

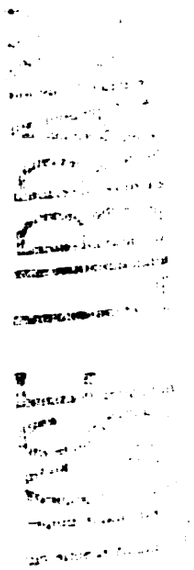
Gordon, D. R. (1988). Tenacious assumptions in Western medicine. M. Lock, & D. Gordon (Editor), Biomedicine examined (pp. 19-56). Boston: Kluwer Academic publishers.

Gortmaker, S. L., Beasley, C. L., Sheehy, E., Lucas, B. A., Brigham, L. E., Grenvik, A., Patterson, R. H., Garrison, R. N., McNamara, P., & Evanisko, M. J. (1998). Improving the request process to increase family consent for organ donation. Journla of Transplant Coordination, 8(4), 210-217.

Guignon, C. B. (1991). Pragmatism or hermeneutics? Epistomology after foundationalism. D. R. Hiley, J. F. Bohman, & R. Shusterman (Editors), The interpretive turn: Philosophy, science, culture (pp. 81-101). Ithaca: Cornell University Press.

Heidegger, M. (1962). J. MacQuarried, & E. Robinson (Translator), Being and time . New York: Harper & Row.

Hibbert, M. (1995). Stressors experienced by nurses while caring for organ donors and their families. Heart & Lung, 24(5), 399-407.



Hickey, M. (1990). What are the needs of families of critically ill patients? A review of the literature since 1976. Heart & Lung, 19, 401-415.

Kandel, E. R., Schwartz, J. H., & Jessell, T. M. (1991). Principles of neural science (3rd ed.). New York: Elsevier.

Kant, I. (1956). H. J. Paton (Translator), Groundwork of the metaphysic of morals 3rd ed.,). New York: Harper.

Kiberd, M. C., & Kiberd, B. A. (1992). Nursing attitudes towards organ donation, procurement, and transplantation. Heart & Lung, 21(2), 106-111.

Lamb, D. (1985). Death, brain death, and ethics. Albany: State University of New York Press.

Lange, S. S. (1992). Psychosocial, legal ethical, and cultural aspects of organ donation and transplantation. Critical Care Nursing Clinics of North America, 4(1), 25-42.

Lindemann, E. (1944). Symptomatology and management of acute grief. American Journal of Psychiatry, 101, 7-21.

Lindsay, K. K. (1995). Assisting professionals in approaching families for donation. Critical Care Nursing Quarterly, 17(4), 55-61.

Lock, M. (1994). Displaced suffering: The reconstruction of death in North America and Japan. Paper presented at a conference on Social Suffering, Bellagio .

MacIntyre, A. (1984). After virtue (2nd ed.). Notre Dame, IN: University of Notre Dame Press.

Malecki, M. S., & Hoffman, M. C. (1987). Getting to yes: How nurses' attitudes affect their success in obtaining consent for organ and tissue donations. Dialysis & Transplantation, 277-278.

Matten, M. R., Sliepcevich, E. M., Sarvela, P. D., Lacey, E. P., Woehlke, P. L., Richardson, C. E., & Wright, W. R. (1991). Nurses' knowledge, attitudes and beliefs regarding organ and tissue donation and transplantation. Public Health Reports, 106(2), 155-166.

Niles, P. A., & Mattice, B. J. (1996). The timing factor in the consent process. Journal of Transplant Coordination, 6(2), 84-87.

O'brien, R. L., Serbin, M. F., O'brien, K. D., Maier, R. V., & Grady, M. S. (1996). Improvement in the organ donation rate at a large urban trauma center. Archives of Surgery, 113(1), 153-159.

Packer, M. (1989). Tracing the hermeneutic circle: Articulating an ontical study of moral conflicts. M. J. Packer, & R. B. Addison (editors), Entering the circle: Hermeneutic investigation in psychology (pp. 95-117). New York: State University of New York Press.

Packer, M. J., & Addison, R. B. (1989a). Introduction. M. J. Packer, & R. B. Addison (Editors), Entering the circle: Hermeneutic investigation in psychology (pp. 13-36). New York: State University of New York Press.

Packer, M., & Addison, R. B. (1989b). Evaluating an interpretive account. M. J. Packer, & R. B. Addison (Editors), Entering the circle: Hermeneutic investigation in psychology (pp. 275-292). New York: State University of New York.

Pelletier-Hibbert, M. (1998). Coping strategies used by nurses to deal with the care of organ donors and their families. Heart & Lung, 27(4), 230-237.

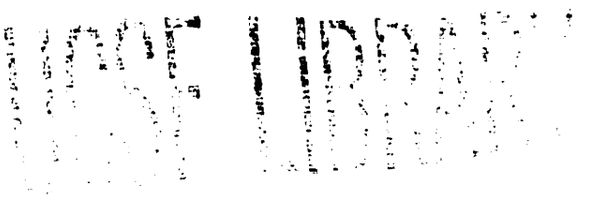
Pence, G. (1990). Classic cases in medical ethics. New York: McGraw-Hill.

Plum, F., & Posner, J. B. (1981). The diagnosis of stupor and coma (3rd ed.). Philadelphia: F. A. Davis Company.

President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. (1981). Defining death. Washington, DC: US Government publications.

Prottas, J. (1994). The most useful gift: Altruism and the public policy of transplants. San Francisco: Jossey-Bass.

Rix, B. A. (1990). Danish ethics council rejects brain death as the criterion of death. Journal of Medical Ethics, 16, 5-7.



Savaria, D. T., & Swnason, M. A. (1995). Organ and tissue donation: Rights and responsibilities. Critical Care Nursing Clinics of North America, 7(3), 569-575.

Shirley, S., Cutler, J., Heymann, C., & Hart, M. (1994). Narrowing the organ donation gap: Hospital development methods that maximize hospital donation potential. The Journal of Heart and Lung Transplantation, 13(5), 817-823.

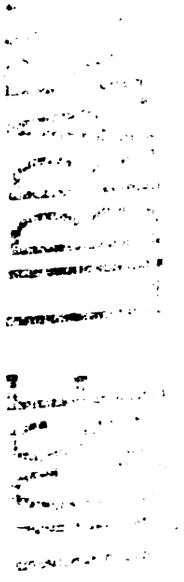
Siminoff, L. A. (1997). Withdrawal of treatment and organ donation. Critical Care Nursing Clinics of North America, 9(1), 85-95.

Siminoff, L. A., Arnold, R. M., & Caplan, A. L. (1995). Health care professional attitudes toward donation: Effect on practice and procurement. The Journal of Trauma: Injury, Infection and Critical Care, 39(3), 553-559.

Sophie, L. R., Salloway, J. C., Sorock, G., Volek, P., & Merkel, F. K. (1983). Intensive care nurses' perceptions of cadaver organ procurement. Heart & Lung, 12(3), 261-267.

Stannard, D. Reclaiming the house: an interpretive study of nurse-family interactions and activities in critical care. Unpublished doctoral dissertation, University of California, San Francisco.

Stark, J. L., Reiley, P., Osiecki, A., & Cook, L. (1984). Attitudes affecting organ donation in the intensive care unit. Heart & Lung, 13(4), 400-404.



Stark, J., Wikoren, B., & Martone, L. (1994). Partners in organ donation: Piloting a successful nurse requestor program. Critical Care Nursing Clinics of North America, 6(3), 591-598.

Stoeckle, M. L. (1990). Attitudes of critical care nurses toward organ donation. Dimensions of Critical Care Nursing, 9(6), 354-360.

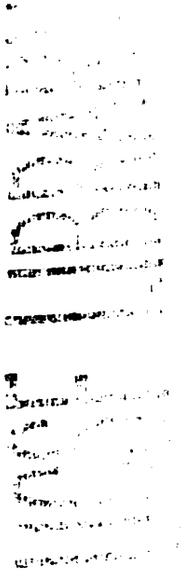
Taylor, C. (1985). Philosophy and the human sciences: Philosophical papers 2. Cambridge: Cambridge university press.

The Quality Standards Subcommittee of the American Academy of Neurology. (1995). Practice parameters for determining brain death in adults (summary statements). Neurology, 45(5), 1012-1014.

Thibault, G. E. (1997). Prognosis and clinical predictive models for critically ill patients. Field M. J., & C. K. Cassels (Editors), Approaching death, improving care at the end of life. Institute of Medicine report (pp. 358-362). Washington, D. C.: National Academy Press.

Thomasma, D. C. (1984). The comatose patient, the ontology of death, and the decision to stop treatment. Theoretical Medicine, 5, 181-196.

Truog, R. D. (1997). Is it time to abandon brain death? Hastings Center Report, 27(1), 29-37.



Veatch, R. M. (1981). Death, dying, and the biological revolution. New Haven: Yale University press.

von Pohle, W. (1996). Obtaining organ donation: who should ask? Heart & Lung, 25(4), 304-309.

Watkinson, G. E. (1995). A study of the perception and experiences of critical care nurses in caring for potential and actual organ donors: Implications for nursing education. Journal of Advanced Nursing, 22, 929-940.

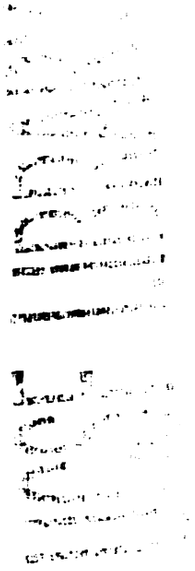
Worden, J. W. (1991). Grief Counseling and grief therapy. New York: Springer Publishing Company.

Wros, P. L. Behind the curtain: Nursing care of dying patients in critical care. Unpublished doctoral dissertation, Oregon health sciences university.

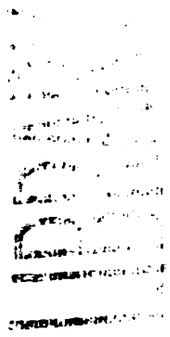
Wros, P. L. (1994). The ethical context of nursing care of dying patients in critical care. P. Benner (Editor), Interpretive phenomenology: Embodiment, caring, and ethics in health and illness (pp. 255-277). London: Sage publications.

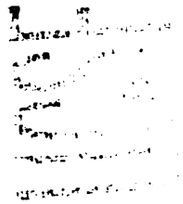
Youngner, S. J., & Bartlett, E. T. (1983). Human death and high technology: The failure of whole-brain formulations. Annals of Internal Medicine, 99, 252-258.

Youngner, S. J., Landefeld, S., Coulton, C. J., Juknialis, M. A., & Leary, M. (1989). 'Brain death' and organ retrieval: A cross-sectional survey of knowledge and concepts



amond health professionals. Journal of the American Medical Association, 261(15), 2205-2210.





Appendix A: Background questionnaire

1. Sex:

2. Age:

3. Date of graduation from original nursing program:

4. Original nursing degree (e.g.: diploma, AA):

5. Highest degree held and in what field:

6. Ethnic background:

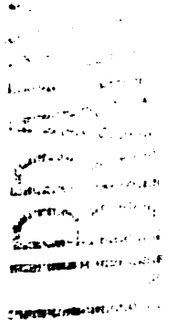
7. Religious affiliation:

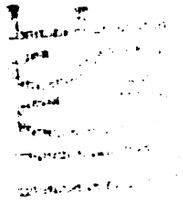
8. How actively involved are you in your religious practices? (circle one)

Not active Somewhat active Active Very active

9. In what area(s) of nursing have you had work experience? (e.g.: med-surg, critical care)

10. In what area(s) are you currently working?





11. Of the areas you wrote for question 10, which is your primary work area?

12. How long have you been at your current primary job?

13. How satisfied are you in your current primary job? (circle one)

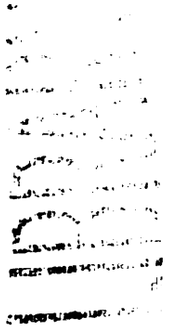
Not satisfied Somewhat satisfied Satisfied Very satisfied

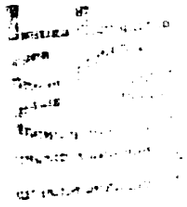
14. How comfortable is the work environment at your current primary job? (circle one)

Not comfortable Somewhat comfortable Comfortable Very comfortable

15. Approximately how many brain-injured patients have you cared for who were identified as potential organ donors?

16. Of the patients in question 15, approximately how many were at your current primary job?





Appendix B: consent forms

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
CONSENT TO BE A RESEARCH SUBJECT:
NURSING CARE OF BRAIN-INJURED PATIENTS IDENTIFIED AS POTENTIAL
ORGAN DONORS

A. PURPOSE AND BACKGROUND

Lisa Day, RN, MS, PhD(c) in the Department of Physiological Nursing is conducting a research study about nursing care of brain injured patients who become potential organ donors. I am being asked to participate in this study.

B. PROCEDURES

If I agree to be in the study, the following will occur:

1. I will be interviewed up to three times by Lisa Day. The interviews may take as long as 3 hours. The interviews will be done privately at a time and place that is convenient to me.

2. I will give Lisa Day permission to make an audio tape recording of my interview.

3. I will complete a background information questionnaire that will take about 15 minutes.

C. RISKS/DISCOMFORTS

1. Some of the questions may make me uncomfortable, but I am free to decline to answer any questions that I do not wish to answer or to stop the interview at any time.

2. Confidentiality: Participation in research may involve a loss of privacy; however, strict procedures will be followed to protect the confidentiality of the information I give. The original study information will be kept in a locked file at all times. Only Dr. Patricia Benner and Lisa Day will have direct access to the original files and audiotapes. After all the data have been transcribed from the tapes, the tapes will be destroyed. While direct quotes and excerpts from interviews will be used, no individual identities will be used in any reports or publications that may result from this study.

D. BENEFITS:

There will be no direct benefit to me from participating in this study. However, the information that I provide may help in understanding the complexities involved in caring for this patient population.

[redacted]

E. ALTERNATIVES:

I am free to choose not to participate in this study.

F. COSTS:

There will be no costs to me as a result of taking part in this study.

G. REIMBURSEMENT:

There will be no reimbursement to me for participation in this study.

H. QUESTIONS:

I have talked to Lisa Day about this study and have had my questions answered. If I have further questions about the study, I may call Lisa Day at home at (415)661-3886 or page her at (415)520-4071, or call Dr. Patricia Benner, faculty advisor, UCSF School of Nursing, at (415)476-4313.

If I have any comments or concerns about participation in this study, I should first talk with the investigator. If for some reason I do not wish to do this, I may contact the Committee on Human Research, which is concerned with the protection of volunteers in research projects. I may reach the committee office between 8:00 am and 5:00 pm Monday through Friday by calling (415)476-1814, or by writing: Committee on Human Research, Box 0616 University of California, San Francisco, California 94143.

I. CONSENT:

I will be given a copy of this consent form to keep.

PARTICIPATION IN RESEARCH IS VOLUNTARY.

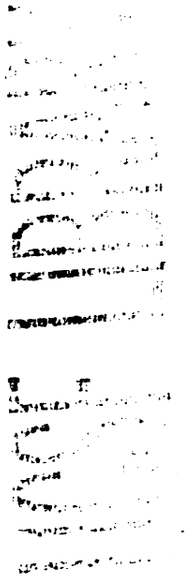
I am free to decline to be in this study, or to withdraw from it at any point. My decision as to whether or not to participate in this study will have no influence on my present or future status as a patient, student or employee at UCSF.

_____ _____

Signature of study participant Date

_____ _____

Signature of person obtaining consent Date



UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
CONSENT FOR OBSERVATION IN A RESEARCH STUDY:
NURSING CARE OF BRAIN INJURED PATIENTS IDENTIFIED AS POTENTIAL
ORGAN DONORS

A. PURPOSE AND BACKGROUND

Lisa Day, RN, MS, PhD(c) in the Department of Physiological Nursing is conducting a research study about nursing care of brain injured patients who become potential organ donors. I am being asked to participate in this study.

B. PROCEDURES

If I agree to be in the study, the following will occur:

1. I will be observed while providing care to a patient identified as a potential organ donor. The observation will last not more than 3 hours. I might be asked to answer questions and discuss what I am doing, and what my concerns are. Written field notes will be kept of the observation.
2. I might later be asked to clarify certain points or notes made during the observation. These discussions will be initiated within three weeks of the observation and will last no more than one hour and will be conducted at a time and place convenient to me.

C. RISKS/DISCOMFORTS

1. Some of the questions may make me uncomfortable, but I am free to decline to answer any questions that I do not wish to answer or to stop the observation at any time.
2. Confidentiality: Participation in research may involve a loss of privacy; however, strict procedures will be followed to protect the confidentiality of the information I give. The original study information will be kept in a locked file at all times. Only Dr. Patricia Benner and Lisa Day will have direct access to the original files. While direct quotes and excerpts from interviews and field notes will be used, no individual identities will be used in any reports or publications that may result from this study.

D. BENEFITS:

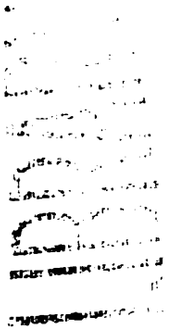
There will be no direct benefit to me from participating in this study. However, the information that I provide may help in understanding the complexities involved in caring for this patient population.

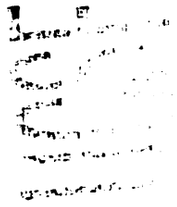
E. ALTERNATIVES:

I am free to choose not to participate in this study.

F. COSTS:

There will be no costs to me as a result of taking part in this study.





G. REIMBURSEMENT:

There will be no reimbursement to me for participation in this study.

H. QUESTIONS:

I have talked to Lisa Day about this study and have had my questions answered. If I have further questions about the study, I may call Lisa Day at home at (415)661-3886 or page her at (415)520-4071, or call Dr. Patricia Benner, faculty advisor, UCSF School of Nursing, at (415)476-4313.

If I have any comments or concerns about participation in this study, I should first talk with the investigator. If for some reason I do not wish to do this, I may contact the Committee on Human Research, which is concerned with the protection of volunteers in research projects. I may reach the committee office between 8:00 am and 5:00 pm Monday through Friday by calling (415)476-1814, or by writing: Committee on Human Research, Box 0616 University of California, San Francisco, California 94143.

I. CONSENT:

I will be given a copy of this consent form to keep.

PARTICIPATION IN RESEARCH IS VOLUNTARY.

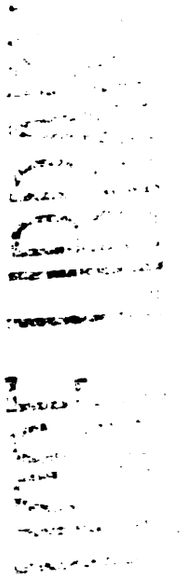
I am free to decline to be in this study, or to withdraw from it at any point. My decision as to whether or not to participate in this study will have no influence on my present or future status as a patient, student or employee at UCSF.

_____ _____

Signature of study participant Date

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Signature of person obtaining consent Date



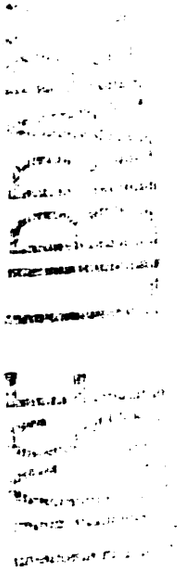
Appendix C: Interview guide A

1. Tell me about a patient you cared for who was a potential organ donor.

2. Interviewer will try to keep the participant focused on what she or he actually did, what she or he felt and thought, and what her or his concerns were in the actual situation

Areas for further inquiry:

1. Physical care of the patient
2. Interactions with family members
3. Interactions with other members of the ICU team related to care of the patient
4. Declaration of brain death - process, concerns
5. Involvement of organ procurement organization



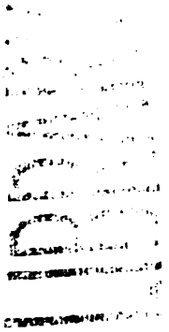
Appendix D: Interview Guide B

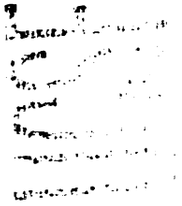
A. Tell me about a specific experience you've had participating in the care of a patient who was identified as a potential organ donor. Just tell me the whole story from beginning to end with as much specific detail as you can remember.

1. What led up to the situation? (e.g., patient's history, how was he/she identified as a potential organ donor?)
2. How did you feel?
3. What were your concerns and how did they change over time?
4. What were your expectations and how did they change over time?

B. In the best possible world, in what you think of as the best case scenario, how would care of the brain-injured patient identified as a potential organ donor be carried out?

1. How would the technical care of the patient go?
2. What would the nurse's concerns be, ideally?
3. What actions would the nurse take related to the patient's identification as a potential donor?
4. How would care of the brain-injured patient change once she or he was identified as a potential organ donor?
5. What or who has helped you in forming your perspectives on patient care in this area?
    a. What kinds of training have you had in organ donation and procurement (classed from CTDN, etc.)? What did you think/feel about the class(es)?
    b. What literature have you read related to organ donation and procurement? What do you feel/think about this literature?





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