Boston College

The Graduate School of Nursing

DECIDING TO WITHHOLD/WITHDRAW LIFE-SUSTAINING TREATMENTS FROM INCOMPETENT ADULTS FOLLOWING UNANTICIPATED, CATASTROPHIC ILLNESSES: A PHENOMENOLOGICAL STUDY OF SURROGATE DECISION MAKERS' EXPERIENCES

a dissertation

by

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submitted in partial fulfillment of the requirements

for the degree of

Doctor of Philosophy

May 1999

BOSTON COLLEGE

GRADUATE SCHOOL OF NURSING

The Dissertation of Carolyn Marie Hayes

entitled Deciding to Withhold/Withdraw Life-Sustaining Treatments From Incompetent Adults Following Unanticipated, Catastrophic Illnesses: A Phenomenological Study of Surrogate Decision Makers' Experiences

in partial fulfillment of the requirements for the degree of

Doctor of Philosopy

in the Graduate School of Nursing has been read and approved by the Committee:

Date March 16, 1999

Deciding to Withhold/Withdraw Life-Sustaining Treatments from Incompetent Adults Following Unanticipated, Catastrophic Illnesses: A Phenomenological Study of Surrogate Decision Makers' Experiences

Carolyn M. Hayes, Doctor of Philosophy, 1999
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The purpose of this study was to describe the experience and meaning of having made a decision to withhold and/or withdraw life-sustaining treatments from an adult who was rendered incompetent following an unanticipated, catastrophic illness. Participants were solicited six to 18 months after the death of their loved ones through personal networking, a flyer, and contact with a bereavement group. Interview data from 13 participants were analyzed using Giorgi's (1990) method for phenomenological inquiry.

Two major themes emerged to describe the surrogate decision-making experience (SDME). The first theme is Representation of Other. The second theme is Memory Manipulation. The themes are presented through the use of an orchestral performance metaphor.

Representation of Other is portrayed as what participants do when they are asked to be surrogate decision makers (SDMs). The participants describe how the patients' advance directives impacted their decision-making experiences. The SDMs also describe advocating for clinical resources and communication while representing the other. Findings also indicate that SDMs are aware of multiple audiences and represent multiple others, including themselves, during the SDME.

The second theme is Memory Manipulation, which describes how SDMs fulfill their role. There are three aspects to this theme. This first is reconciling memories of their respective loved ones with an unanticipated, catastrophic reality. The second is orchestrating memories through the decision-making process itself. The last aspect of Memory Manipulation is when the SDMs reconcile their SDME memories with their grief.

In qualitative research, the researcher is the instrument. Therefore, there is only one person who has been part of this research from start to finish. I dedicate this dissertation with admiration, love, and gratitude, to my father, John Mitchel Hayes Jr., Boston College Class of 1953.

ACKNOWLEDGMENTS

I wish to acknowledge the people who have participated in my learning and well-being during my doctoral studies and dissertation research. First, my sincere appreciation is extended to the members of my dissertation committee, Dr. Sara T. Fry, Dr. Susan Chase, and Dr. Mary Duffy, for being so generous with their time, patience, and expertise. I would also like to thank Dr. Dorothy Jones for her guidance as I struggled to incorporate my evolving nursing knowledge into clinical practice.

I am also indebted to my classmates for sharing their knowledge and themselves with me throughout my studies. To protect the anonymity of my participants, I will not name specific individuals, but I owe a special debt to classmates and friends who solicited participants for my study. I could not have completed my dissertation without their initiatives and support of my efforts.

I have been blessed with supportive family members and friends my entire life. Over these past five years they have tolerated many things while I pursued this degree. They individually and collectively supported and encouraged me and I am very grateful. Unfortunately, I lost two family members while in my doctoral program. I am grateful to my mother, Ruth, and my Aunt Dot for the lessons learned by the examples of their faith, lives, and deaths.

Additionally, I was fortunate enough to have colleagues and mentors in a challenging clinical environment that fueled my spirit of inquiry. Specifically, I would like to thank Dr. Ned Cassem and the members of the Optimum Care Committee at Massachusetts General

Hospital. For the patients and families with whom I have been fortunate enough to journey through decision-making experiences over these past five years, I am sincerely grateful.

Finally, I would like to acknowledge and thank the Alphi Chi Chapter of Sigma Theta Tau for their generous funding of this research.

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CHAPTER ONE: THE PHENOMENA OF CONCERN

Introduction

Advances in biomedical technologies in the latter half of this century have created medical situations that sometimes require making difficult treatment decisions. The use of cardiopulmonary resuscitation, ventilators, hemodialysis, toxic chemotherepeutic agents, invasive delivery systems for fluid/nutrition, and other therapies have become topics of health care debates because they create ethical and legal questions about how decisions for these therapies are made. Should individuals have the right to request any treatment even when health care providers do not believe it will benefit the individual? Should individuals have the right to cease any treatment even when health care providers believe treatment would benefit the individual? Who decides what treatments will or will not be used in the care of incompetent individuals or those who can not make such decisions? What information is most important to consider when a decision that can not be reversed is being made? All of these questions highlight ethical issues that arise in decisions to withhold and/or withdraw a life-sustaining treatment.

In the United States, legal and professional standards have supported the American value for autonomy (self-determination) even when individuals no longer have the capacity to make autonomous decisions. Thus, incompetent patients, those unable to make autonomous decisions, are represented by surrogate decision makers (SDMs) within the health care system.

Standards Used In Surrogate Decision Making

The protection of a right to autonomy when a person is unable to act as an autonomous decision maker requires consideration of the legal standards of best interests and substituted judgment. Court decisions have supported use of the substituted judgment standard when a person's wishes were clear prior to their incompetency (Brophy v. New England Sinai Hospital, 1986; In re Eichner, 1981; Kennedy Hospital v. Bludworth, 1984). Court decisions have also supported the best interests standard when the wishes of the incompetent person were not made known adequately prior to their incompetency, but could be deduced from other expressed values (In re Peter, 1987; In re Spring, 1979).

Court decisions also have supported the best interests standard for surrogates' decisions when the wishes of the incompetent patient were difficult to deduce from previously expressed values. The lack of specific or deduced knowledge about patients' wishes creates the situation where the surrogates must use the best interests standard as their framework for decisions to withhold and/or withdraw treatments for the incompetent patient (Barber v. Superior Court, 1983; Corbett v. D'Alessandro, 1986; In re Conroy, 1985; In re Jobes, 1987).

Types Of Decisions Made

There have been a variety of decisions that surrogates may be called upon to make. Some of these cases concern the withdrawal of respirator support (Bartling v. Superior Court, 1984; In re Eichner, 1981; In re Farrell, 1987; In re Hamlin, 1984; In re Quinlan, 1976; Kennedy Hospital v. Bludworth, 1984; Satz v. Perlmutter, 1980; Tune v. Walter

Reed Hospital, 1985). Other cases concern the use of artificial nutrition and hydration (Barber v. Superior Court, 1983; Bouvia v. Superior Court, 1986; Brophy v. New England Sinai Hospital, 1986; Corbett v. D'Allessandro, 1986; In re Conroy, 1985; In re Jobes, 1987; In re Peter, 1987). Still others concern the withholding of dialysis treatments (Commissioner of Correction v. Myers, 1979; In re Spring, 1979). The refusal of chemotherapy (Superintendent of Belchertown v. Saikewicz, 1977), blood transfusions, (In re Osborne, 1972), amputation (Lane v. Candura, 1978), and cardiopulmonary resuscitation (In re Dinnerstein, 1978) have all been supported by court decisions despite the competency, or lack thereof, of the patient.

Professional Codes And Other Documents

Professional codes, the recommendations of legislated investigative groups, and other documents support the appointment of surrogates to make treatment decisions for those who are incompetent. For example, the interpretive statements of The American Nurses Association Code for Nurses (1985) state, "In situations in which the client lacks the capacity to make a decision, a surrogate decision maker should be designated". Following the standard of substituted judgment, the President's Commission for the Study of Ethical Problems in Biomedical and Behavioral Research (1983) (hereafter referred to as "The President's Commission") noted that a surrogate must attempt to reach the decision that the incompetent person would make if able to decide on his or her own behalf (1983). Following the standard of best interests, The President's Commission

noted that if an incompetent patient has not made preferences known, then the surrogate is to make decisions based on the best interests of the patient.

To support the right of all individuals to refuse treatments in advance while they are competent, The Patient Self Determination Act (PSDA) (1990) empowers patients to select a surrogate decision maker (SDM) who may then direct the course of their medical treatment if they should become incompetent. Health care agencies have supported the use of SDMs by soliciting information upon entry into health care agencies. The courts support the use of SDMs by ruling in favor of their decisions in many, but not all, legal proceedings.

After the passage of the PSDA, the American Nurses Association (ANA) published other relevant documents to guide nursing practice. Both the ANA Position Statement on Promotion of Comfort and Relief of Pain in Dying Patients (1995) and the Social Policy Statement (1995) inform nurses on professional standards of care for patients at the end-of-life. Additionally, there are ANA position statements on euthanasia and assisted suicide because these issues have become active in social debates about end-of-life care (1994).

Factors Influencing Surrogates' Decisions

The factors that influence SDMs' judgments have just begun to be empirically studied. Factors known to influence surrogates' decisions to withhold and/or withdraw life-sustaining treatments identified by research studies include: (a) relationship to the patient (Ouslander, Tymchuk, & Rahbar, 1989; Tomlinson, Howe, Notman, & Rossmiller,

1990; Ulhmann, Pearlman, & Cain, 1988, 1989), (b) age of the patient (Hare, Pratt, & Nelson, 1992), (c) health of the patient (Hanson et al., 1994; Hare & Nelson, 1991; Sehgal et al., 1992; Uhlmann et al., 1989), (d) spiritual considerations of the patient and the surrogate (Hare & Nelson, 1991; Sehgal et al., 1992), (e) the perceived quality of life for the patient (Sehgal et al., 1992), (f) the perceived family burden of continued treatment (Hare et al., 1992; Sehgal et al., 1992), (g) the surrogate's knowledge of advanced directives (Ouslander et al., 1989; Pijnenborg et al., 1995; Sehgal et al., 1992), (h) communication between health care providers and surrogates during the decision-making process (Higginson, Priest & McCarthy, 1994; Ouslander et al., 1989; Reckling, 1997), and (i) time available to make the decision (Hare et al., 1992; Tomlinson et al., 1990).

Surrogate decisions can lead to the death of a loved one. Grief research has identified factors in the bereavement process that are similar to those identified as important in surrogate decision-making research. These factors include: (a) the influence of the patient's age, (b) time, (c) the bereaved person's relationship to the deceased, and (d) the bereaved person's spirituality related to the grieving process in general (Parkes, 1972). Factors identified by other researchers, but not identified by the research findings in the studies listed above include: (a) the understanding that the personal meaning of death reinforces the influence of identified factors such as the bereaved's relationship to the patient, (b) his/her understanding of the situation, and (c) any factor the bereaved would use to interpret the situation (Neimeyer, 1994).

It is known that grieving can manifest itself in both physical and psychological distress (Lev, Munro, & McCorkle, 1993). It is also known that a person's personal meaning of death may influence one's ability to accept loss (Neimeyer, 1994) while a person's ethical ideology is known to influence one's sense of self-satisfaction and guilt following a moral decision (Forsyth & Berger, 1982). These potential aftereffects of a loss have not been studied in the context of surrogate decision making for life-sustaining treatments.

Overall, studies examining grief, personal meaning of death, and ethical ideologies point to a need for research to explore the surrogate decision-making experience (SDME) from the surrogate's perspective, but the studies examining surrogate decision making have not addressed any aftereffects experienced by the surrogates. Therefore, what is not known is the effect of the surrogate role, supported by society and health care institutions, upon the surrogates themselves. In particular, studies are needed to explore the experience and meaning of surrogate decision making to withhold and/or withdraw life-sustaining treatments.

Statement Of The Problem

It is known that grief is affected by some of the factors that influence surrogate decision making and it is known that grief may manifest itself physically and psychologically in a bereaved person. Additionally, there is knowledge that moral decisions can result in feelings of dissatisfaction and guilt. However, the meaning and

experience of the role of SDM when deciding to withhold and/or withdraw life-sustaining treatments remains largely unknown.

Purpose

The purpose of this study was to describe the experiences and meanings of surrogates' decisions to withhold and/or to withdraw life-sustaining treatments from adults who were rendered incompetent following unanticipated, catastrophic illnesses.

Research Question

The specific research question addressed was: What has it been like for a surrogate decision maker (SDM) to make a decision to withhold and/or withdraw life-sustaining treatment(s) from an incompetent adult following an unanticipated, catastrophic illness?. Specifically, six to 18 months after the incompetent adult's death, how did the SDM experience his or her role and what did making the decision mean to the surrogate?

This research question was answered through a phenomenological investigation guided by the method described by Giorgi (1985, 1989a, 1989b, 1990). Phenomenology is a form of qualitative research that attempts to disclose the essential meaning of human experience and is well suited to nursing inquiry (Benner, Tanner, & Chesla, 1996; Bishop & Scudder, 1991). Since the research question concerns a human experience, it is answered appropriately through phenomenological inquiry.

Conceptual and Operational Definitions

The following are conceptual and operational definitions for the study:

1. Adult Patient: A person 18 years of age or older.

2. Unanticipated, Catastrophic Life Threatening Illness: An unforeseen accident or disease that may imminently cause death.

3. Surrogate Decision Maker (SDM): A person who has personal knowledge of a patientand who is recognized by a health care system as the decision maker for an incompetent patient (via formal or informal processes).

4. Incompetent Patient: A person not able to understand medical information conveyed, not able to evaluate the options presented to him or her, and not able to make a decision to accept or refuse a medical treatment.

5. Life-Sustaining Treatments: Medical interventions designed to preserve physical life (e.g. cardiopulmonary resuscitation, cardioversions, ventilator support, surgery, or vasopressors).

6. Substituted Judgment: A decision-making standard based on what the incompetent person would want done if able to make decisions on his or her own behalf.

7. Best Interests: A decision-making standard based on what is believed will protect/benefit the person's welfare.

Study Sample

The participants in this study met the study assumptions and definition of surrogate decision maker as indicated above. They made a decision or decisions to withhold or withdraw life-sustaining treatments for an adult incompetent patient who had an unanticipated, catastrophic life threatening illness. The decision to withhold and/or withdraw life-sustaining treatments contributed to the death of the patient and the death

had occurred between six months to 18 months prior to the participant's participation in the study.

Assumptions

The study included surrogates who made decisions for incompetent patients who subsequently died. This approach eliminated bias potentially introduced by a difference in patient outcomes after the decisions. It also avoided researching what a surrogate may experience while waiting for an outcome of his or her decision. The generalizability of this study is limited because the study population was obtained predominantly through personal networking and the resulting population had limitations in demographic variability that are detailed in chapter 3. Those limitations include lack of variability in cultural, socioeconomic, and religious demographics. Those demographic variables are known to be important in end-of-life care (Hern, Koenig, Moore, & Marshall, 1998; Wolder Levin & Glick Schiller, 1998).

The waiting period of six to 18 months after the loss of the deceased for whom the SDM made decisions prior to inclusion in the study was consistent with prior grief research to minimize the effects of the grieving process (Lev et al., 1993). On average, the impact of the loss before six months is too acute for surrogates to separate their feelings of loss from any antecedent events they went through. After the 18 month period, the experiences and their grief are integrated into who they are. The experience is no longer a separate event.

Significance

An organization of over 40 separate organizations of American caregivers and religious groups put forth ten principles they said should govern end-of-life care (Knox, 1997). Among these principles was concern for grieving survivors. Neveloff Dubler (1995) argues for a focus on the ethical duties, emotional supports, and guidance owed by physicians to SDMs. This study explored the impact of withholding and/or withdrawing life-sustaining treatment from incompetent adults on surrogate decision makers and therefore addressed these concerns.

It is anticipated that gaining knowledge of the experiences and meanings of the surrogate role when deciding to withhold and/or withdraw life-sustaining treatments in an unanticipated, catastrophic life threatening event will provide nurses with practice guides to better meet their patients' and the surrogates' needs. Recommendations are detailed in chapter 6. Overall, findings from this study will guide future nurse and surrogate interactions to improve the experience for surrogate decision makers. Findings may also guide nursing education regarding end-of-life treatment decisions to prepare future nurses to assist people as they assume the role of surrogate decision maker. Findings may also inform primary care providers, physicians, and advanced practice nurses about the impact of prior knowledge or lack of knowledge of patients' wishes on surrogates.

Additionally, findings have implications for ethical and legal discussions of the surrogate decision-making role. The existence of the surrogate decision-making role is an outcome of well-intentioned ethical debate. However, some findings from this study

indicate that the role proved to be harmful in some circumstances and beneficial in others. The new knowledge gained from the study findings of the surrogate decision-making experience (SDME) presented here should assist these ethical discussions.

Summary

This study aimed to describe the experience and meaning of surrogates' decisions to withhold and/or to withdraw life-sustaining treatments from an adult who was rendered incompetent following an unanticipated, catastrophic illnesses. The findings inform future research intervention studies, practice, education, and policy formation. The knowledge gained from the findings of this study about the meanings and experiences of surrogates' decisions should guide future nurse and surrogate interactions.

Specifically, findings should guide nursing education regarding end-of-life treatment decisions. They should inform primary care providers, physicians, and advanced practice nurses regarding the impact of prior knowledge of patients' wishes on surrogates' well-being after the experience. Findings should also influence ethical and legal considerations of the surrogate decision-making role.

The surrogate experience for end-of-life treatment decisions has received little attention in research studies. Yet, end-of-life care and support for family members in the grieving process is an important value articulated by the majority of health care providers and/organizations. Findings from this study generate new knowledge that contributes to the legal and ethical debates about end-of-life care. Findings also increase understanding of professional and personal obligations surrounding end-of-life care.

CHAPTER TWO: REVIEW OF THE LITERATURE

Introduction

Surrogate decision making in life-sustaining treatment situations is a complex process. Previous research has helped define some of the most significant factors influencing this process. It has demonstrated that the surrogate decision-making process can involve a variety of people depending on the specific situation and that the process, in part, can be influenced by the people involved (Ouslander, Tymchuk, & Rahbar, 1989; Tomlinson, Howe, Notman, & Rossmiller, 1990; Ulhman, Pearlman, & Cain, 1988; 1989). Those people may include, but are not limited to: (a) the patient, (b) the surrogate, (c) other family/friends, (d) the various health care team members, and (e) even the members of the society within which the decision is being made.

Research also has demonstrated that the surrogate decision-making process includes contextually pertinent factors such as: (a) the conditions of the precipitating event (Ouslander et al., 1989; Pijnenborg et al., 1995), (b) the patient's prior health history (Hanson et al., 1994; Hare & Nelson, 1991; Sehgal et al., 1992; Uhlmann et al., 1989), (c) the surrogate's personal experiences with decisions, health care, and death (Epting & Neimeyer, 1984), (d) the ethical context (Forsyth & Berger, 1982), (e) the surrogate's prior knowledge of patient wishes (Ouslander et al., 1989; Pijnenborg et al.; 1995, Sehgal et al., 1992), and (f) other factors. Communications during the process and the effects of time also have proven to be influential factors on the surrogate's decision and aftereffects (Higginson, Priest, & McCarthy, 1994; Ouslander et al., 1989).

Overview Of Review Of The Literature

The literature describing the societal structure for surrogate decision making in health care and related research findings was reviewed prior to this study. The ethical framework and standards with which surrogate health care decisions were made are presented first to establish the context for the study. Studies describing findings of patient wishes and patient factors found to be relevant to decisions are presented next as they constituted the foundation of the knowledge currently used in clinical settings. The populations studied previously are reviewed to explain the inclusion criteria for this study. To establish the need to explore the experience from a surrogate perspective, grief and personal meaning of death research findings are then presented to establish the probability that physical, emotional, and psychological aftereffects may occur in surrogates. Last, research findings that establish a connection between moral decision making and an impact on the individual making the decision are presented to further establish the need to examine the experience of surrogate decision making.

Standards Of Surrogate Decision Making

As stated in chapter 1, the protection of a right to autonomy when a person is unable to act as an autonomous decision maker requires consideration of the legal standards of best interests and substituted judgment. *Substituted judgment* is a decision-making standard based on what the incompetent person would want done if able to make decisions on his or her own behalf. *Best Interests* is a decision-making standard based on what is believed will protect or benefit the person's welfare.

Tomlinson et al., (1990) found that decisions made using the substituted judgment standard were statistically significantly closer to patient decisions for themselves than decisions made based on the standard of best interest. However, the studies that measure reliability of substituted judgment have demonstrated that surrogates are limited in their abilities to make the same decisions for the patient as the patients do for themselves (Danis et al., 1991; Hare, Pratt & Nelson, 1992; Higginson et al., 1994; Lavizzo-Mourey, Zinn & Taylor, 1992; Ouslander et al., 1989; Sehgal et al., 1992; Uhlmann et al., 1988).

Danis et al. (1991) had found surrogates tended to want more life-sustaining treatments than competent patients would have wanted for themselves. Hare et al. (1992) found surrogates, although they expressed a high degree of confidence that they knew what the patient wanted for himself or herself, were only in 70% agreement with the patients. Physicians in that study also were found unreliable when asked to use substituted judgment. Higginson et al. (1994) found weak correlations between family members and patients when assessing anxiety, pain, and symptom control. Ouslander et al. (1989) found physicians were less aggressive than patients who chose for themselves. They also found that physicians used advanced age as a determinant in deciding and that family members had a low level of agreement with the patients. However, family members were closer to the patients' decisions than physicians, social workers, and nurses were in that order. Uhlmann et al. (1989) found surrogate decisions were no more accurate than random chance would have been.

Seghal et al. (1992) found that patients had different opinions about how much leeway they wanted their designated surrogates to use when deciding for them. In related studies examining the personal meanings of death researchers have found that every individual approaches death from a unique perspective (Epting & Neimeyer, 1984). Together these studies raise issues regarding substituted judgment versus best interest as a frame of reference for surrogate decisions and should prompt health care providers to consider if substituted judgment is a reasonable expectation.

Ott (1999) completed a review of research to date on advance directives and concluded that research done so far "is not yet large enough or well controlled enough to answer conclusively many of the questions about planning of end-of-life care" (p. 514). The studies completed used hypothetical patient care scenarios so the comparison with the patients' decisions could be made. There were no studies that researched surrogates who were in the process of or who had actually made a decision for a loved one. The standard of substituted judgment is more supportive of the principle of autonomy than the standard of best interests, but has been proven in these studies to be a more difficult goal to achieve.

The Patients' Wishes

Of those studies examining human versus written proxies (advance directive documents, living wills, power of attorney statements), some compared decisions of health care providers to decisions of personal surrogate decisions and found that the latter more closely approximated the patient's wishes, but neither group was completely consistent

with the wishes of the patient (Tomlinson et al., 1990; Uhlmann et al., 1988). Some research findings demonstrated that patient wishes are not what determine life-sustaining treatment decisions. Pijenborg et al., (1995) conducted an extensive study in the Netherlands that researched personal surrogates and physicians who had made withholding or withdrawing life-sustaining treatment decisions. The value system in the Netherlands concerning these decisions is significantly different from the United States, but the findings were of interest to the researcher's explorations. Fifty-nine percent of the decisions to withhold or withdraw were made without patient involvement. The decisions varied based on the clinical area of expertise of the physician. In the United States it is not known how many withhold or withdraw decisions are made without patient involvement.

Principal investigators from the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) (1995) conducted their study in the United States with the stated objective to improve end-of-life decision making and to reduce the frequency of mechanically supported, painful, and prolonged process of dying. This study involved a specially trained nurse meeting with patients, families, and health care team providers as an intervention. The study findings showed the intervention failed to improve care or patient outcomes. However, Hiltunen, Medich, Chase, Peterson, and Furrow (in press) conclude, "The SUPPORT study shows that judgment and mutual human support are required at many levels." Communication with patients and surrogates was highlighted both in Pijenborg et al., (1995) and the SUPPORT (1995) studies as problematic.

Patient Factors

Some studies have sought to identify patient factors that direct life-sustaining treatment decisions. Some studies examined the relationship between patient incompetence and the decision to withhold life-sustaining treatment (Hanson et al., 1994; Sehgal et al., 1992). Hanson et al. (1994) found there was a statistically significant difference in treatment decisions to withhold cardiopulmonary resuscitation made for competent patients versus incompetent patients. Seghal et al. (1992) found that patients varied in what they wanted considered when decisions were to be made for them. Hare et al. (1992) found that physicians tended to view quality of life more negatively than the patients viewed it for themselves. These studies begin to question what factors are used and what factors should be used in making end-of-life treatment decisions. As previously reviewed, there are other studies that examined those questions as well (Hare et al., 1992; Ouslander et al., 1989).

One study examined the "leeway" that patients want surrogates to have when written advance directives are available (Sehgal et al., 1992). Findings of the Sehgal et al., study concluded that predictor variables include: (a) demographic/medical variables, (b) a previously communicated advanced directive, and (c) choice of surrogate. The authors recommend that patients be asked about leeway and that quality of life issues should be discussed as well.

In addition to the concepts of patient competence and quality of life, there are other recurring findings found in surrogate studies. Findings support that religious beliefs

appear as considerations in the decision-making process (Sehgal et al., 1992). Lastly, fear of death and family burden are sometimes mentioned as possible factors in decision making (Hare et al., 1992; Hare & Nelson, 1991; Sehgal et al., 1992).

Patients Studied To Date

None of the studies reviewed involved patients and surrogates who were actually involved in situations where the patient had been rendered incompetent in a sudden or traumatic event. The studies concentrated on: (a) elderly (Danis et al., 1991; Hanson et al., 1994; Lavizzo-Mourey et al., 1992; Ouslander et al., 1989; Tomlinson et al., 1990; Uhlmann et al., 1988,1989), (b) chronically ill (Hanson et al., 1994; Sehgal et al., 1992; Uhlmann et al., 1988, 1989) and (c) terminally ill (Higginson et al., 1994) patients. Situations involving acute events were limited and tended to involve elderly patients and be hypothetical in nature (Hare et al., 1992). Again, no studies were found that examined surrogate decision making in sudden or traumatic patient populations.

Surrogate Aftereffects

Studies addressing the aftereffects for the surrogate are virtually non-existent when directly examining the surrogate decision-making role and/or process. Berns and Colvin (1998) found family members and friends want to be present at the time of death of a love one. The family members and friends want to be present to give the dying patient permission to die and to make promises. These authors found that following the patient's death, family and friends feel compelled to keep those promises made. They also found family and friends wanted consistent, honest, and thorough communication with health

care providers. Saunders (1989) states that people hold onto memories of how their loved ones die. Lynn et al. (1997) also supports those findings.

Grief research provides some indication of possible aftereffects of the surrogate decision-making process. Viney (1991) found that when faced with their own imminent death or likely death of a loved one, people experience major changes in their reality. Viney found that negative feelings occur when people are not able to effectively interpret and anticipate events. They then experience invalidation. Positive feelings result from confirmation of their interpretations and accurate anticipation of outcomes. The implications of these findings establish a need for health care providers to facilitate surrogate decision making in a manner conducive to maintaining the SDMs' overall well-being as well as obtaining desirable patient outcomes.

Higginson et al. (1994) found that there was strong evidence to support that a family member's perceptions of the patient's death experience alters during a bereavement period. These authors recommended that retrospective studies take mood and grief into consideration when analyzing findings. This study supports the rationale to interview the study participants after six months, but at or before eighteen months after losing a loved one.

Bereavement research has included: (a) theoretical and clinical treatments of grief reactions (Bowlby, 1969; Worden, 1982), (b) variables affecting grief (Bugen, 1977; Doka, 1989; Parkes, 1972; Rando, 1984; Raphael, 1982), (c) descriptions of the grief reaction (Parkes, 1972; Parkes & Weiss, 1983; Volkan, 1975), (d) elapsed time since the

loss (Jacobs et al., 1986; Klerman & Izen, 1977; Parkes & Brown, 1972), (e) length of illness prior to death (Parkes, 1975), (f) relationship to the deceased (Fulton, 1987), (g) and conjugal bereavement variables such as time since loss, grief, and health of the survivor (Bowling, 1988-1989; Demi, 1984; Lieberman, 1989; Thompson, Breckenridge, Gallagher, & Peterson, 1984; Vezina, Bourque, & Belanger, 1988; Windholz, Marmar, & Horowitz, 1985; Zisook and Shucter, 1985).

In summary, these grief research studies have found that:

1. The loss of a central relationship produces more intense reactions than the loss of a peripheral relationship (Bugen, 1977),

2. Mourners who are bereaved for one year were distinguished from the non-bereaved by depression and autonomic symptoms (Parkes & Brown, 1972),

3. A steady decline in depression and autonomic symptoms continued until three years after a death (Parkes & Brown, 1972),

4. Length of illness affected the outcome of bereavement (Parkes, 1975),

5. Unresolved grief was associated with a brief illness in the person who died (Parkes, 1975),

6. Surviving spouses or parents reported symptomatology of grief while adult children who had anticipated a death reported no disturbance in life pattern (Fulton, 1987).

Impact Of Moral Decision Making

Research findings examining the ethical framework from which the surrogate

forms decisions may also contribute to understanding the surrogate experience. Life-sustaining treatments incorporate values and moral principles. Forsyth and Berger (1982) found that a person's ethical ideology may not affect their decisions, but self-satisfaction and guilt are different for individuals who endorse different ethical ideologies.

Summary

Previous research supports that surrogate decisions for end-of-life treatments are multifactorial. Factors identified include: (a) relationship to the patient, (b) age of the patient, (c) health of the patient, (d) spiritual considerations, (e) quality of life, (f) family burden, (g) knowledge of advanced directives, (h) communication during the process, and (i) time. Research on ethical ideology supports that moral decisions have aftereffects on individuals. Research on the personal meaning of death reinforces consideration of the surrogate's relationship to the patient, his/her understanding of the situation, and any factor the surrogate would use to interpret the situation. Grief research supports consideration of some of the same variables identified in both the surrogate decision making and personal meaning of death research, including relationship to the patient and time.

There was no identified research on patients and surrogates involved in sudden or traumatic injuries or illnesses. Furthermore, there was no research identified that directly explored the experience and meaning of the surrogate decision-making experience (SDME) for surrogates.

CHAPTER THREE: METHODOLOGY

Purpose

The purpose of this study was to describe the experiences and meanings of surrogates' decisions to withhold and/or to withdraw life-sustaining treatments from adults who were rendered incompetent following unanticipated, catastrophic illnesses. The research design, method, and data collection procedures were selected to achieve this purpose.

Research Design

The specific research question to be addressed was: What has it been like for a surrogate decision maker (SDM) to decide to withhold and/or withdraw life-sustaining treatment(s) from an incompetent adult following an unanticipated, catastrophic illness? Specifically, six to eighteen months after the incompetent adult's death, how did the SDM experience his or her role and what did making the decision mean to the surrogate?

This research question was answered through a phenomenological investigation guided by the method described by Giorgi (1985, 1989a, 1989b, 1990). Phenomenology is a form of qualitative research that attempts to disclose the essential meaning of human experience and is well suited to nursing inquiry (Benner, Tanner, & Chesla, 1996; Bishop & Scudder, 1991). Since the research question concerns a human experience, it is answered appropriately through phenomenological inquiry.

Giorgi's Method for Phenomenological Inquiry

Giorgi (1990) states that "The aim of phenomenological analysis would be to

understand the natural attitude better than it understands itself..." (p.67-68). Giorgi presents phenomenology as descriptive in two ways. First, the data are descriptions of situations experienced by the participants and second, the results provided by the researcher are descriptive as well. The researcher uses more technical terms of the discipline, but still provides description.

Giorgi (1990) summarizes phenomenological analysis as follows:

> In my view, a phenomenological analysis essentially means an analysis of descriptions from within the perspective of the phenomenological reduction which teases out the essential meanings of the experiential descriptions through a process of free imaginative variation (p.65).

Giorgi describes this method as hesitant and empirical allowing for the discovery of meanings without a priori structures.

A search of the computerized CINAHL database revealed 80 abstracts that cited Giorgi's phenomenological method in their references. Twenty-two of these abstracts were about the methodology. The remaining 48 were studies completed on a variety of topics with significant relevance to Nursing.

Ten studies described the meaning and experience of a particular health condition in specific populations, namely: (a) memory loss (Moyle & Clinton, 1997), (b) gastrostomy tubes in children (Thorne, Radford, & McCormick, 1997), (c) stress in children (Jacobsen, 1994; Wilkinson & Pierce, 1997), (d) diabetes in Native Americans (Parker, 1994), (e) cancer treatment completion from children's perspectives (Haase &

Rostad, 1994), (f) leg ulcers (Charles, 1995), (g) psoriasis (Chrissopoulos & Cleaver, 1996), and (h) cancer (Tishelman, 1997). My study investigated the experience of surrogates who were grieving for now deceased adults who had an unanticipated, catastrophic illness/event.

Six studies presented the meaning and experience of specific roles and relationships of certain populations. Those populations included: (a) individuals caring for adults with schizophrenia (Tuck, du-Mont, Evans, & Shupe, 1997), (b) parents caring for diabetic infants and toddlers (Hatton, Canam, Thorne, & Hughes, 1995), (c) health and caring in the context of maternal care (Bondas-Salonen, 1994), (d) family members of people with Huntington's Disease (Semple, 1995), (e) siblings of people with eating disorders (Garley & Johnson, 1994), and (f) parents who experienced the death of a newborn whose birth was on the margin of viability (Kavanaugh, 1997). My study investigated the experience of the role of surrogate decision maker.

Five studies described the meaning and experience of people who had lived in various social/environmental conditions. Those conditions were: (a) healing from an abusive relationship (Farrell, 1996a), (b) being at home (Hammer, 1991), (c) living alone at home (Donalek & Porter, 1994), (d) resettlement without support of an ethnocultural community (Baker, Aresenault, & Gallant, 1994), and (e) perspectives on nursing home quality (Gjerberg, 1995). My study described the meaning and experience of people who lived in the social context of surrogate decision making.

Twenty studies explored the meaning and experiences of varied concepts. The concepts explored were: (a) hope (Flemming, 1997), (b) aloneness (Wilkinson, 1997), (c) wanting to help others (Mitchell & Heidt, 1994), (d) stigma (Donohue, 1991), (e) fear (Dunn, 1989), (f) patient compliance (Brooks, 1986), (g) drive (Santopinto, 1989), (h) support (Baker et al., 1994; Henderson, 1995; Lynam, 1995; Nystrom & Segesten, 1995), (I) fatigue (Pearce & Richardson, 1994; Pearce & Richardson, 1996; Ream & Richardson, 1997), (j) caring (Owen, 1995), (k) sense of relationship (Farrell, 1995, 1996b), (l) motivation (Tham & Borell, 1996), and (m) staying healthy (Smith, 1989, 1995). It was accurately anticipated that concepts would emerge from my study.

Sixteen studies described the meaning and experience related to a specific professional role. Those roles and experiences included: (a) several student nurse or nursing education studies (Baird, 1996; Fagerberg & Ekman, 1997; Hanson & Smith, 1996; Smith, 1996; Stew, 1996), (b) nursing role competencies, developmental issues and experiences (Arslanian-Engoren, 1995; Bonaiuto, 1995; Bousfield, 1997; Graham, 1994; Timpka, Svensson, & Molin, 1996), (c) health care delivery systems or issues (Gmeiner & Poggenpoel, 1996; Jacobsen, 1995; Olsson, Sandman, & Jansson, 1996), (d) ethics (Smith, 1996a, 1996b), and (e) therapeutic use of self (Conti & O'Hare, 1996). My study, as expected, indirectly generated role knowledge for health care professionals.

Data Collection Procedures

This study was conducted in the participants' home or the participants' office except for one interview that was conducted in the researcher's home per request of the

participant. The participants had been solicited to participate in the study through personal networking, posting of a flyer (see Appendix A), and a letter to a bereavement group (see Appendix B). Participants were given the researcher's telephone number and were asked to contact the researcher. The researcher responded to the calls by a return telephone call. At this time the researcher obtained verbal consent to question for eligibility to participate in the study (see Appendix C). The participants and the researcher selected a time and location for the interview to occur. The researcher gave a verbal explanation and written documentation of informed consent sheet at the interview (see Appendix D).

The interviews took between 50 minutes to two and one-half hours to complete. The majority of interviews were between one hour and one hour and 15 minutes. Interviews were taped for later transcription. Participants were aware that they could stop the interview immediately upon request, but none chose to do so. Participants were instructed that they could contact the researcher for any follow-up necessary. The need for a follow-up interview was never determined to be necessary by the researcher or any of the participants.

Protection Of Human Participants

Participation in this study was voluntary. Approval to conduct this study was obtained from the Boston College Institutional Review Board (see Appendix E). The initial contact resulted from personal networking, letter to a bereavement group (see Appendix B), and advertising by flyer (see Appendix A). The potential participants then

contacted the researcher by telephone if they chose to consider participation in the study. This telephone screening requested study participation and explained the risks and benefits to the potential participants. The researcher and the participant then established a mutually agreeable time and place to meet for the interview. The potential participants were solicited with no obligation to respond either at first contact or during the telephone screening process.

Clearly, no coercion was felt by potential participants as two interviews were scheduled, but then cancelled by potential participants. One was cancelled because of another family crisis. That participant never re-contacted the researcher as promised. The second was rescheduled and completed five months later. In addition, three other participants declined to participate. The three told a mutual friend that they felt it would be too difficult for them to participate. At no time did the researcher contact a potential participant directly as it was deemed easier for the participant to decline to another person. The refusals reinforced that this was an accurate assumption.

All participants were identified with a fictitious name that was chosen by the participant or assigned by the researcher. Participants were given an informed consent sheet for completion. Participants were made aware that there were no anticipated consequences for refusing to participate in or withdrawing from the study. All data is reported by fictitious name and without identifying information.

This study was considered low risk because none of the measures involved physical interventions or intrusive techniques. Since it was possible that some participants

might experience emotional distress from the decision-making experience and that distress might be increased by participation in the study, the researcher was prepared to terminate interviews. If the researcher had determined that any participant might benefit from professional, clinical intervention, then the researcher was prepared to refer him or her to an acute care setting and/or a bereavement counselor who had agreed to accept referrals from this study. Two participants were already receiving professional therapy and no other participant required intervention.

Population And Sample

The target population of this study was the population of surrogate decision makers for now deceased, incompetent adults who had suffered an unanticipated life threatening catastrophic illness/event and for whom they made a decision to withhold and/or withdraw life-sustaining treatments. Inclusion criteria for participants were that the withhold/withdraw decision and subsequent death had occurred six to 18 months prior to the study. A sample size of 13 was completed because saturation was reached. Saturation was established when the interviews stop yielding meaning units that provided any new insights for the researcher.

Sample Size

A sample size of 13 participants was consistent with the other studies using Giorgi's phenomenological method as per the CINAHL search. Twenty-nine of the 58 studies that used Giorgi's phenomenological method reported the size of their study sample in their abstract. The sample sizes ranged from a low of four (Arslanian-Engoren,

1995; Flemming, 1997; Tham & Borell, 1996) to a high of 60 (Chrissopoulos & Cleaver, 1996). The average was 18.1, but only five studies used a study sample of greater than 20 (Chrissopoulos & Cleaver, 1996; Gjerber, 1995; Stew, 1996; Tishelman, 1997; Timpka et al., 1996). Accessing the population for this study was difficult because of: (a) the specificity of the inclusion criteria, (b) confidentiality issues, (c) awareness of health care providers that these events have occurred given the brevity of contact, and (d) fear of stimulating a grief response.

Demographics

Demographic variables collected on the 13 participants, (See Appendix F), yielded several findings.

Age

The mean age of the surrogate decision makers (SDMs) was 47 with a range of 37 to 75 and a standard deviation of 9.8. The mean age of the deceased was 73 with a range of 53 to 90 and a standard deviation of 9.6.

Relationships Of The Surrogate Decision Maker/Patient

Two participants are wives of husbands who had passed away. One participant is a same sex partner of a woman who passed away. Three participants are sons of mothers who passed away. Three participants are daughters of fathers who passed away. Two participants are daughters of mothers who passed away. One participant is a niece of an aunt who passed away. One participant is a best friend of a woman who passed away.

Religious Affiliation

Ninety-two percent of the SDMs declared Catholicism as their religious affiliation. Nine participants said they are Catholic, two participants said they were raised Catholic, one participant said he is a "quarterly Catholic", and one participant said he has no formal religious affiliation. However, the deceased for whom the "no religious affiliation" SDM made decisions was his mother who was raised Baptist but converted to Catholic. The participants reported that the deceased were also 92% Catholic. The remaining one deceased person was Jewish.

Cultural Group Identification

Cultural identification of both the participants and the deceased was predominantly Americans of Western European decent. In the SDM group there were six Irish Americans, two Italian Americans, one Irish/Italian American, one Irish/Scottish/English American, and one Irish/Finnish American. One person said she identified with no cultural group, and one participant identified herself as 'American Eclectic' which was defined as a combination of Irish, Native American, and French Canadian ancestry. In the deceased group there were seven Irish Americans, one Italian American, one Jewish American, one Scottish/English/French Canadian American, one Swedish American, one French American, and one identified with no cultural group.

Gender

In the SDM group there are three men (23%), and ten women (77%). The deceased group was 38% male, (n=5), and 62% female, (n=8).

Time Lapsed Since Death Of Loved One

The deceased had died, on the average, 11 1/2 months prior to the SDMs' interviews. The range in months since the death was six months to 18 months. The numbers tended to gravitate to the ends of the range with two at six months, three at seven months, one at eight months, one at ten months, one at 12 months, four at 17 months, and one at 18 months, after the death of the patient.

Cause Of Death

Data was available on the cause of death and specific decisions made even though they were not explicitly asked for as demographic variables. Through the interviews it was revealed that one person died of Creutzfeldt Jakob Disease (CJD). Two people died from cerebrovascular accidents. One person died from a myocardial infarct. Three people died from pneumonia. One person died from an ischemic bowel. Two people died from cancer. One person died from sepsis of unknown etiology. One person died status post abdominal aortic aneurysm repair. One person died from emphysema.

Surrogate Decision Makers' Decisions Made

Decisions for these patients included: (a) not hospitalizing a patient, (b) withholding resuscitation efforts, (c) withholding fluid and nutrition, (d) withholding antibiotics, (e) withholding a tracheostomy procedure, (f) withholding gastric-tube placement, (g) withdrawing ventilator support, and (h) increasing analgesic support while withholding resuscitation efforts.

Surrogate Decision Makers' Occupations

Also not requested, but gained through the interviews were the occupations of the participants. Of note, seven of the participants were registered nurses and the impact that may or may not have had on this experience was addressed during the interviews.

Variety Of Hospitals Involved

All 13 patients were hospitalized at a different hospital. Three of the participants live outside of the Commonwealth of Massachusetts. This indicated to the researcher that the issues were more a reflection of current nursing practice than a reflection of any one nursing staff or hospital's practice. This was perceived by the researcher to be a strength of the study.

Details Of The Steps In Analysis

To answer the phenomenological question posed by this study, 13 interviews were conducted. These interviews were guided by the questions as per Appendix G and supplemented with demographic data as per Appendix F. The demographic data were collected to describe the study sample and to guide description of context for each interview. The interviews provided the participants' descriptions of the experiences that were then analyzed using Giorgi's method for phenomenological inquiry.

Giorgi's method for phenomenological inquiry is a four step method (Giorgi, 1985). The steps outlined by Giorgi are;

1. One reads the entire description in order to get a general *sense of the whole* statement,

2. The researcher goes back to the beginning and reads through the text with the specific aim of discriminating *meaning units* from within a discipline perspective with a focus on the phenomenon being researched,

3. The researcher transforms the meaning units by expressing *insight* contained within them more directly,

4. And the researcher *synthesizes* all the transformed meaning units into a consistent statement regarding the participant's experience.

The first step of Giorgi's method is reading the entire description for a sense of the whole. Giorgi (1985) states that reading the entire description to obtain a sense of the whole may take several readings depending on the length of the description. The general sense is not interrogated or explicit. In this study, each interview was transcribed and read for a sense of the whole. At the conclusion of all 13 interviews, the interviews were read another three times for a sense of the collective whole.

The second step is identifying constituting meaning units. A focus on constituting meaning units is justified based on the impossibility of dealing with an entire description at once. According to Giorgi, one experiences a meaning unit before one understands its meaning. Giorgi (1985) states that "In a certain sense the procedure being outlined here is the practice of science within the 'context of discovery' rather than the 'context of verification'" (p.14). In this study, each individual transcript was read for meaning units. The researcher, and a second reader, highlighted the meaning units of each transcript.

The third step of the analysis returns to the meaning units and asks what is happening that reveals something about the phenomenon being studied. The transformed meaning unit is where the researcher attempts to say what the participant said, but in the technical terms of the discipline. Giorgi (1985) suggests the use of 'imaginative variation' to discover the essential features of the phenomenon under examination. Imaginative variation is the process of actively imagining other possibilities or alternatives to assist in the discovery of the essences of the phenomenon under study.

In the analysis of the study data, each transcript had margin notes written to transform highlighted meaning units into insights to be analyzed. Those margin notes were coded and re-coded several times as the researcher gained new insights from other interviews and the study sample as a whole.

The fourth step of Giorgi's analysis is synthesis of the transformed meaning units. Giorgi (1985) states that "the last step of the analysis is for the researcher to synthesize and integrate the insights contained in the transformed meaning units into a consistent description of the psychological structure of the event" (p.19). In this study, the researcher wrote out all of the margin note insights identified. Then under each insight listed the researcher noted which and how many participants had discussed that insight. The insights were then reassembled to describe the essence of the surrogate decision-making experience (SDME) as experienced by the study participants.

Scientific Rigor

Lincoln and Guba (1985) present criteria of trustworthiness, credibility, transferability, dependability, and confirmability as necessary for scientific rigor in qualitative research. These criteria are to ensure in qualitative studies what reliability and validity ensure in quantitative studies. Guba and Lincoln (1989, 1994) propose authenticity criteria which include: (a) fairness, (b) ontological authenticity, (c) educative authenticity, (d) catalytic authenticity, and (e) tactical authenticity. These authenticity criteria were applied to this study.

Fairness refers to the extent to which different constructions and their underlying value structures are solicited and honored within the evaluation process (Guba & Lincoln, 1989). For this study, fairness was addressed by the use of free imaginative variation. The use of phenomenological reduction and the search for essences by a phenomenological researcher means the researcher brackets or renders non-influential what they know about the phenomenon under study (Beck, 1994). Reduction is motivated by the wish to avoid error. The search for essences also keeps the researcher from speaking about particulars and directs expression toward the essentials. Through the process of free imaginative variation that Giorgi (1990) outlines, essences are attained.

Specifically, in this study a second expert reader was asked to read the interviews and a field notes diary was maintained by the researcher and shared with the second reader. The benefits of the second reader were twofold. The first benefit was that the second reader identified the same meaning units from the data that the first reader

identified. The second benefit was that the second reader identified meaning units that the first reader did not perceive as present in the data. The use of this second expert and the maintenance of a field notes diary therefore address fairness in the study. The researcher and the second reader met on two occasions to compare meaning units identified and review the field notes diary.

Ontological authenticity criterion refers to the extent to which the individual respondent's own emic constructions are improved, matured, expanded, and elaborated, in that he or she now possesses more information and has become more sophisticated in his or her use (Guba & Lincoln, 1989). It is "improvement in the individual's (or group's) conscious experiencing of the world" (Lincoln & Guba, 1986, p.81.). This study was designed with two opportunities to assess this criterion.

First, the participants were allowed to access the researcher for any follow-up they desired. None of the participants contacted the researcher after the interview, but three did request they receive information at the completion of the study. Additionally, six participants specifically articulated during the interview that they had gained an insight or were planning to follow-up on something they had not thought of before the interview. For example, this was demonstrated when one participant, Chrissy, stated, "...your questions have been great, really thought provoking and I have to go back and think of some others." It was also clear when another participant, Buck, sought clarity about the Catholic Church's doctrines about withdrawing life support. He said near the end of his

interview, "Actually talking to you right now is not bad. I have answered a couple of questions, but other than that I am all set."

The second way in which the ontological authenticity criterion was addressed was by altering the interviews themselves. Later interviews were informed by the earlier interviews. This strategy created an opportunity for more reflection as some participants were asked specifically to review transformed meaning units and insights as certain trends began emerging.

Educative authenticity represents the extent to which individual respondents' understanding of and appreciation for the constructions of others outside their stake-holding group are enhanced (Guba & Lincoln, 1989). This criterion was addressed during interviews when participants solicited information about the constructions of others. In addition, the interview guide was altered for later interviews as emerging data presented itself from previous interviews.

Catalytic authenticity is defined as the extent to which action is stimulated and facilitated by the research process (Guba & Lincoln, 1989). This criterion will be met when the study findings are complete and information can be disseminated to health care providers. In addition, it is anticipated that nursing practice will be influenced by the study findings.

Tactical authenticity refers to the degree to which stakeholders and participants are empowered to act (Guba & Lincoln, 1989). This criterion was met when the participants solicited or presented as requiring additional information about the deceaseds' deaths and

their experiences. The researcher experienced four occasions when teaching occurred during the interview either by request or apparent need. The topics discussed on these occasions were: (a) the meaning of health care proxy versus advance directives, (b) sanctity of life, (c) futility, and (d) therapeutic effects of morphine. Two participants were currently receiving clinical interventions for themselves before the interview because their grief responses were problematic for them. None of the other participants exhibited a need for such interventions. However, three of the participants did contact the mutual acquaintances who arranged the connection and who reported back to the researcher that those participants felt the interview was healing in some way for their grieving.

Summary

The purpose of this study was to describe the experiences and meanings of surrogates' decisions to withhold and/or to withdraw life-sustaining treatments from adults who were rendered incompetent following unanticipated, catastrophic illnesses. The research question was: What was it like for a surrogate decision maker (SDM) to withhold and/or withdraw life-sustaining treatments from an incompetent adult following an unanticipated, catastrophic illness? Specifically, "How did he/she experience the surrogate decision-making role, and what did making the decision mean to the surrogate?" The research question was answered using Giorgi's method for phenomenological research. The method accommodated voluntary interviews and anonymity as per the study design. Scientific rigor was obtained with the method.

CHAPTER 4: THE THEME OF REPRESENTATION OF OTHER

Introduction

Individuals in our society are asked to make health care decisions for incapacitated others because we value autonomy and self-determination. As a society, the United States has legislated that health care providers obtain consent to withhold and/or withdraw medical interventions. If this consent cannot directly be obtained from the patient because of incapacitation, then a surrogate decision maker (SDM) representing the patient is sought. The surrogates are asked to represent the respective patients in these decisions to withhold and/or withdraw medical interventions. Preferably the surrogates do so by using the standard of substituted judgment, deciding for another what they would decide for themselves if capable of doing so. It can be reasonably inferred that this is meant as a positive, protective, and respectful role to assume. However, there was no previous research completed to establish if the SDMs experienced the role in that way.

Thirteen surrogate decision makers were interviewed for this study to describe the experience and meaning of the surrogate decision maker (SDM) role. Transcripts from those interviews were analyzed using Giorgi's method of phenomenological research as detailed in chapter 3. That analytical method yielded a description of the essence of the surrogate decision-making experience (SDME). Findings reveal that the essence of the SDME consists of two major themes as interpreted by a metaphor.

This chapter will present the first theme of Representation of Other through the use of an orchestral performance metaphor, the meaning units, and the insights that

contributed to its emergence. The second theme, Memory Manipulation will be presented in chapter 5 as the orchestral performance metaphor continues. Practice, research, education, and policy development implications will be presented in chapter 6.

Themes Emerging Through A Metaphor

One study participant, Monica, said her parents completed their advance directives and named their children as health care proxies instead of each other in an attempt to "orchestrate memories". It was from this meaning unit that the sense of music and orchestral performances first consciously arose for the researcher. However, once the researcher was conscious of this metaphor it seemed to capture the essence of the SDME portrayed by other participants as well. For example, another study participant, Chrissy, described guidelines to be used as her expressed wishes with a musical reference as well. She told her daughter, "If you start singing and you see nothing and you don't see a tear or flicker then you will know. That will be the measurement and you tell the neurologist." The metaphor is useful to portray the essence of all the individual participants' stories and it also represents the essence of the collective experience as portrayed. Therefore, the themes will be presented using an orchestral performance metaphor as shown in Figure 1.

The first use of the metaphor is in analogizing the deceased to the composer. While the composer is rarely present at a performance, it can never be denied that the music would not exist without the composer's unique talents, efforts, and life. This analogy begins to explain the theme of Representation of Other. It is clear in the retelling of the SDMEs that the deceased person has as much to do with the SDME as the SDM.

When the SDMs reflect on their decisions, they sometimes question if the composer would have liked their interpretations, but they can never know for sure.

The Finding	The Metaphor
1.The deceased	The composer
2.Past experience with loss and conversations about expressed wishes	Rehearsal time
3.The SDM, family members, and health care team	Musicians needing to play in concert
4.The deceased, other family members, the health care team, and society at large	Audiences
5.The other people involved and/or who hear the story out of context	The critics
6.The other life/family sagas	Off-beats disrupting the rhythm of the music
7.The need for translation of medical terminology	Transposing music to a different key

Figure1: The Orchestral Performance Metaphor

The metaphor continues with the preparation phase of the performance. The interviews reveal that despite researching SDMs who made decisions for unanticipated illnesses only, there is an expressed sense of preparation for the SDME. That preparation may have been preparation of an advance directive, a previous experience with loss, or simply life experiences between the surrogate and the deceased that became the foundation of surrogate decisions.

The metaphor also allows for the variety of 'players' in the experience that must reach agreement or move together to provide the best outcome possible from the surrogate's perspective. The many players must work 'in concert' or risk a cacophonic sound. The participants, while feeling accountable for the decision, allowed for other loved ones and professionals to play significant roles in the outcome. Nobody decided alone. When there was a 'solo', the participant felt the accountability accordingly.

In fact, some participants may even have felt more like the conductor than a musician. For example, Fred felt he had to take the lead for his family, Mary had to "take the bull by the horns" and Buck felt his mother expected him to "chair the committee". Even if they took a lead, none of the participants portrayed their SDME as something done alone.

As participants told of their SDME they described cocnurrent family crises, off-beats. They also told of 'audiences' for their decisions. The participants also spoke of decisions made along the way for people other than the patient. They balanced decisions needing to be made with intricate relationships. The SDMs responded to personal audiences, health care providers and systems, and society at large. The participants expressed a need for translation of medical terminology. Metaphorically, this is transposing music to a more comfortable key for the musician to play.

After the loss, the SDMs did not feel they should share their decisions with everyone. They felt that way because at the time of their loss and still at the time of their interviews they did not believe everyone would understand their decisions when retold out

of context. In their recollections after the loss, the participants spoke poignantly of feedback they received or feared receiving about their decisions. This served as a 'critics' review' of the performance from which there were efforts to protect themselves and to protect their memories.

Representation Of Other

The first major theme that emerged as a study finding is Representation of Other. The essence of 'what' the SDMs do is captured in this theme. It may have been an obvious assumption to think that the essence of the SDME would be making decisions. However, findings from this study portray the essence of the SDME is more accurately described by the theme Representation of Other. It is more encompassing than making decisions. The SDMs make decisions to represent the other, not vice versa. Figure 2 highlights the various aspects of Representation of Other.

1. Representing a full life led
2. Relating to the SDM role
   a. being formally designated or not
   b. valuing written documents
   c. experiencing a sense of burden
3. Sensing an audience
4. Making other decisions along the way
5. Seeking clinical resources

Figure2: Aspects of Representation of Other Theme

The SDMs present themselves and the deceased as an intertwined dyad experiencing events. The SDM is the one capable of representing anything and so he/she represents him/herself and they represent the other. Representing the other is what SDMs do in their SDME. In many cases, they represent more than just the one other, they represent multiple other loved ones. The SDMs represent the patient, and at times other loved ones, before and beyond the time periods when they are asked to make decisions. The SDMs, having been asked by health care providers to represent the wishes of his/her loved one, continue to represent this other person through their grieving. Overall, the SDME is not portrayed as one person's experience.

Music Appreciation: The Purpose Of Representation Of Other

Just as nobody would attend an orchestral performance unless he or she either appreciated music his/herself or were with someone who wanted them to share that experience, so too no SDM would become a SDM unless he or she were connected to another human being. The SDM is part of a larger whole, connected to another. Every participant in this study was connected to multiple others.

Every participant had been asked by a team of health care professionals to represent the patient for whom he or she decided to withhold or withdraw life-sustaining treatments. However, for purposes of this study the surrogate was asked to talk about his or her experience, to represent his or herself if you will. However, none of the SDMs limited themselves in that way. The surrogates continued to represent the now deceased

patients in all-encompassing ways when they recounted their experiences to the researcher.

In doing so, the SDMs did not describe the portrayal of their SDME as only the catastrophic illness and decisions made. When the researcher left each SDM, she left with an image of the deceased. This image was portrayed in seven cases by literally showing a picture and in all cases by stories of who the deceased was and how he or she lived his or her life. There were also lasting impressions of other loved ones presented by the SDM. If you consider that one definition of memory is "the reputation of a person or thing, especially after death", then this representation is not unrelated to the second major theme, Memory Manipulation (Flexner & Hauck, 1987, p.1199).

In fact, the two major themes are as inextricably woven as the SDM and the deceased. However, as Giorgi points out, there is an impossibility of dealing with an entire description at once. That is the rationale behind focusing on meaning units. So the two themes are presented with as much distinction and clarity as possible.

Already Knowing The Music: The Response To Advance Directives

Participant meaning units and researcher insights describing SDM responses to advance directives portray the SDME in relation to this societally established decision-making role which is intended to facilitate representing another person. Those findings include discussions on the impact of having a formal designation as a surrogate. Findings also include participant and health care provider perceptions of the value of written documents. Lastly, there are meaning units that address whether or not the SDM role is

considered "burdensome" to the study participants. Unfortunately, findings from this study demonstrate that there are negative aspects of this experience despite the foundation of good intentions.

Conductor, Lead Chair, Or Member Of The Orchestra

Not every participant in this study was a formally, legally designated health care proxy. Only three of the 13 surrogate decision makers interviewed--Michelle, Monica, and Buck--were legally designated as health care proxies. Paula and Patty had legal claims per state laws because they were wives. Patty's husband and Camille's father had completed living wills. Mary's mother had a will about distribution of her property in which she stated she wanted no resuscitation efforts, but did not designate a specific health care proxy or complete a living will. Six of the 13 were children from families where they were not the only offspring of the patient. However, in all six of those cases the participants had the support of their siblings while making the decisions. In fact, no surrogate in this study believed they made these decisions without support from all family members involved.

The last two participants, Tara and Anne, each had a unique situation. Tara, a same sex partner, had no legal claim despite being in a committed relationship for over 30 years. However, all health care providers and Margaret's family members agreed that she was to assume the role. Anne was in the most precarious position of the 13 participants. Rachel's mother in another state had the legal right to be Rachel's surrogate in lieu of any legal document appointing Anne, but all of the health care providers

recognized that Anne knew Rachel the best. The health care team asked Anne to provide substituted judgment decisions for Rachel. Fortunately, Rachel's mother, who lived and was out of state when her daughter was dying, did not disagree with Anne's decisions or there may have been additional complexity to the role Anne was asked to assume.

Overall, formal appointments as health care proxies were not necessary before a SMD was asked to assume the role. In addition, formal designation did not mean the SDM was the only person making decisions. Lastly, there were times when the legal SDM was not the person who fulfilled the functions of the role.

How Important Is The Actual Sheet Of Music At Performance Time?

Some participants who did not have written documents from the patients in these stories did express a desire to have had a written document. Anne expressed regret for resuscitating Rachel in their home because she felt she had no choice without a legal document stating to withhold that effort. As she stated in her interview:

> I could not call the doctor and tell him she was dead at home. I probably wouldn't be sitting here right now. I would be in (name of a state penitentiary) prison, but you know...I, I knew that that was not what she wanted. Again I think she would want me to be safe too and covered as far as legality wise was.

However, Anne also said of Rachel's health care providers' approaches to her despite the absence of an advance directive or proxy designation, "I felt good, that they didn't sound like they were holding it to a real piece of paper." Anne's mixed responses to actual legal documentation was not an uncommon experience in the study insights. For

example, while projecting to surrogate decision making in the future for her parents Tara said, "...there's something there if I had something in writing, that they could help to write would free me to make those decisions easier."

Fred said his mother would not sign paperwork to designate a power of attorney. He described not having that document as leaving his family feeling "powerless". He said:

> ...we were trying to sort out what ...she could decide and what she couldn't decide...there were no legal documents...and our family tried to look around to see if there was some legal way that we could, um, take responsibility and at that time we couldn't find a way that she wasn't coherent enough to really sign something.

Of course, legally the family does not lose its right to decide because there is no formal document, but none of the health care providers shared that with Fred.

Fred has a legally designated proxy for himself because he has a same sex partner for whom he is a legal surrogate. They are protecting their relationship and rights through the only legal channel possible. Patty had completed an advance directive for herself at the same time her husband Sammy had. However, the majority of the participants, 77%, had not completed any health care proxy or advance directive document for themselves despite having gone through an end-of-life treatment decision-making experience.

Some of the participants who had not completed legal documents did say they have had preliminary conversations with their would be surrogates. Many of them used their experience as a surrogate to explain what they value for themselves. They all used

quality and meaning of life criteria. For example, Chrissy described guidelines she has shared with her daughter. She told her daughter, "If you start singing and you see nothing and you don't see a tear or flicker then you will know. That will be the measurement and you tell the neurologist."

Camille said of her parents' foresight to complete an advance directive that she often thought:

> ...how grateful we were that they had done this themselves and how easy it made life for us and um we told that to my Mom numerous times too....also very considerate ...for your children. That they didn't have to deal with these issues because my parents laid it out for us...wasn't it a blessing.

Camille also had experienced a potential life threatening illness with her husband, but still they have not completed advance directives. She provided a kitchen junk drawer analogy as her reason. Camille said:

> ...we're probably at the same stages pre-crisis when you think life is going smoothly and you think... "Yes, I'll get to that at the same time I clean my junk drawer in the kitchen." Yes, I know I need to do it and I will do it. It's just that I haven't had time this week.

When speaking about advance directives, Mary said, "All the written words in the world, they're still just words. You probably can't really know." Similarly, Monica said, "...the piece of paper itself, nobody even asked for it. In the end because it's not what it's about. No, its about relationships." Overall, the participants' lack of follow-

through to complete advance directive documents for themselves appears to indicate they do not place as high a value on written documents as they do on the conversations. Mary's and Monica's expressed sentiments reinforce that the essence is about representing the other, not a document or decisions.

Professionals in these stories also seemed less than committed to the legal papers that their patients had completed. Monica said the nurses asked if her father had an advance directive, but they did so in the middle of a series of questions that Monica recalled sounding like, "'Does he wear glasses? Does he have contact lenses? Does he have false teeth? Does he have advance directives?'...just in the litany of things they sort of tucked it way in there." Patty questioned the purposefulness of her husband's living will since she was asked what she wanted to do about ventilator support despite her husband's declaration that he did not want that intervention.

None of the participants ever were asked to produce any legal documents. Some participants were consoled by the existence of a written document just as the musician may know the piece by concert time, but they still place the music on the stand in front of them. However, the musician should be transcending the notes and playing the music in an interpretive manner by performance time. So too, the study findings indicate that the people, not documents, represent people in life-sustaining treatment decisions when the decisions need to be made.

Hitting The High Notes: A Sense Of Burden When Representing Other

There were rationales provided for the three formal designations of a health care proxy and the living wills executed by Patty's husband and Mary's mother. One common insight was the idea that formal documentation would relieve loved ones of a sense of burden. However, two out of the three formally designated surrogates expressed feelings that legal documentation felt like a different level of accountability. Three out of the total 13 participants literally used the term "burden".

Monica's father designated her a health care proxy at the same time that her mother designated her brother to be her health care proxy. Monica reported that her parents completed health care proxies to protect each other from having to make decisions for a spouse. They completed the documents in response to media attention, a reinforcement of the need through their religious community, and a Roman Catholic opposition to euthanasia. Monica said of her parents' decision to designate their children versus each other, "...maybe they knew themselves well enough to know that there would be sequelae. There would be, whatever the memories were, there would be memories from this time. And they didn't want burdens from those memories of second-guessing."

While the intention was to prevent a sense of burden, Monica recounted experiencing a time in the hospital when she "snapped to attention" because her mother had just reminded Monica that she was the decision maker. Monica wanted to make sure her mother and brother felt included in all decisions. However, her mother was clear that

the final accountability rested with Monica. That's why she and her husband designated their children instead of each other. The "burdens from those memories of second-guessing" in this case could not be avoided, just shifted to another loved one.

Michelle said she accepted formal designation as her aunt's health care proxy "When it was hopeful that she would be fine." She said she felt "burdened" about being selected. She described a great deal of second-guessing while executing the role of SDM and said, "...we were in agreement and I didn't feel completely alone. But uh, my name was on the paper." She was not the only surrogate to express an added level of accountability because of paperwork involved in withholding and withdrawing life-sustaining treatments. Referring to a document to withhold cardiopulmonary resuscitation, Paula said, "...we all made the decision together. Which we did, but I'm the one that signed that paper." "That paper" added a sense of burden for Paula.

Patty and her husband Sammy completed living wills. They did so because they thought they should, "...do it now while (they) are both in full command of what (they) are doing...(they) were two very independent people even though (they) have three kids...it will take a lot of pressure out of the kids." Patty prearranged funeral arrangements for both of them for the same reason. It was important to Patty and Sammy that they represent themselves in the decisions that may have to, and in Sammy's case, did have to be made. They did not want to burden their children with those decisions and arrangements. However, Patty still was asked to represent Sammy. She was asked to make a decision to remove ventilator support despite the preventative effort Sammy made

to have his wishes put in writing. The health care providers sought out a person rather than a document to represent the patient.

However, not all surrogates felt a sense of burden. Buck believed he was selected as his mother's health care proxy because he was the eldest child and a compassionate man. Buck said he was "flattered". He described the reality of being her proxy as being asked to "chair the committee". He did not believe he was supposed to make decisions in isolation from his siblings. His father had suffered from Alzheimer's Disease. That had provided a context of a family history with surrogate decision making that Buck believed precipitated his mother completing the legal documentation. Similarly, Mary stated that she felt "empowered" by knowing what her mother would not want done.

Overall, the legal documents, and the level of accountability they represent, were deemed burdensome by two thirds of the surrogates formally designated and by one wife who had to sign a document to withhold resuscitation efforts. Conversely, the absence of a document was deemed problematic for one participant and a living will made another participant express a feeling of empowerment. Others vacillated between wanting something in writing and being glad they were not held to any legal documents. There was little evidence that the participant's felt completing an advance directive for himself or herself was essential. Each participant in this study worked towards and achieved family unity in their decisions. Therefore, the potential value of the legal documents in the absence of a unified decision did not present itself in this study. What was clear was the sense that people, not documents, represent the other.

The Musicians' Actual Representations Of The Composers

It was very early on in the data collection process that it became apparent the participants were doing more than retelling how they made decisions. They were continuing to represent the deceased. In seven situations, the surrogates literally showed the researcher pictures to represent the lives of which they were speaking. All of the participants told side stories that somehow portrayed the deceased before they were patients. The researcher left each interview with an image of who the deceased was and what was now missing from the lives of the participants.

The surrogates represented the deceased other predominantly with memories. The SDMs presented the deceased as people who had lived, had values, had relationships, and had personalities. Since every participant at a minimum developed tears in their eyes during the interview, and most cried, it was clear that these were memories stored not just in their minds, but in their whole being.

Michelle is a nurse. She has never been married nor had any children. She lives alone. She has two living parents and four siblings. Michelle is also a niece who decided to withhold any resuscitation interventions, nutrition, and hydration. She also decided the amount of pain medication her aunt received for symptoms experienced from a brain tumor. Michelle describes her relationship with her aunt as closer than her relationship with her mother. Michelle considers herself to be very much like her aunt. Her aunt entered the hospital system capable of making her own decisions and not knowing she had a brain tumor. The aunt never went home.

When Michelle's interview was completed, the researcher had seen a ring her aunt left her and a photograph that Michelle went into her bedroom to retrieve without being asked to do so. Michelle portrayed her aunt throughout the interview as very much like Michelle. They even shared the same birthday. Michelle described her aunt as an independent, feisty, caring, nurturing, active woman. A woman committed to her family. A woman who cared for that family even in death by leaving a surprise will in a brown envelope hidden in the leaves of her dining room table. The outside said, "My will, Ha, Ha." Michelle told multiple stories of how hard her aunt worked, how simply she lived, and how much a part of Michelle's childhood her aunt was. Michelle speaks of feeling her aunt's presence with her now and wondering if she comes to Michelle because her aunt is angry about the decisions Michelle made. Michelle's aunt was presented as a giver.

Fred is a counselor. He is a partner in a long-term committed relationship. Fred is also a son, one child from a large family, who made decisions to withhold any resuscitation interventions, remove ventilator support, and aggressively manage pain for his mother. Fred felt he and his mother had a "resolved relationship". He considered himself to be his mother's favorite child. Fred's mother had entered the hospital with an acute onset of pain of unknown etiology, but capable of making her own health care decisions. She died in the hospital eight days later from a just diagnosed cancer.

When Fred's interview was completed he had left lasting images of a stoic, independent mother of a large family. His mother was also a widow who had been married to a difficult man. Fred spoke of his mother's refusal to retire despite her

children's desires for her to do so. He told of how his mother protected and cared for an adult, alcoholic son in recent years. She had tried to get Fred and his other siblings to promise to do the same. Fred's mother was presented as a determined woman.

Camille is a nurse. She is married and has two children. Camille is also a daughter who decided to withhold resuscitation efforts, and fluid and nutrition from her father who suffered a cerebrovascular accident. Camille was very close to both of her parents. She spent as much time as she could with them. Camille had seen her father doing yard work the Friday before the catastrophic stroke that was just two and a half weeks prior to his death.

Camille showed a picture of her parents to the researcher. She left a lasting image of a strong, caring, active man who was devoted to his faith and his family. Camille's father was presented as a loving man.

Mary is a parish-worker. She is married and has two children. Mary is also a daughter who stopped resuscitation efforts and removed ventilator support status post myocardial infarct. Mary considered herself extremely close to her mother. They spent a great deal of time together. Mary's mother had her fatal heart attack on the way to mass that day. She too was completely capable of making her own decisions until she suffered that catastrophic myocardial infarct.

Mary portrayed her mother in multiple non-patient stories as well. Mary's mother was a devoutly religious woman who Mary described as, "a kind woman that just

generated fun and peacefulness. She wasn't a backstabber, she was just a nice lady and so she just generated niceness." Mary's mother was presented as a nice lady.

Tara is a nurse. She and Margaret had been in a committed relationship for thirty plus years. Tara never had any children. Her parents are both still alive, but she lost her only sister to a fatal heart attack within two years of this study. Tara made decisions to withhold further resuscitation efforts and to withdraw vasopressors and ventilator support that were in place after an attempt to surgically repair her partner's abdominal aortic aneurysm. The day before she passed away Margaret was capable of consenting to the surgery from which everyone believed she would recover.

Tara spent a great deal of time telling stories of Margaret. They were stories of Margaret's intelligence and humor. Tara discussed what pictures of Margaret she liked and what they said about Margaret that made her like them. Tara portrayed Margaret as self-sacrificing when she quit smoking because Tara had bought a new home, as funny when she was threatening to turn in the nurses for giving her an enema so late the night before her surgery, and as a woman who fought getting too dressed up. Margaret was presented as a humorous woman.

Monica is a nurse. She is a married mother of two. Monica is also a daughter who decided to withhold further resuscitation efforts and hydration as well as remove ventilator support and oxygen from her father who died from sudden onset pneumonia. She also made decisions about medications for labored breathing. Monica was very close to both of her parents. Her father was capable of making his own health care decisions until he

respiratory arrested within 24 hours of the admission to the hospital from which he never was discharged.

Monica spoke mostly of her father's gentility. She spoke of how he would visit people who had been incarcerated for embezzlement, how he helped an elderly widow with her book keeping, and mostly how he cared for his family. Monica also spoke of his lifelong battle with depression and how that impacted her decisions. She showed a picture of her father at the beginning of the interview. When asked why she chose to show the picture she responded, "I thought because we were going to be talking about him. Because um, I wanted it to be more real to you and um, I thought you might be curious; but would be too polite to ask." Monica's father was presented as a gentle soul.

Paula is a manufacturing plant worker. She is a mother of two, stepmother of two, and grandmother of an infant. Paula is also a wife who decided not to consent to a tracheostomy procedure for her husband before attempting to remove him from ventilator support. Even though Paula is only 37, she and Harry had been together for 23 years, nearly two-thirds of her life. Paula's husband, Harry, had decided to be intubated during that same hospital admission, but his condition worsened and it became Paula's decision to withhold a tracheostomy procedure and resuscitation interventions and ultimately to withdraw ventilator support.

Paula had pictures of Harry out all over her living room. She spoke of his devotion to her, his love for his twin sister, and how he raised her two children. Paula was consoled at his funeral when, "they all said that you know he really looked nice. I tried

having a good one for him and uh he deserved it. You know, he worked all those years and brought the kids up and you know he deserved it." Paula portrayed Harry overall as a hard working, caring, family man. Harry was presented as a good man.

Patty is a widowed mother of three adult children. She is a grandmother. Patty is also a wife who decided to have her husband's ventilator support withdrawn and resuscitation efforts withheld after her husband had surgery for an ischemic bowel. Patty and Sammy had been married for over 50 years. She considered him to be part of her. Patty's husband was capable of consenting to the surgery from which he never recovered.

Patty told more side stories than stories of Sammy's last hospitalization. She and Sammy were together for fifty-two years. She portrayed their relationship as playful and loving. Patty showed pictures of Sammy's family of origin. A family she hopes he is at peace with now. Sammy was presented as the missing half of Patty.

Joe is a financial professional. He is married and is a father to four children. Joe is also the oldest son who decided to withhold resuscitation efforts and stop nutrition and hydration for his mother who died of Creutzfeldt Jakob Disease (CJD). Joe speaks of talking to his now deceased mother over 20 times per day because he was very close to her when she was alive. His mother was capable of making her own health care decisions until the sudden onset of symptoms from the CJD that took her life.

Joe also represented his mother before her CJD. He portrayed her as a woman who loved life, enjoyed her grandchildren, who was "always the one to get people

together", and who was "the glue to our family." Joe's mother was presented as a much-loved matriarch.

Eileen is a nurse. She is married and has two children. Eileen is also a daughter who decided to withhold all resuscitation efforts and increase analgesic relief for her mother who had a sudden onset of severe abdominal pain. The etiology of the pain will never be known. Eileen was her mother's primary caretaker for over 17 years because the mother had had a devastating stroke. Eileen describes the difficulty of caring for her mother, but also the benefit of having her mother present at the dinner table and at every family occasion till she died. Eileen's mother was making her own health care decisions prior to that last hospital admission.

Eileen's mother was feisty. She rebelled against convention with her stubbornness. She found quality of life when and where others could not see it. Eileen represented her mother as a woman who had much more life in her than was reasonably apparent to others. Eileen's mother was presented as a fighter.

Buck is a salesman. He is a single man without any children. He lives with one of his brothers. Buck is also a son that made a decision to withdraw his mother from ventilator support after a catastrophic cerebrovascular accident. Buck was very close to both of his parents. He felt his mother had a renewed freedom in her life after his father, who suffered for many years with Alzheimer's Disease, passed away. He felt good about watching his mother enjoy that freedom. His mother was making her own health care decisions until the morning that she had the catastrophic stroke.

Buck's mother had had a difficult time when her husband was suffering from Alzheimer's Disease. After her husband died, Buck's mother was enjoying life. She loved her grandchildren and children. The one time Buck obviously was emotionally moved during the interview was not when he was speaking of making decisions. He got "a little choked up here" when speaking of how he gets sad reflecting on "all the things she gave us." In doing so, Buck represents his mother as giving. Buck's mother was presented as a caretaker.

Chrissy is a nurse. She is a never married mother of one adult child who currently lives with her. Chrissy is also a daughter who made a decision not to re-hospitalize, not to resuscitate, and then to stop antibiotics for her father who died from pneumonia in a rehabilitation center. Chrissy describes being closer to her mother than her father, but also speaks of how close her father and her daughter were to each other. Her father was making his own decisions until the one and only hospitalization of his life from which he never returned home.

Chrissy portrayed her father as independent, opinionated, not very communicative, set in his routines and anti-social at times. Conversely, she also portrayed him as adored by his granddaughter. She describes how he allowed his wife to make most of the major decisions during their marriage and how he deferred to her always to make any social plans. Chrissy's father was presented as a unique character.

Anne is a nurse. She is a single woman with no children. She currently lives alone in a state separate from her father and siblings. Anne is also a best friend who decided not

to resuscitate Rachel after she had respiratory arrested in their home, was resuscitated, and transferred to a hospital. Rachel and Anne lived together, traveled together, and shared many friends and common interests. Anne describes Rachel as part of her family. Rachel was completely independent and alert when Anne came home from work that day. She died within 12 hours of her admission to the hospital.

Anne, who had said she does not find people who want to hear stories of Rachel often enough for her liking, portrayed how Rachel lived her life consistently through the telling of her SDME. Rachel loved life, loved people, loved children in particular, loved travel, loved to work, would not compromise on quality of life, and was spiritual in her everyday existence. Anne spoke of a healing memorial service at which many people who knew Rachel, but not Anne, came up to Anne to share multiple stories. Rachel had a collection of clowns that Anne was instructed to donate to a children's hospital. Anne also made it clear during the interview that she did not believe Rachel's mother understood her daughter. Anne told a lengthy side story of another woman Rachel was close to who died a few months after Rachel. Anne cared for that woman out of respect for and in an attempt to feel close to Rachel. Anne told stories about Rachel for an hour after the interview had concluded and the recording had stopped. Rachel was presented as a lover of life.

Playing To A Different Audience: Representing Self Or A Third Person

Every story included at least one decision made by a surrogate because each

surrogate, though none of them alone, made a conscious decision or decisions to withhold and/or withdraw life-sustaining treatments for the now deceased patient. Therefore, every story also included one person, the SDM, representing one other person, the deceased. However, the decisions to withhold or withdraw treatments were not the only decisions that these surrogates made and the deceased were not the only others represented.

Nine out of the 13 surrogates in this study also made treatment decisions that could be perceived by the surrogate and/or health care team as harmful to the patient. Harmful in varying degrees, but all involving physiological interventions or non-interventions to the patients for the emotional well-being of a SDM or another family member. Throughout the SDME, the SDMs were representing the patient, but they were also representing themselves and other loved ones.

The potential harm to the patient was balanced in the minds of the surrogates by the future benefits they provided to themselves and/or another family member, thereby creating a better memory. These were self or other protective decisions. In some cases these decisions or actions were made by consciously balancing benefit to self or another against harm to the patient. In the other cases, it was a less conscious decision.

The first example of this type of decision would be Michelle's request to withhold pain medication from her aunt in an effort to demonstrate to her siblings that Michelle was not having her aunt purposely overmedicated. This was done in response to her siblings' inquiries and specific accusations that the surrogate was hastening her aunt's death. Similarly, Fred allowed his mother to have surgery despite his belief that it was not in her

best interests. Fred allowed the surgery so that he could turn to his siblings after his mother's death and say they had done everything they could.

Surrogates also shared that some delays in reaching/stating a decision to withhold or withdraw treatment were made for the benefit of the surrogate or another family member. For example, Chrissy delayed withdrawing antibiotics from her father until her daughter was more ready to accept the loss of her grandfather despite Chrissy's belief that it was in her father's best interests to stop the treatments sooner. Monica planned with the registered nurse caring for her father not to increase her father's morphine drip until her mother returned to the hospital so that her mother could be present when he died. Monica said:

> And I was uncomfortable at that time because I felt like my father needed me to up the medication because he's laboring, my mother needed me not to do that because she needs to be here. So, what do I do. So I said well, I know my father would do that for my mother. I know he would breathe hard for a long time so that my mother could be at peace.

Perhaps most dramatically, Anne resuscitated Rachel in their home even though she believed it would not be what Rachel would have wanted. She said:

> ...I felt bad even though...because I knew how she felt and even calling 911 and having her intubated. I could not call the doctor and tell him she was dead at home. I probably wouldn't be sitting here right now. I would be in (name of a state penitentiary) prison, but you know...I, I knew that that was not what she

wanted. Again I think she would want me to be safe too and covered as far as legality wise was.

Anne's rationale, like Monica's rationale, was that the patient would have made sacrifices for the other person involved in these stories.

In addition to decisions made for the benefit of someone other than the patient, there were meaning units presented about protecting oneself from future problems or from future questioning, either internal or external to the surrogate's own reflections. For example, Eileen purposely poked her mother's abdomen to make sure she winced in pain so that Eileen could minimize self-doubt. Eileen said, "...That I know because I would touch her stomach to see if she would wince and she would even under the dose of medication. Like I, it was almost like I had to prove it to myself while she was in the bed."

Paula questioned whether or not her decision not to insert a tracheostomy in her husband was in part because she had a heavy burden as a caretaker if he lived. For Tara, Margaret's family members quickly deferred to her as the surrogate despite no legal or genetic connection, and an unclear personal relationship. Tara believes they did so to protect themselves from the accountability. She said, "...I think it was easier for them to let, to be able to give that decision to somebody else...because they did it so willingly."

Overall, this insight of possibly playing for a different audience while representing other created potential conflicts for SDMs because there are multiple others, including

themselves, to represent. Again, if they were not connected to others, then they would not be SDMs. However, this insight reveals that connections to others can create conflict.

Acoustics And Other Attempts To Accentuate Sound: Seeking Resources

As the SDMs progressed through each movement of the piece they were playing, interpreting the composer's music, the SDMs sought out clinical interventions, information, and emotional support. At times, the entire orchestra played in perfect harmony. At other times, the SDMs were leading a small section playing through a transition or even playing solos. This was evidenced when 85% of the surrogates in the study talked about their role as advocate for more, improved, or different care for the patient. The SDMs considered representing their loved ones during the illness that precipitated the death as part of their SDME.

An overall impression of surrogate as advocate is portrayed. The SDMs recounted seeking resources through continued emotional expressions of anger and frustration. Once again, it is difficult to separate when they sought resources for the patient and when the resources were sought for their own comfort because the experience is an interwoven one. However, the surrogates clearly considered these advocate activities as representing the needs of their loved ones and as important during the process of making their decisions.

More Vibrato: Clinical Attention

Some of the SDMEs required the surrogates and other family members to be very assertive and resourceful. Fortunately, other accounts included collaboration and even initiation from the health care team members. In the telling of these stories the surrogates

acknowledged these acts are important aspects of representing their loved ones. They are memories of advocacy. The SDMs told the researcher about these issues without a prompt to do so because they considered this part of their SDME. These efforts were part of their attempts to represent their loved one.

For example, Paula told her story about her husband's illness and death as an almost continuous attempt to elicit more or better care for her husband. Paula reported a time when her husband's monitor was alarming and she left the room to find a nurse. She tells the story as follows:

> And that's when everything started going haywire. You know, ...the heart monitor was going off and buzzing and that's when I went and I came out there and I said "Can't you hear it?" ...he said, "Well, I should know if there's anything wrong" and I said, "That's why the monitor is going off"... And this was before I even knew what was wrong with Harry you know.

As Paula continued this story she reports having threatened the nurse by saying, "...if he dies you're going to be along side him." This situation led to a response from a nursing supervisor who approached Paula. Paula's recall of this interaction was not one of resolution or support. It was confrontational. Paula presented a distant response from the supervisor saying, "All I can remember is this clipboard."

This scene in particular had a feel like the scene from the movie, Terms of Endearment, when Shirley McLane screamed for pain medication for her dying daughter. While nobody would condone threats or screaming, it is clear from Paula's perspective

that at one point during Harry's illness she believed loud threats were her only recourse.

Camille reported that her mother would come in at seven in the morning to talk to the doctors because that is when they 'rounded' and, "...if she wanted to talk with them she would just make sure she was there." Joe said during his interview that frustration during the period of time when no prognosis was known precipitated his most assertive behaviors. He said:

> I mean I was always after them. I was over there every day. I was constantly "What have you done today?, What are the results?, What's going on?, What do you have scheduled for tomorrow?, and What's this?" Ba, Ba, ba boom (gesturing with hands in a linear forward movement).

Joe reported that he perceived the health care team members to be supportive, but he still described his approach in the following quote, "I put the pedal to the metal with these doctors the whole way through I've got to admit it." In retrospect Joe said, "They really were a great staff and great people over there...and what not, but it was frustrating for all of us. It was a particularly frustrating time because of the fact...we were not able to know exactly what was going on." They were not being asked yet to make decisions, but they felt they were there to represent their mother. That is why he needed information.

Optimizing The Acoustics: Controlling The Environment

Including Paula's attempt to get a nurse to respond to a monitor, there were seven accounts of trying to control systems or the health care providers in the stories told. These stories portray the SDMs representation of the needs of their loved one. Their inclusion of

these vignettes during the interviews means the SDMs considered these experiences were part of their SDME and that these experiences had meaning for them. Again, it is a role of advocacy, an attempt at Representation of Other, which they portray as part of their SDME.

Tara controlled the environment in advance by admitting Margaret to the hospital in which she works. During her interview she acknowledged that she was not worried about an official designation as Margaret's health care proxy. Her rationale was as follows:

> I guess what I know is that there would have been no question that we would have done that and any other legal thing that we thought we needed to do is she was going somewhere like into (large urban teaching hospital) I or to (a second large urban teaching hospital) or to somewhere we weren't connected with intimately.

The easiest environmental accommodations were references to moving the patient to patient care areas where the families could be alone and have privacy with the now dying patient (Fred and Monica).

I Want To Hear A Virtuoso: Seeking Resources Outside Of The System

Many of the SDMs (69%) specifically referred to having received resources because they had connections to members of the health care team or another health care system. They felt privileged enough to hear the finest musicians in the world, virtuosos. Some of the participants themselves identified that they wondered what people with less

knowledge or resources would/could do in the same circumstances in which they found themselves.

For example, Michelle said she advocated for her aunt to be transferred to a rehabilitation facility even though the treatment plan was hospice, not rehabilitation in nature. She felt it was important because those health care providers knew her aunt and her aunt had "loved the people there." Joe was another one of the participants who felt he had connections within health care systems. He was able to access a world-renowned neurosurgeon from a health care system outside of the one in which his mother was being treated. Joe called the neurologist from another institution directly because his, "frustration level was pretty high at that point." He spoke to this consulting neurologist on his car phone. Joe had stated, "If there were any place in the world that I could bring her I would bring her." In lieu of being able to do that, he got the best consult from outside of the institution providing care.

The Audience: To Whom Do I Represent Other?

It was explicit in seven of the study interviews that surrogate decision makers were aware of an audience watching how and what they decide. In acknowledging this, the SDMs are clear that they represent their loved one to audiences. This awareness of an audience has already been partially described in the insight that there are other loved ones for whom the SDMs altered decisions. SDMs altered decisions because they were aware others were listening and watching. Additionally, there are meaning units and insights presented as Memory Manipulations in chapter 5 that demonstrate an awareness of

audience. Examples include the overwhelming amount of participants (77%) who discussed the desire/need for family unity in decisions and the amount of participants (69%) who discussed the need not to make these decisions alone. Both of these insights generate a belief in another level of audience awareness that was present, but less explicitly stated.

Summary

The essence of what the SDME is can be described by the theme of Representation of Other. The SDMs represent themselves, the patient, and other loved ones in a variety of ways. They officially represent their loved ones in response to advance directives and the SDM role established by our society's value for autonomy and laws. In doing so the SDMs are asked to make specific decisions. However, the SDMs are not making decisions by weighing harms and benefits of an intervention the way clinicians do. They are making decisions by means of representing the other. They are representing values and whole lives led and shared.

They also represent the patient when they advocate for resources and more or different health care. The SDMs represent the now deceased patient as a person who lived a full life when they present reflections of their SDME. Long after the decisions are made and implemented, the SDMs in this study clearly continued to represent the deceased as part of their SDME.

The SDMs also represent other loved ones affected by the decisions made. They present all of these representations to various audiences. This Representation of Other

occurs during and after the actual decision-making process they are asked to complete. Chapter 5 will discuss the 'how' of the SDME by presenting the second theme, Memory Manipulation, as it emerges through the continuation of the orchestral performance metaphor.

CHAPTER 5: THE THEME OF MEMORY MANIPULATION

Introduction To Memory Manipulation

The second theme that emerged through the participant meaning units and the researcher's insights was Memory Manipulation. The highlights of this theme are represented in Figure 3. Specifically, Memory Manipulation consists of activities to reconcile memories of a loved one with a catastrophic reality, to orchestrate memories as the decision-making process unfolds, and to reconcile the surrogate decision-making experience (SDME) memories with the grief the surrogate decision maker (SDM) experiences after the loss of the loved one.

1. Reconciling memories of the loved one with a catastrophic reality
2. Orchestrating memories
3. Reconciling SDME memories with their grief

Figure3: Three Aspects of Memory Manipulation

Again, this theme encompasses more than making decisions because the SDMs portrayed more complexity in their SDME than decision making alone would have. Indeed, the SDMs make decisions, but they do so by manipulating memories as they attempt to represent the other. This experience is not inherently linear. As the participants describe their experiences it is clear that they move around in their past, present, and future more often than not. The orchestral metaphor for the essence of the experience as described in chapter 4 continues to be useful in describing the essence of Memory Manipulation. Metaphorically, Memory Manipulation efforts are a combination

of rehearsal activities, actual performances, and continue through to reviews of those performances.

Learning Through Rehearsals: Reconciling Memories With A Catastrophic Reality

Memory is defined as: "... 3. the act or fact of retaining and recalling impressions, facts, etc.; remembrance; recollection; to draw from memory" (Flexner & Hauck, 1987, p.1199).

As the participants describe their experiences, they portray a life shared with the person for whom they made life-sustaining treatment decisions. The SDMs use memories to construct or to recall substituted judgment statements and shared common past experiences. These relationships and memories set the stage for the decision-making process, the actual performance. Thus, all of the surrogate's memories of their respective loved ones serve as rehearsal time for the performance. How seriously the SDMs took the rehearsals varied because the unanticipated nature of the event meant the surrogates could not know when the performance would occur. Some of them never expected to be selected to play. They certainly did not all expect to be lead chair, but they were. Some even had to be the conductor.

The SDMs came to the SDME knowing who some of the other players there would be and having ideas of how to get the best quality sound from those family members. Some of the other players, however, were unknown such as the health care

providers. Along with conversations about advance directives or other conversations that made known substituted judgment statements, SDMs use prognostic information and decision-making capacity of the patient to reconcile what they know of their loved one, their memories, and the catastrophic reality they both are experiencing.

Selecting The Music For The Program: Advance Directives

As cited in chapter 4, the legal documents and the level of accountability they represent were deemed burdensome by two thirds of the surrogates formally designated and by one wife who had to sign a document to withhold resuscitation efforts. Conversely, the absence of a document was deemed problematic for one participant and a living will made another participant express a feeling of empowerment. Others vacillated between wanting something in writing and being glad they were not held to any legal documents. Each participant in this study worked towards and achieved family unity in their decisions.

The overall effectiveness of advance directives when SDMs are reconciling memories of their loved ones prior to a catastrophic reality and that catastrophic reality is questionable. The benefit derived from advance directives for each participant in this study was that, when present, these documents facilitated discussions. The SDM was able to use those discussions to extrapolate substituted judgment statements. Substituted judgment served as a bridge to reconciliation between memories of the loved one and acceptance of the catastrophic reality.

Following The Conductor's Lead: Applying Decision-Making Standards

As discussed in chapter 1, there are two standards for decision making. One is substituted judgment. This is the standard that states that the surrogate decides what the patient would decide for themselves in capable of doing so. The other standard is best interests. This is the standard that states that the surrogate decides for the incapacitated patient what the surrogate believes to be in the patient's best interests.

Substituted judgment, through a formal document or verbally, was experienced universally as a liberating standard for decision making in this study. The need to consider what the deceased wanted and/or would have wanted proved significant to surrogates when making decisions and after they experienced the loss of their loved one. Therefore, meaning units about substituted judgment constituted the single most prevalent insight described by surrogate decision makers in this study. Even in situations when no specific substituted judgment statements had been made, participants tried to infer the patient's wishes and not just use best interests. It was that important to them that they do what the patient would want. They accomplished this by using memories they had shared with the patient.

Most participants presented a continuum of substituted judgment to best interests as opposed to two distinct standards. Surrogates on one end of the continuum had legally documented statements and, on the other end, surrogates inferred substituted judgment statements from quality of life conversations and/or analogous situations the patient had experienced. Mary's story anchors one end of the continuum.

Mary told the strongest example of applying and drawing comfort from substituted judgment. Mary described advocating for her mother in the emergency room in the following passage, "I felt empowered by my mother. Because I knew her so well and I knew exactly what she wanted ... And she was so clear about all of that that I knew I was doing it for her...I was getting strength from her to follow out her wishes."

Michelle represents the other anchor point of the continuum. While it was true overall that there was a benefit to clear substituted judgment statements, she was the one possible exception. Michelle was in the disturbing situation of believing it was in her aunt's best interests to override her expressed wishes. However, even in Michelle's situation, an inferred substituted judgment statement from a past common experience along with a new context ultimately led Michelle to decide to withhold and withdraw life-sustaining treatments against her aunt's expressed wishes "to live".

In Michelle's own words her aunt, "...was fighting the whole time. 'I want to live. I'm not ready to die. I don't want to die'". She had consented to all treatments, including brain surgery. However, when Michelle's aunt lost her capacity to make decisions she was unable to process the new context that she had a terminal diagnosis. Michelle's decisions were to be made in this different context. Michelle had to override her aunt's substituted judgment for her best interests. What Michelle did to rationalize this was to infer from another aspect of her aunt's life, visiting another elder and ill relative years ago, that in this context her aunt would agree with Michelle's decisions. She used a combination of best interests and inferred substituted judgment to decide not to continue

treatments for her aunt. This story emphasizes the importance of context when using substituted judgment. It highlights efforts to reconcile memories with a catastrophic reality. This insight also had implications for the aftereffects Michelle experienced.

Eileen also expressed a discrepancy between what she may have thought was in her mother's best interests and her mother's choices that historically favored aggressive treatment. Until the last episode, she deferred to her mother's expressed wishes. Even though her mother had lost capacity, to be comfortable deciding to make a decision to turn to analgesic relief versus a surgical intervention Eileen looked for signs of approval from her mother. Eileen inferred a change in her mother's wishes from a change in her mother's behaviors. This attempt to find even soft substituted judgment/approval was important to Eileen.

Monica actually began the story of her SDME with the preparation of her father's advance directives. She said she felt it important to talk to him about his wishes because, "It's not a straight and simple process...we sat down together to go over his advance directive because I had concerns that he didn't know what it meant." During the course of this conversation Monica, a nurse, wanted to make sure her father understood the terminology in the document he had completed. Her conclusion from this conversation was encapsulated in her statement that she, "...felt that it was, he was, if you want to say naïve about what were the implications of the things that he had written down." However, Monica did not force the conversation with her father because doing so, "...felt like it would've been a brutal thing" and the discussion left her with some "latitude" which she

felt was not necessarily a bad thing. This entire exchange was rehearsal time for Monica. The conversation became a memory she could draw upon to orchestrate memories.

With or without formal documents, all of the participants felt they had substituted judgment statements from the now deceased that they could use as their guide. Meaning units from each participant are in Appendix H. As stated, the participants overall gave legal efforts to facilitate end-of-life treatment decisions for incapacitated patients mixed reviews about their usefulness. What was clearly a better source of solace to the surrogates were conversations that relayed substituted judgment expressions. However, to the extent the documents empower surrogates or create an environment that generated these conversations, the documents proved useful. In and of themselves, without conversations, they were burdensome. In fact, advance directives sometimes were problematic because they were completed out of context.

However, each of these participants told stories that worked toward and achieved family unity. When asked what they would have done if that proved unattainable, all of the surrogates said they would have fought to do what the patient wanted. The legal power behind that fight may have proved beneficial if that were the case. Fortunately, in these cases, there was no attempt to negate a surrogate's moral authority to decide for the deceased regardless of whether there was a legal claim to the role.

There are many meaning units that emphasize the importance of context when using substituted judgment. Examples include Michelle recalling visiting an elderly great aunt with her aunt or Camille recalling her father's response to others being wheeled into

church. These are meaning units that demonstrate surrogate attempts to reconcile their memories of their loved ones with the catastrophic reality. Those findings depict the experience SDMs have while trying to reconcile the person they know with the catastrophic reality they are currently experiencing.

A Broken String: The Element Of Surprise

Memory is defined as: "... 10. the ability of certain materials to return to an original shape after deformation" (Flexner & Hauck, 1987, p.1199).

The specific aim of this study was intended to capture a sample population that was not anticipating assuming the role of surrogate decision maker. Therefore, the element of surprise was part of the essence of these SDMEs. All of the participants in this study told of how they were in some way surprised that their loved one was suddenly ill or that they themselves had to make a decision. However, in at least three cases--Patty, Eileen, and Paula--there were opportunities to anticipate the events. Overall, the element of surprise caused urgency to surrogates' attempts to reconcile the patients they knew with the catastrophic reality in which they found themselves.

For example, Paula's husband had emphysema. He suffered a cardiopulmonary arrest the October before his December death. He was on home oxygen therapy, was followed by the visiting nurses, and took over 20 pills per day. However, Paula describes the episode leading to Harry's death with this statement, "...I knew he had a cold, that he was sick; but this was December and he always came down sick."

Paula describes her life with Harry's illness as a matter of fact. She did not realize he was dying. After he passed away she thought, "...why the hell didn't I know this...I

didn't see this coming, no." Paula was only 37 when her husband died, but she and Harry had been together for 23 years. Harry was 30 years older than Paula, but still she stated, "... you're brought up that...parents do pass away and you're not really brought up that a spouse passes away..." She was surprised that he died.

Eileen's mother had a severe cerebrovascular accident seventeen years before she died, but lived her life with aphasia and right-sided paralysis. In more recent years she had been followed for ovarian cancer, believed to be in remission; but not an unknown diagnosis to Eileen. Eileen's mother had a sudden fall and onset of pain that may have been caused by an abscess, as indicated by a very elevated white count, or by ovarian cancer, as indicated by a slightly elevated CA125 level. Eileen did not determine which was the etiology of her mother's pain because the surgeon had said the patient was not a surgical candidate no matter what the cause.

What was difficult for others to see was that Eileen's mother just prior to her fall was at the health state baseline she had had for seventeen years. The patient and her family were surprised by her sudden illness and subsequent death because they had all normalized her disabilities as their routine. Eileen described how they had become accustomed to her mother's health state by saying, "It is funny because to look at her, other people would look...let's just put her out of her misery, not knowing. Because to look, to know the pain, maybe we just got used to it."

During her interview Patty said she was surprised that her husband died. Sammy had a long medical history full of reasons why he would not survive the surgery he had to

repair his hip after he fell out of his wheelchair. However, as Patty stated, "I didn't think my husband was going to go that day. I did not because like I said Carol(yn) it was seven years and...as a matter of fact the doctor said he has got nine lives." Patty's belief that every episode was correctable was reinforced by her communications with his doctors. When Sammy spoke of dying that day, Patty reassured him that he would be fine because she believed he would be.

SDMs like Patty who expected her husband to bounce back with his "ninth life", or Paula who assumed her husband Harry just had another "December cold", had to reconcile what was really happening to their loved ones with their memories trained to see past a crisis. They had histories that included very difficult medical situations that turned around. Their experience with normalizing chronicity compounded their efforts to reconcile their reality with the new catastrophic reality. It tested the SDMs belief that their loved one could always "return to an original shape after deformation" as per the definition of memory above (Flexner & Hauck, 1987, p.1199).

The other ten participants were also surprised by the sudden onset of the respective deceased's illness. This element of surprise seemed to be influential in the time and timing of decisions made to withhold or to withdraw life-sustaining treatments. The rehearsals were over. They needed a longer time to warm up than they may usually need because they were not expecting the performance to start. It also had an effect on the second-guessing some of the surrogates have done since their loss as will be detailed in the section on sharing the SDME with others.

Overall, while trying to reconcile what they were hearing from the healthcare team about their loved one, the surrogates were remembering their respective loved one as they were just a day before. The element of surprise contributed to the incommensurable feeling between what they were being told and what they believed to be true based on very recent memories. It meant they had more work to do to reconcile their memories with the catastrophic reality.

Finding Synchronicity: Desiring A Clear Prognosis

Nine participants incorporated an expressed need for a clear prognosis as an important in the process of decision making and/or important to how they felt after the patient died. The difficulty with this is that prognostic clarity is often unattainable. However, the strength of the declared need for clarity reinforced the importance of at least acknowledging its absence and the possibility that it can not be obtained in the respective patient's situation. Some of the surrogates expressed comfort and trust in the health care team because this was communicated. It reinforces the importance of communicating the health care providers' strong desire to move toward a goal of prognostic clarity for the patient and for the surrogate. Sample meaning units from the surrogates about prognostic clarity are in Appendix J. Prognostic clarity is the catastrophic reality with which the SDMs are to reconcile their memories. It is to where the conductor is leading the orchestra.

Losing The Lead Violin: A Sudden Loss Of Decision-Making Capacity

One specific aim of this study was to capture a sample population that

was not anticipating assuming the role of SDM. Therefore, all of the deceased patients had full capacity to make their own decisions just prior to the catastrophic illness that caused their death. Just as the element of surprise contributed to the incommensurable feeling between what the SDMs were being told and what they believed to be true based on very recent memories, the surrogates also were surprised by the impact of a sudden loss of decision-making capacity. This change in decision-making capacity was discussed explicitly during their interview by seven of the participants.

The altered decision-making capacity became part of a new reality the SDM had to reconcile with very recent memories. The SDMs had to use more distant memories of their loved to reconstruct similar circumstances. Therefore, the patients' dramatic change in decision-making capacity was present as meaningful to the SDME. The SDM had to use memories of the patient making decisions to transcend the current decision-making capacity. The patient had been capable of playing first chair just recently and now the SDM had to change seats right when the conductor was walking to the orchestra pit to start the performance.

For example, Eileen spoke of capacity as a precursor to her mother's acute episode. Capacity was discussed to represent her mother's baseline medical, quality of life, choice patterns and Eileen's awareness of an audience. Of her mother's capacity Eileen said the following:

> ...she was on the floor for six hours with the kettle on and a cigarette burning and she thought that was okay. That was her choice and some people would still say

if that was the way she wanted to go. The people in the Emergency Room were starting to look at us like you've got to do something. So there was a question of her competency versus her stubbornness.

For Eileen, her mother's "feistiness" and capacity were difficult to separate.

Chrissy spoke of her father's capacity to make decisions to explain how he was, "giving (her) signs, like this is it, enough, enough is enough...", but Chrissy had to make decisions. She said of her father, "I think he understood, but he had just the effects of the pneumonia." Fred spoke of how frustrated he was that his mother had capacity for the first 24 hours of her hospitalization, but that no decisions were made during that time. He also felt powerless because no legal documentation to turn that decision authority over had been signed.

Michelle had to reconcile her aunt's expressed wishes when capable compared to the newly added context of a terminal illness diagnosed at the same time her aunt lost capacity. The proximity of her aunt's loss of capacity to the actual change in prognosis created the tension Michelle felt about overriding her aunt's expressed wishes for her best interests. Similarly for Camille, the fact that her father had capacity immediately after surgery and "gave (them) a thumbs up" added hope for her and her family. Unfortunately, her father's capacity remained difficult to assess because of his stroke and he did not have the capacity to make the final decisions to withhold resuscitation and fluid/nutrition.

It appears in Patty's situation that she may not have had to be a surrogate decision maker because Sammy had capacity till the one last decision for which he had documented

his wishes prior to this hospitalization. Patty said of her husband's consent to surgery, "In all this around my husband has known everything that has been going around. He was completely aware of everything--everything--everything." Sammy also had a living will expressing his wishes not to be on ventilator support if there was no hope of recovery. Removal from ventilator support was the only decision Patty was asked to make because Sammy had decision-making capacity until after his operation. Patty was clear that she would like not to have been asked about removal of the ventilator because of the existing document.

Anne also spoke of Rachel's decision-making capacity as part of her SDME, specifically in her situation when reconciling memories after Rachel had died. In particular, she questioned why she waited to intervene at home as long as she did. Anne did not call for an ambulance until Rachel respiratory arrested. Of that decision Anne said:

> That is why, I was even wondering...when I realized Rachel wasn't understanding what was happening to her, why did I wait for her to go into respiratory arrest. So that has, was something that I carried around for a while too that what happened would have happened if at 11 o'clock when I knew that she was not well that I should have called an ambulance then and had her brought to the emergency room. What I did instead was I waited until she arrested...when should I have made the decision that it was out of her hands to call?

For Anne, not taking over decision making as soon as she realized Rachel was not capable was something she "carried around for a while."

Perhaps the most poignant story where capacity played a role in the SDME, both while deciding and then with memory reconciliation efforts after the loss, was discussed during Paula's interview. Paula's husband was capable of making his own decisions at the time a decision was made to remove him from the ventilator. He refused to do so. Paula said of his refusal to decide:

> I explained it to Harry, so Harry understood what I was saying. I said "Harry, what do you want me to do?" I said do you want me um to put you on. I said say you say you have let them take you off of it. And I said do you want to be taken off of it? And he shook his head yes. And, I said "Well, what if you can't breath?." I said, "Do you want to be put back on it?." And he wouldn't answer me. And then the doctor asked him and as he ignored me and wouldn't answer the doctor. And then finally I asked him again and he pointed to me. And I said "Do you want me to make the decision?" and he said yes.

Paula also spoke of Harry's decision-making capacity when reviewing past discussions they had had about his wishes. The criteria they agreed upon for themselves to stop life support was if they were ever not able to understand what was happening. That did not happen to Harry. As Paula stated, "If he lost his mind, then it would've made it a little easier." Harry's deference to Paula so that he did not choose the time and circumstances of his death leaves a question in the air: Do any of us ultimately want to say exactly when we are to die?

Overall SDMs in this study are faced with unanticipated, catastrophic circumstances. Some had the benefit of substituted judgment statements and some used memories to infer substituted judgment. The SDMs then reconcile those memories with prognostic information to define their situations and options. Because of the unanticipated natures of the situations, the SDMs have to overcome the element of surprise and in some cases a pattern of normalizing chronicity to reframe this catastrophic reality as an extreme from which their loved one is not going to recover. They move swiftly, because of sudden loss of decision-making capacity, from being a musician in an orchestra that is rehearsing, to being at least lead chair in an actual performance. The SDMs now can begin to orchestrate future memories, but they return to this reconciliation work because the SDME is not a linear experience.

Time To Perform: Orchestrating Memories

Memory is defined as:"... 1. the mental capacity or faculty of retaining and reviving facts, events, impressions, etc., or of recalling or recognizing previous experiences". (Flexner & Hauck, 1987. p.1199).

A number of studies that examined factors used in end-of-life treatment decisions have been completed as discussed previously in the review of the literature. Some of those same factors appear as insights of this study as well. However, there were additional insights and insights with decidedly different meanings discussed by the participants in this study.

The SDMs portray previously established factors as part of their efforts to orchestrate memories. In this study, these insights are all considerations for the SDM as

they make decisions, as they actually perform. These factors are the basic equipment for the performance. The SDMs decisions actually create memories to reconcile after the loss.

In addition to those insights directly used to make decisions, there are additional insights that SDMs use to orchestrate memories and that are just as prevalent, if not more so, in the portrayal of the SDMEs in this study. Metaphorically, the complexity of the music affects how confident an unsure, by virtue of the element of surprise, first chair would be. Processing hope and denial along with witnessing suffering create complexity for the SDMEs. The resources sought are the extra strings and reeds necessary for the performance to go smoothly. The relationships are the other musicians with whom the SDM must play in concert, the conductor the SDM must follow, the composer the SDM must represent, and the audience for whom the SDM plays.

The established and the new insights collectively portray the surrogates' efforts to orchestrate memories. Part of that orchestration includes making decisions. However, there are multiple other insights that SDMs described as important to their SDME. The SDMs shared the memories they orchestrated. They also shared the audiences in front of which they performed as they portrayed their SDME.

Preparing To Perform: Factors Considered In Life-Sustaining Treatment Decisions

There are basic needs for any musician attempting to perform. He or she needs his or her instrument, usually a chair, the music, something to hold sheets of music, and visual access to the conductor. So too, the SDMs had basics they needed to help orchestrate their memories. Those basic needs include: (a) assessments of quality of life, (b)

explorations of personal meanings of death, (c) remembrances of past experiences with loss, (d) attention to spiritual beliefs, (e) explorations of meaning of life, and (f) decisions about the relevance of age. These insights were all established by previous research as factors in life-sustaining treatment decisions.

Assessing Quality Of Life

Eleven participants in this study specifically discussed assessing quality of life as a consideration during the process of deciding to withhold or withdraw life-sustaining treatments. As previously discussed some participants used quality of life examples to explain why they were able to infer substituted judgment decisions. One participant, Eileen, used quality of life examples to demonstrate the different perspectives that she and her mother held. Even for the two participants, Monica and Patty, who did not explicitly speak of quality of life as a determinant in their decisions; there was evidence in their stories that they considered quality of life an important issue. Additionally, many of the participants discussed their wishes for themselves or another loved one based on quality of life determinants. Sample meaning units expressed by the participants regarding quality of life are in Appendix I. Assessments of quality of life helped SDMs decide and became memories for the SDMs to reflect on after their loss.

Exploring Personal Meaning Of Death

Eleven participants spontaneously discussed during their interview either their or the deceased's personal meanings of death and what they believe happens after death as considerations in the decision-making process. Though specifically speaking of their

beliefs about death, this section is difficult to separate completely from spiritual beliefs because these beliefs can be laden with after life conceptualizations. It is also difficult to separate out the SDMs' personal meanings of death from the deceaseds' personal meanings of death because the SDMs relay their entire experience as an interwoven tale that both they and the deceased were part of together.

Two of the surrogates, Michelle and Buck, specifically stated that the deceased had a fear of dying. Michelle was concerned about her aunt's fear of dying. Michelle did not understand her aunt's fear and Michelle said of her own beliefs:

> I feel like in my head like if somebody told me I was going to die next week that somehow I could be ok with that because um its not like I have kids or somewhat, you know. I don't feel afraid to die because I think that its probably better (giggling). I think we have other lives, I think that you know. I'd like another start (laughing) a do-over.

Buck said of his mother's fear, "That was just fear of the unknown. I think she was afraid to die. She didn't want to, she wanted to live."

Fred, the only participant in the study that did not state he was Catholic, explained that he framed his surrogate decision-making experience within the context of his experience as a volunteer HIV counselor. He has been with many people who have died and as such had a level of comfort with death that he did not believe his other family members had. He also described the vigil around his mother's deathbed in the following passage:

> We had done all of the family circles and asked her to let go and saying it, we um, we had you know each one of us had said it would be ok. We had tried all the traditional and, I don't know, the methods that we know. I don't know how traditional they are.

He spoke of his mother's spirit not being in her body at that time.

Camille specifically stated that her parents were not afraid to die. She said of her parents that:

> They had lived their life well and uh, felt that there was a hereafter and they would probably see each other then. So I don't think, um they needed to resolve issues with that. So I think overall, you know I can't say it was an easy decision...but I think one ... never regretted.

Mary also presented a strong belief in life after death and found peace in her decision because of it. She said, "...the most wonderful thing for my mother and that has sustained me all this time. Even though I miss her so much. She prayed for all her elderly life that she would die quickly and not ever be a burden to her daughters..."

For herself, Mary believes her husband and her children know, "...if all means had been attempted to investigate whether or not we would be functioning people I would definitely want to go to God. They know that." Tara stated she believed that she, "will be in heaven at some point and that in some way (she) will be reconnected with (her recently deceased sister) and Margaret and everyone."

Monica discussed how the actual day of the week, time of year, and time of day of her father's death had "religious significance" for her. He died between noon and three o'clock, the time of day that Jesus died on the cross according to Christian beliefs. It was just the week after Christmas. There was no doubt throughout her interview that Monica believed in life after death.

Patty reported that her husband looked in the corner of his hospital room for an extended period of time. Patty believed he was looking at his deceased mother. Clearly she believes her husband is in heaven and acting as her "guardian angel". Joe reported, "God I say a prayer to her and I talk to her and I say I miss you Ma kind of thing and I go on." Anne joked that she thinks Rachel arranged to have John Denver die because she wanted some music in heaven. She said of Rachel, "But I think she believed there was going to be life after, well not a life but there was another spiritual world." She also spoke of being aware of Rachel's presence/spirit since her death.

Eileen did not specifically talk about what meaning she ascribed to death or beliefs in any afterlife. Chrissy said when asked that her father never talked about what he thought would happen after death and that she herself believes, "there's got to be something, I don't know what it is...Do I believe in heaven? Again I think there is some place, but I'm not actually I am not big into life after death." For these last two participants the meaning of death or any ideas of an afterlife were not part of either their decisions or their seeking comfort after the death. For the others, reflecting on their SDME includes recalling memories of their loved ones discussing their beliefs about death.

The SDMs use those recollections to determine if the loved one would prefer to die instead of live their lives given that their quality of life would change.

Remembering Past Experiences With Loss

Ten participants spoke of other experiences with loss when discussing the process of their decision making. Remembering these past experiences with loss provided context for their surrogate decision-making experience. For example, past experiences with loss were used to explain why there were advance directives (Mary and Buck). Another reason to discuss past experiences with loss was to explain something relevant about the patient's quality of life (Mary, Buck, and Chrissy). As previously cited, sometimes a past loss could be used to explain inferred substituted judgment (Michelle, Eileen, and Anne). Lastly, past experiences with loss were used to explain some aspect of the surrogates' grieving (Tara, Monica, and Paula). Eileen and Camille spoke of the subsequent loss of their second parent to compare and contrast the loss of the first parent for whom they had made decisions. For them, that meant both of their parents died within 18 months of each other.

Turning To General Spiritual Beliefs And Formal Religions

Nine participants specifically referenced their own or the deceased's spiritual beliefs as an important to consider when making decisions for their loved one. As previously discussed, some participants specifically spoke about beliefs in life after death. Nine participants also referenced prayer as an aspect of their experience during the dying process or in their grieving. In every case, spiritual beliefs were presented as a comfort to

the surrogate. Those who spoke of life after death were positive about believing the deceased is in a better situation than prior to their death.

Responding to religious personnel at end-of-life. While describing spiritual beliefs, the participants also offered meaning units about the presence of religious personnel at their loved ones' death beds. Michelle and Patty spoke of positive experiences of having priests present with their dying loved ones. Tara spoke highly of a Catholic nun who was by her side during her two-day ordeal. Similarly, Anne spoke of a Catholic nun who was very close to Rachel and who was present at the time of Rachel's death. Rachel was Jewish, but she attended Catholic masses often and was very close to Sister Claire. Michelle believed visits from priests helped alleviate some of her aunt's fear of dying. Patty said during Sammy's last hospitalization she went to confession because she questioned God sending her so much to handle. She also told of how one of her husband's physicians would bring Holy Communion to Sammy and how much that meant. She said, "...when we knew he was so sick, we, my daughter tried to get a hold of Father Steve, but they couldn't. Anyway, Father Pauley from St. Thomas came and gave him last rites." Clearly for Patty, the presence of clergy was beneficial.

However, Mary expressed mixed feelings about the presence of clergy with her mother at her mother's time of death. Mary's mother suffered her heart attack on the way to mass that day, however Mary said:

> ...in the old days,...you have a vision that we've got to get a priest. Well,
>
> ...thinking back, there was no priest. And, in the, I would have liked, I would

have liked to have had a priest there because it just would have been important to her. Not so much for me, but thinking back even further to when my father died. There was a priest right after he died and it was almost worse than having no priest because he just, it ...if you are going to be a hospital priest I think that you need to be a little compassionate. And we didn't have that sense so I guess I didn't miss it. Uh, this time.

Mary's perspective seems to highlight the variation in ministry skills and left the researcher believing Mary was neutral about calling a priest as an intervention for her mother.

Considering formal religious teachings about end-of-life. Also while depicting spiritual beliefs in general, there were two examples in the study where religious beliefs generated some disturbing moments for the deceased and/or the surrogate. Although ultimately happy that there were priests there for her aunt, Michelle spoke a great deal about her devoutly Catholic aunt's fear of dying. Michelle stated that her aunt, "...loved life. She had such a fear of death. I think...I don't know why." She said her aunt, "resorted to constant praying...And you know she reverted to prayer because she wanted to get better. I think she was terrified." Her aunt's reaction to dying from Michelle's perspective was not in concert with her aunt's life as a whole. Michelle stated:

> That I'll never understand. We talk about that in the family all the time. Why when you've never done a wrong thing in your whole life would you be that terrified to die? Why? I can't ever remember her doing anything mean or anything wrong. That you could even consider being wrong in my whole life.

The memory of her aunt's fear of dying still haunts Michelle.

A concern more directly related to a life-sustaining treatment decision was present when Buck talked about "the Catholic thing" during his interview. Buck gave two reasons for taking time to decide to remove ventilator support from his mother. One was to be sure he had done everything possible and the other was because he was not sure it was an allowable action to take according to the doctrines of the Catholic Church. Buck said:

> We realized that there was nothing else we could do. So that's when the decision was made. I think that's when we all said yes, that's the right thing to do. There is also a Catholic issue in this too. The Catholic issue is can you do that, I don't know. You know, who are you to say, to play God. I felt that was a big issue.

As the interview moved from this point Buck brought it back to this issue because the researcher had indicated the Catholic Church would support the decision he made. He wanted and received an explanation of the Catholic Church's position on removal of life-sustaining treatments.

When asked if Buck had asked for a priest to discuss his concerns he stated that, "...kids from (name of hometown) don't ask priests questions". He also said he thinks "most people feel uncomfortable with asking a priest, you know...I do personally...It would probably be a great idea, but you know its just I don't know." Buck stated he would have welcomed a conversation when asked if he would have spoken to a priest if someone had consulted one for him and his family. There was a priest present to give his

mother last rites, but neither the priest nor Buck initiated a conversation about the decisions made.

When asked if Buck was concerned about how the Catholic Church would view him or view his mother when making this decision he said, "I would think a little of both. Obviously concerned for my Mom, but the other reason you are concerned, 'gee is that a mortal sin or is that not the right thing to do?'" He was expressing feeling reassured while the researcher was explaining the Catholic Church's perspective on what decisions he had made. When later discussing if he retells this story to anyone, Buck expressed that he believes the SDME to be a very personal experience that he would not discuss readily. Despite that belief he went on to say, "I am okay with it. Actually talking to you right now is not bad. I have answered a couple of questions, but other than that I am all set." Again, he expressed relief from gaining knowledge about something that had troubled him for the past seventeen months since his mother's death. Buck had a haunting, lasting memory that had been created during his SDME.

Exploring Meaning Of Life

Three participants--Mary, Chrissy, and Monica--spoke about the meaning of life as an important consideration during their decision making and/or their grieving after the loss. These expressions of purpose were slightly different than expressions of function and activity presented as quality of life considerations. The participants again wove their beliefs in with the beliefs of their loved one leaving an overall sense of unity in this experience.

Mary stated she considered her mother's death a "triumph" not a "tragedy" because of her "full life led". Chrissy said her father would comment, "I have lived long enough, I don't know what I am doing here. What am I here for?." Chrissy resonated with her father's view that life should have meaning. Ironically, Mary and Chrissy were the only two who acknowledged age as a consideration in their SDME.

The other participant to speak of meaning of life was Monica. Monica was dealing with a separate family crisis at the same time her father was dying. Of her father's death versus the meaning of life Monica had this to say:

> A lot of the meaning of his dying is wrapped up in the broader picture of suffering and notions of whom we are to each other and what we, who we believe, what we what we do for each other. And I am in awe of what the dying process is, as well as what the living process is because there's no joy in um, in, joy isn't the right word. This, there was no, its not what you would say "well dying is one thing, but life is really truly beautiful". It was just um terrible stuff happens. And yet, the way people cared for each other was so um that was meaningful. Very. So, um, that it made me see what life is. In that, you know, new way or whatever.

For some participants meaning of life was an insight used to make life-sustaining treatment decisions, used to create memories.

Deciding The Relevance Of Age

As presented in the demographics, the mean age of the deceased in this study was 72, with a range of 53 to ninety. Only two of the participants discussed age as a

consideration during their decision-making process. They were Mary and Chrissy whose parents were 82 and 90 respectively. For both of these participants, the idea of a long life led well made it easier for them to decide not to aggressively treat their parent. Chrissy said, "But as you get into your ninth decade that's pretty good and again a full life with total health. I mean none of us could ask for more than that." Mary was slightly more hesitant admitting age was part of her decision. She said:

> You know young, younger people, it's, I don't even want to say more of a chance because then it sounds like you, the elderly people you can let them go and I am not trying to say that; but maybe I am (giggling) saying that. But I don't really mean that. Because that's something I don't want to think about...but it gives you food for thought when you're in your forties and your husband, your spouse, is going to make a decision for you and what would he do and what would I do...It does feel different. Maybe because it's the full life led of an older person.

Anne referred to Rachel's young age, 53, only in reference to why she did not push for her to document her wishes in a legal document, but did not present age as a consideration in her decision to withhold resuscitation. Overall, although well-established as a factor in previous studies, age did not contribute much to decision making for the participants in this study.

Harmonizing: Witness To Suffering

All 13 participants detailed during their interviews how they were either grateful that their loved one did not suffer or how they did witness the deceased suffering.

Therefore, patient suffering was portrayed in this study as a consideration during the decision-making process for every study participant. At times, the impact that witnessing suffering had on either their decision and/or the aftereffects experienced from having made the decisions that they made was dramatic. Witnessing suffering makes dying preferable to life. And so, witnessing suffering in an unpredictable way becomes a consoling memory to the SDM.

The continuum of this variable is anchored by the experiences of Buck and Eileen. Buck acknowledged that with a clear advance directive, communications from the physician to withdraw treatment, and a grim prognosis, he and his family needed time to make sure they had done everything possible. His mother was not suffering. Conversely, Eileen speaks of not having a known etiology for her mother's pain, but because Eileen was witnessing her mother in severe pain she agreed relatively quickly to a comfort-measures-only treatment plan.

In addition to influencing the decisions and timing of the decisions, there is evidence that having witnessed suffering is helpful to the surrogates reflecting after the death has occurred. Examples of that can be found when Eileen says, "Like I said now talking about it more I am really visualizing her pain and it's making me like, getting the inner voice that you did the right thing." Another example would be Paula assuaging her second-guessing by thinking, "And uh, but in the back of my head I say well he's not suffering no more either." Other sample meaning units about suffering can be seen in Appendix K.

Crescendos And Decrescendos: Processing Hope And Denial

Six participants spoke of hope as a relevant concept in their experience. The surrogates had to reconcile feelings of hope and feelings of denial to reach decisions. Therefore, processing hope and denial was part of their SDME. For example, Fred was frustrated by the hope offered by the medical staff. He expressed that frustration in the following passage:

> As much as he would say, "You know this is a woman who on a scale from one to one hundred, I would give a five". Um, my family would hear five. You know it's just a matter, and I needed to, for him to say, I need him to stop putting those, that context was so confusing. Because if you put a hope in there...

Fred would have preferred the medical team present five percent as not hopeful. He believed his family clung to the hope when there really was none.

Camille also spoke of the role hope had for her and her family. She told of two physicians who varied up front in their prognoses for her father. One offered "a glimmer of hope" while the other would reinforce that the family should "not get (their) hopes up." Later in the interview Camille said of the less optimistic physician and her views on hope, "Not trying to be harsh, but not giving us false hope and that actually can be a comfort, is to not be given false hope. So it worked out well with him and he like I said he was very, very good."

Buck wanted to be sure there was no hope. He didn't want to "give up" until certain. Tara said of hope in her interview that, "...something would go well for a couple

of hours and, but it wasn't really good. You know, it was just an improvement from miserable and you couldn't help but get a little hopeful, you know." It felt in Tara's case that hope had slid into a support for denial. Fred felt that way about his family's response to hope too.

Monica had a similar experience to Fred when it came to hope and the health care providers. Monica said during her interview when speaking of how she saw her father's condition versus the health care team:

> The doctor, the doctor was much more hopeful. All along (giggle). Until obviously when the doctor lost hope...I felt bad because I felt as if based on what the physician was saying that I was predicting, that I was exaggerating what the situation was. You know, so I had to sort of keep myself in check a little bit in the way I talk to her (referring to her mother) because I thought that I was not hopeful the way the physician was. I clearly was not objective either, but I was not hopeful the way he was and to me we were in a completely different arena now.

Monica did not want to be the first to give up hope for her father, but she was.

Joe spoke of hope in the context of needing a diagnosis and the trajectory of the family's experience. He spoke of first thinking that all his mother would need would be a little physical therapy. Joe then expressed that as things progressively pointed to CJD and in fact a physician he trusted called to say it was most likely that, then Joe described his loss of hope. He described that phone call as, "probably the most emotionally low point for" him. Of hope he said, "You think there's not much hope and by the time we got the

spinal tap done, again, sent down to that lab in Bethesda, we had pretty much, I pretty much knew what it was. Or at least I had a pretty strong conviction it was CJD." When that diagnosis was confirmed Joe appears to be consoled by the certainty that there was no hope. He said when speaking of continuing to treat his mother given her prognosis, "...all it would mean's a different date on your tombstone."

Overall, there is a need to examine when hope is beneficial and when it is harmful to families given what has been reviewed by way of the importance of clarity of prognosis and these expressions of the potential problems with hope. Unfortunately, prognostic clarity and determination of when hope becomes denial may be some of the more unattainable goals for health care providers. Even if the health care providers could be sure, family members varied in their response to hope.

Coming In On Cue: Seeking Validation, Emotional Support, And Translation

Even if a musician is confident that they know their instrument and the music, they still look for feedback from others who know the composer, the conductor, and/or the music. Sometimes they look toward people who are playing with them and sometimes they turn to others they assume have more expertise. So too, the SDMs seek validation from their mutual loved ones and from health care team members as they make their decisions. The SDMs in this study also reflected on specific resources that were or would have been to them to feel confident they were making the right decisions.

Specifically, the SDMs spoke of emotional resources they had or desired. They also provided many meaning units about the need for translation as a specific resource the

health care professionals should provide to them. A health care professional needs to translate terminology for the SDM just as the conductor offers his interpretation of the music for the musicians in the orchestra.

Seeking Validation

Six of the participants cited examples of when they sought or gratefully received some form of approval for the decisions they had made from a member or all members of the health care team caring for their loved one. Participants expressed their need not to feel they are making these decisions alone and an awareness of the multiple audiences, including the health care team members, they perceive are watching them make these decisions. They also discussed seeking support from personal resources as well. These expressions of approval were very important to the participants who received them. Seeking and receiving validation was an important activity during the decision-making process and they were important memories when reflecting on the SDME after the loss.

For example, Buck said of people at his mother's wake:

> ...they kind of reassure you that you did the right thing. You know, if there was a bunch of people coming up to you saying, "Gee, I don't know if you should have done that." Then you would feel bad. I don't know if people would actually do that, but everyone was very nice.

Fear of this type of response was present in other participants' interviews as well. The need for health care team members to acknowledge and support, if possible, the decision made was perhaps clearest in Paula's story. Had she not received support from

the nurse Paula considered almost a hero, then her sister-in-law's accusation presented below may not be as bearable for Paula now.

Paula had specifically asked the nurse taking care of Harry what she, the nurse, would do if she were Paula. The nurse expressed support for Paula's decision. Paula was not as fortunate with her sister-in-law who hung up on Paula during a telephone call subsequent to Harry's death. Before hanging up, the sister-in-law said to Paula, "You killed my brother." Paula's response to that was, "She put me a guilt trip on me...God forbid I cause anyone ...to pass away." She was very teary in her retelling of the telephone call and accusation.

In summary, meaning units about approval from health care providers in the SDME reflections reinforce the need SDMs have not to feel they are making these decisions alone. They also reinforce an awareness of the multiple audiences, including the health care team members, the SDMs perceive are watching them make these decisions. These expressions of approval were very important to the participants who received them. Additionally, fear of a negative response when seeking validation was present in participants' interviews. Again, the SDMs sought validation to orchestrate future memories and they use these memories to reconcile their decisions with their loss after their loved one died.

Seeking Emotional Support

In addition to seeking more attention/care from the health care team for the patient, as described in chapter 5, the surrogates also shared stories of seeking personal

resources for themselves. There was a very strong presence, 69%, in the study of surrogates either purposely seeking additional family, friends, or spiritual support and/or stating that it was beneficial to them when it was present. At times the search to find support appeared very deliberate and at other times it appeared more instinctual.

Some participants had or sought support from a professional at the time and described the difference the intervention made for them. The supports were used to reframe or reconstruct events as they happened. They ultimately optimized memories. Some participants had or sought support from a professional at the time and described the difference the intervention made for them. Others stated during the interview what they did not have, but would have found helpful during the process. Fred stated, "...I think we could have used a social worker to be more present." Tara spoke of her nurse colleague and a hospital chaplain of whom Tara said, "...I don't think she hardly ever left my side for those two days that this was all going on. Between her and Anna one of them was always there."

Mary had mixed feelings about the presence of a priest as previously discussed. Monica praised her father's primary care physician who was also a family friend, but felt physicians could benefit from more exposure to dying patients to be able to recognize better/sooner the signs and symptoms of the dying process. Paula stated, "...counselors right there or something like that you know to counsel you. I don't think they even had anybody like that. To come up and discuss anything because that is a hard decision for someone to make." Eileen thought hospice should follow patients and their families in

acute care settings. Patty praised the support of her parish priests, her children, and her nephew. Buck told the most compelling story of how a priest would have made a difference to him and his family.

Of note, specific recommendations came from five of the participants indicating that a professional, clinician or clergy, familiar with these types of decisions and dying patients would have been welcome during these times. These surrogates all decided to withhold or withdraw a life-sustaining treatments from a critically ill loved one. Using patient outcomes as a measure may not capture this need for support during the process. Clearly, those that had support believed it made a significant difference for them even though the patient died in each case. These resources transposed the music to a key in which the musician was more comfortable playing. It gave the musician confidence to perform and alleviate fears of critics' reviews because someone already said they played well.

Needing Translation

Either from a professional or a personal source, 62% of the participants specifically discussed their need for some translation of medical information. Buck and Fred reported having registered nurses in the family. They introduced this information when explaining that having these family members available to serve as a translator was very helpful in their decisions to withhold and withdraw life-sustaining treatments. Fifty-four percent of the participants in this study were themselves nurses. When asked if being a nurse made a difference during their SDME, even the participants who felt it had little or

even a negative impact reported that being able to translate medical information was an asset. Again, seeking validation and resources, including translation, provides the SDM with what they perceive to be necessary support to orchestrate better memories as they made decisions. Metaphorically, translating is the equivalent of transposing music to a key in which the musician is able to perform.

Tempo: Time

The need for time for various reasons was a recurring insight in the study findings. Nine participants in this study talked about time and timing as a relevant in the process of making surrogate decisions. Four participants also spoke specifically of a "surreal" feeling of time during this process. There were also many meaning units about the value of family "vigil" time that will be reviewed. In addition, there were meaning units that articulate a sense of loss before the time of physiological death which call into question the timing of perceiving a loss.

Time is an important aspect of being able to orchestrate memories for these surrogates in this study. Time is a very important resource sought. Imagine different musicians changing the tempo of the piece out of sync and how that would alter what the listener experiences. Imagine how confused the musicians could get.

The Need For And The Surreal Nature Of Time During A Crisis

The need for time to make these decisions was reinforced at almost every turn. Camille expressed a need for time to build trust with a physician and time needed to decide to withhold treatments. Tara needed time to recover from a sense of "shock" before she

could make withhold and withdraw decisions. Monica needed time for her mother to get back to be at the bedside for when her father, her mother's husband, died. Paula needed time to consider every option before she could let go of Harry. Joe recognized his family needed time to reach the same conclusions. Buck also needed time to be sure he wasn't "giving up" too soon. Chrissy needed time to get her daughter to accept the inevitable loss of her grandfather, Chrissy's father. Appendix L contains meaning units from each participant that highlight their reflections about time and timing.

In addition to expressions of the need for time or the need others had for time, there were four participants who clearly articulated experiencing a surreal nature of time during their SDME. Other participants had difficulty telling their story in chronological order and they struggled to remember days of the week or times of day. Overall, the linear nature of time was elusive.

The following are examples of how the participants--Fred, Tara, Monica, and Anne--specifically described this effect. While describing his mother's illness and death, a time in his life of great significance, Fred said, "It may not even have been two days, but it felt like a long time. I really wouldn't be surprised if it was only seven or eight days. I wouldn't be surprised if it might even be less than that, but I think was about eight days, could've been less." Fred was not the only participant who described an inability to recount the total timeframe of this experience.

Tara recounted:

> And it's funny because that night, the first night, um, I mean the whole thing was so surreal to me...I'm not sure that I can even, I don't know that I can put it into words. It was like, I could see me. It was really like I could see me, it was like I was outside of myself somewhat and just trying to, you know, function in a certain way like I would normally. And um, and I did for, I did a few things. Then all of a sudden, you know, I was back down the unit with Margaret. And uh, and its like somehow that, the reality kind of broke through. I had kind of kept it away. That I knew she was very sick, but I knew she was where she needed to be.

Similarly, Monica recounted her experience in the following passage:

> ...it's funny. I thought it was all very clear in my head and now that I try to say it chronologically, let's me see, he died on Friday, so they removed the tube New Year's Day, uh, I felt two things together, simultaneously like you do in a dream. While I felt that these things were coexisting...

Anne described her experience, which in actual linear measurement was a little over twelve hours, in the following passage:

> ...well actually it seemed very slow being alone with somebody who was so sick and I was very frightened because I didn't know. She had never been sick like that before. And what, deciding what to do, I sometimes think I never want to be in that position to make a decision like that. I mean just, well just like again the timeframe, when should I have made the decision that it was out of her hands to

call? ... So sometimes it seemed very, very, very long it seemed like days. Then when everything happened it happened so quick.

There was also evidence of other participants having had difficulty following linear time measured in hours or days. Camille said, "I can't remember how long that took, probably a couple of hours." Eileen said, "So, um, we made the decision, it seemed like Saturday, she went into the hospital on Saturday and she died on Monday." And Buck said "Ya, the timeframe is a little off. I am not remembering it that well. I am trying to remember how long my mother was actually in there." Chrissy had difficulty with days or even weeks of the total experience as evidenced by her statements, "...I think almost ten days, maybe fourteen...So it was a total of um, a month or maybe a little over a month."

Paula tracked linear time well because she was told Harry could only remain on a ventilator for eight days before he would need a tracheostomy. Therefore, she had to make a decision on a certain day. That organized her experience in a linear manner.

Building To The Crescendo: Vigil Time

Ten participants specifically spoke about the impact the time they spent with other people who were concerned about the patients had on them during their decision-making process and after their loss. In every case, this "vigil" time was positive in some manner. However, there were also experiences where family tensions or distrust for the health care team built during vigil activities. Again, there needed to be time allowed for these processes to unfold.

Appendix M contains meaning units from those ten participants. Some of these meaning units highlight the physical and emotional fatigue of the surrogate decision makers. Some of them highlight the opportunities vigil time allowed for people to say goodbye to the patient. Overall, they highlight the poignant moments shared at the end-of-life. Vigil time allowed opportunities for people to say goodbye to the patient. Therefore, time is used to orchestrate meaningful memories, to create lingering melodies.

Is There An Encore?: Timing Of Perceiving The Loss

Eight participants stated in a variety of ways that they perceived the loss of their respective patients at a different time than the health care team and/or before physiological death had occurred. These surrogates sometimes spoke of intuitively knowing their loved one was not going to get better or in some cases even believed their loved one already had left them. This notion of loss before physical death presented itself in the stories told by Fred, Camille, Tara, Monica, Paula, Patty, Buck, and Chrissy.

For example, Fred said of his mother when describing the difference he perceived in his mother before and after moving her out of the intensive care unit:

> ...her spirit felt present. In this room upstairs her spirit did not feel present...I really felt that this was the body that required a lot of respect, but really needed to die. Really needed to stop...I wouldn't be surprised if she was present, but she was definitely not in that body. Take it from me...

Similarly, Camille appeared to view her father's body as separate from his mind and spirit before he physically died. She described the context in which she decided not to place a feeding tube in the following manner:

> ...it was not the father that I knew that was so active. You know he was just um, just there in body; not in mind. And really that once we put the feeding tube in that was making the decision, um to really accept life at that level because then we are nourishing this body that is in this state...I think we actually got comfort in knowing ah that we were actually setting him free from that...You're grieving from the day he has the stroke.

Chrissy also said of her father's illness, "I think I knew in my head this was probably becoming um, the beginning of the end" even though she was continuing treatment at that time.

Tara said of her time with Margaret before her physical death, "...that I probably felt that she probably was dead already." Monica felt she was ahead of the health care providers in believing her father was not going to recover from his pneumonia. Monica had difficulty talking to her mother about decisions because as Monica said of herself, "I had to sort of keep myself in check a little bit in the way I talked to her because I thought that I was not hopeful the way the physician was." Monica said of her less than optimistic outlook that, "...I started to think he will not recover from this. And in my thinking was as just the daughter's way of knowing the person...You want to look into the person's eyes."

Similarly, Patty said the following despite the fact that she saw her husbands cardiac monitor registering a rhythm and all the nurse were telling her he could hear Patty's last words to him:

> ...And uh, I kept stroking his head. I said "so you hear me?" Nobody there, so we cried and Carol(yn) I keep batting, beating my brains because I don't know if he really died on the operating table...I don't know if he died on the operating table. It was quarter after eight when it just went straight line.

Paula had left the hospital to shower when Harry had become comatose after the ventilator was removed. She said that while in the shower:

> I just had this feeling that in the shower that everything was lifted off my shoulders...I just had that feeling he was going and I just, I didn't even want to you know dry my hair, I just left. I knew there was something wrong and when I walked in there, I, you know, it was only myself.

Buck, in saying the following, "I think we just realized that my mother was going or gone" also acknowledged that he lost his mother before she physically died. Overall, time has a great deal of meaning in the SDME. It is a necessary aspect of all Memory Manipulations.

The Other Musicians In The Orchestra And The Audience: Relationships

Perhaps the most obvious memory orchestrations focus around relationships. "Relationships" as researched in previous studies refers to a label, e.g. "son". Findings from this study portray relationships as intricate, multi-level, and complex insights of the SDM process. That complexity includes: (a) patterns of decision making,

(b) resolved versus unresolved natures of relationships, which include dyad, triad, families, and at times societal relationships, (c) an audience for the decisions, and (d) health care team interactions. Each transcript and the collective transcript depiction speak to an ever-present consideration of relationships before, during, and after the SDME that the participants were consciously aware of to varying degrees while orchestrating memories. Metaphorically, a single musician can not create an orchestral sound and if there is no audience, then it is not a performance.

Patterns Of Decision Making

With only one exception, each surrogate described a pattern of decision making that they either personally followed, or the surrogate/patient dyad followed, or the family as a whole followed. These patterns were important to the orchestration of memories. They are the metronomes that keep a constant predictable beat.

One example of these patterns would be Joe who when explaining how and why he advocated so strongly for a definitive diagnosis/prognosis said:

> I put the pedal to the metal with these doctors the whole way through. That is just my personality because it is the nature of the beast here (referring to his work environment). So that is what I did. I said okay let's see, let's get...what are we going to do to find out if this is it...

Joe sought facts and was relentless about doing so. It was how he always made decisions.

Monica also described her personal pattern of decision making in the following passage:

> And I guess I'd rather look back and say we all came to the same conclusion given enough time because that's my life experience and my husband and I run our marriage that way. If there is something we don't see the same way we know from years of experience if you give it enough time we will come to some conclusion that we both are comfortable with.

An example of a decision-making pattern on the dyad level would be Paula and Harry. Paula said, "You know, he knew I made decisions in the past, I always made the decisions usually...He knew I would make the right one...He knew I was telling the truth." Over the years Harry and Paula had established a relationship pattern that allowed him to defer major decisions to her, knowing she would be honest with him and trusting she would do the right thing.

On a family level, nine participants talked about close and supportive their families were. When asked what he would have done had there been family disunity in the decision to withdraw life support, Buck said, "Well, first of all there wouldn't have been, because we are not that type of family, but if there was I would go with my mother's wishes." Fred said he asked the physicians to conduct a family meeting because as he stated, "My brothers and sisters wouldn't have done that. And um, when I pushed that it brought at least a core group of people together to hear this information and ...we asked this doctor to be as clear as possible and kept challenging his hopefulness." Throughout his interview he described the different approaches various siblings would take. As a family, the pattern was established that he take a lead or consensus was unattainable. Not

breaking these patterns of decision making during the SDME is an important insight for the SDMs. Again, the SDMs were orchestrating future memories. These memories outlive the loved one for whom they are making decisions.

Playing In Harmony: Natures Of Relationships

Every participant referenced their relationship with the deceased and/or another family members' relationship with the deceased as a significant insight that contributed to their decision-making process. These relationship insights present as an influence on either a decision to continue/withhold/withdraw or in the timing of their decisions. There are multi-leveled relationships presented by the SDMs in this study. There are: (a) dyads, (b) triads, (c) families, and (d) societal relationships. At times, there were concurrent family crises that impacted the SDME. There are meaning units that led to an insight that no SDM wanted to make a decision alone. Every participant also discussed the relationship with the health care team as part of the overall SDME. Five of the participants specifically referred to the patients' and/or the surrogates' relationship with the health care providers caring for the now deceased patient as having impacted specifically on the decisions made. Lastly, there are findings that portray an awareness of audiences with whom the SDMs perceive they have had, do have, or will have relationships. Examples of each type of relationship and its influence on the SDME follow.

A dyad relationship, duet. Eileen described her relationship with her mother as difficult because of the seventeen year long need for care after her stroke. She stated, "It was a lot of work to take care of (her) mother." Because this was the relationship

dynamic at decision-making time, Eileen now expresses concern that she may have had a conflict of interest in fulfilling her role as surrogate. As Eileen stated during her interview:

> So sometimes I think the person that has done most of the care taking should be the one making those decisions because they have been there, but when it...I think being human I say "Did I do that just to put me out of my misery?". Which like I said, maybe two percent of me feels that way.

In this particular case, the nature of the relationship affects the surrogate's feelings after her mother passed away. To the extent that surrogates seek to avoid these feelings, this type of unresolved relationship could prevent surrogates from making withhold/withdraw decisions. At a minimum it is something health care providers should be aware of and work through with surrogates.

A triad relationship, trio. Michelle described her relationship with her aunt as very close. Michelle's relationship with her mother, her aunt's sister, and the two sisters' relationship had an impact on what Michelle felt free to do for her aunt and how she feels after her aunt has died. Michelle believed she was asked to be her aunt's surrogate because the two of them were so much alike. During her interview she told of how important family support for her decisions was to her. Michelle discussed the problems she had during her aunt's illness because Michelle's mother would not participate in the decisions. Michelle said of her mother:

> You know she made every excuse in the world not to go in. And then one Sunday she went in and she couldn't look at her. She couldn't stand it you know. And

ugh, she's never accepted this. Never. Not even at the wake. ...so, that's why. It was like losing her mother all over again. You know. So, ugh I had a lot of doubts.

This triad relationship still has implications for Michelle and her mother. Michelle said later in the interview, "I actually used to cry for my aunt when I was a little kid. And my mother never forgot it." Balancing the dynamic between the two sisters and their respective relationships with Michelle was clearly something she was aware of while trying to make decisions for her aunt.

"Family" relationships, ensemble. Fred explained the different views his family members held at the beginning of his mother's hospitalization as resulting from the nature of the relationships in question. During his interview he shared the following belief he holds about one sibling who was more resistant than Fred to withhold or withdraw treatment:

...he had struggled a great deal with my mother. I was the favorite child of my mother and he was the favorite child of my father and we were played against each other and had a lot of unresolved anger about it...and he had to deal with the dying and his inability to really even participate without really being lost in his own emotions.

Conversely, Fred felt he was able to, "experience this whole thing differently." He described his relationship with his mother and her death in the following statement, "... my experience with my mother and my relationship with her was resolved...there was dealing

with all of my personal loss, but there was no great feeling of loss...it felt like a life lived that was over." While his brother believed his mother had more work to do before dying, Fred was comfortable she had lived a full life. Therefore, Fred believed the root of the discrepant views is in the nature of the different relationships, specifically his brother's need to resolve his relationship with his mother before she died.

Fred also acknowledged that different perceptions existed with more than just that one brother. He believed withhold decisions were appropriate for his mother almost immediately upon her admission to the hospital. The time needed to decide to forgo life-sustaining treatments was longer in Fred's mind in order to preserve or restore relationships that would outlive the patient for whom decisions were to be made. Fred stated, "It was really important that we work together and collaborate and care for each other through our decisions." These sentiments repeat themselves as important when issues of time and family unity are presented.

To the extent that surrogates seek to reconcile relationships and avoid ill feelings after the loss, this nature of relationships could slow or prevent surrogates from making withhold or withdraw decisions. One example would be Eileen who described her relationship with her mother as difficult. Eileen now expresses concern that she may have had a conflict of interest in fulfilling her role as surrogate because of her role as caretaker. At a minimum it is something health care providers should be aware of and work through with surrogates.

One percussionist keeps playing off beats. In addition to family issues directly related to the decisions at hand, seven participants told of problematic family dynamics that were either happening when the deceased suddenly became ill, or were dormant; but became active because of the catastrophe, and/or were at a minimum highlighted because of the crisis. These dramas were invisible to the health care team caring for the deceased. While invisible to the health care team, they were very visible and significant to the surrogate who made the decisions. These issues were part of the decision-making process. These dramas accounted for some of the time needed by surrogates to decide. Time needed to orchestrate future memories.

The first example of the subtle effect family dynamics can have on a surrogate is Michelle. Michelle told of her mother's inability to accept the impending death of her sister because of a dependent history between the two sisters, Michelle's aunt and Michelle's mother. Michelle said of her aunt, "This aunt took care of my mother her whole life. You know, so that's why. It was like losing her mother all over again. You know, so ugh, ya, I had a lot of doubts. What if this is the wrong thing to do?" Michelle was trying to have a meaningful goodbye time, but her mother's reluctance to accept the inevitability of a loss was part of Michelle's experience of surrogate decision making.

Other subtle family dynamics and their influence were told in Mary's and Camille's stories. Here they both spoke of being one of two children and the need to balance long standing sibling issues against the impact of their decisions on the patient. Camille spoke of tense moments between her and her sister because of her sister's history of dependency

on their father and what Camille perceived was a subsequent inability to let him go. She described the need for the physician to spend extra time with her sister to make her more comfortable with a decision not to provide artificial nutrition. She said of this time:

> ...when my father's physician came back from China, the nurses must have gotten to him. Because, either that or he is extremely perceptive. Because his first meeting with us, and as I said he sat down with us for probably almost two hours. He singled out my sister and said "Anne I can really perceive you are having a hard time with this and I can tell a lot of things". And he spent quite a bit of time just giving her personal guidance about emotions dealing with the death of a parent, uh and really assessing where she was at, offering her um, some guidance for counseling after this was over.

Fred told of a more obvious influence on decisions made when he talked about his brother who was in an alcohol rehabilitation center at the time his mother suddenly became ill. Fred spoke of how his brother could only be present in limited timeframes because of his treatment plan. He also spoke of this one sibling's influence on the legal course of this experience. Of this brother and his mother, Fred said:

> However, she had no power of attorney. No anything written. And it, she would not agree to anything unless we agreed to take over care of him. And for lots of reasons, many of us philosophically thought that was inappropriate thing to do and um, nobody wanted to take on that responsibility. So we didn't sign any of that stuff.

Additionally, Fred stated his original agreement to treatment and the time needed to agree otherwise was because of this brother. He said:

> ...he still continued to want to do that and um, so we decided with his feelings, strong feelings about it, we decided to do it. And so we went through the operation...And the idea of the dying and he had to deal with the dying and his inability to really even participate without really being lost in his own emotions.

Similarly, Mary's mother had not specifically assigned a health care proxy, but had listed Mary's brother-in-law as her power of attorney over her property. Of this decision Mary said, "...because she knew I had a stronger self image she always gave those kinds of designations to my sister. Because she knew it wouldn't upset me, but it would upset my sister if I were in that position. So, so I could, you know I could tough that out."

Monica, like Fred, was dealing with a concurrent addiction problem with another family member. In this situation, it was Monica's sister-in-law who was addicted. This meant that Monica's brother could not be as present with Monica, their mother, and their father as he would have otherwise been. Monica stated the following when describing trying to balance her brother's physical absence with Monica's need to have him be aware of decisions regarding his father's care:

> You know, we weren't keeping stuff from him so we didn't have to deal with his upset if he wanted us to do something different. But, we did delay a little bit until my mother and I had really hashed things out and got the information that we

needed. And then we talked with my brother to let him know what we thought we would like to do.

Later in the interview Monica also said:

> ...We were a little uneasy that he might, because he was in such a difficult place with um, his family right then; we were a little concerned that this might be too hard for him or we didn't know how he would manage this extra load to know that his father, now, you know, would die.

None of her father's health care providers, even a physician who was also a trusted family friend, was aware that their patient's daughter-in-law was struggling at the same time.

Overall, Monica said the following to describe the impact this second family crisis had on her surrogate decision-making experience:

> ...And so he (referring to her brother) couldn't be there, so my faith, my mother's sister, went to be with him and his children and care for them and that overshadowed all the rest. Because, it's a very caring family, and it would be, like I said my mother would leave her husband's death bed, go leave to take care of a grandchild. And dying was second to what looked like an episode that was really going to break up a family. And separate parents and children.

Paula experienced what is probably a reasonably common family dynamic. Her husband Harry had children from a first marriage. Here the second wife decided to withhold and withdraw life-sustaining treatments from a father of children who are not her children. Paula attended to this potential problem by calling those children to come be

with their father, witness his suffering, and hear straight from the physicians that Paula had exhausted all alternatives for their father. In her attempt to orchestrate memories, Paula said of Harry's daughter:

> And she was the only one that hadn't seen him...I asked his daughter to come up and she was telling me no, that she couldn't handle it, you know. And I said well I want, I need you to come up. He's waiting for you. And you know, I said, you know Diane you probably wouldn't live with yourself if something does happen.

Overall, these additional family crises added complexity to the SDMEs. Time was needed and personal resources expended because of them. They required the SDM to orchestrate even more complex dynamics than the health care providers ever knew.

Relationships within our society. On a larger scale, Tara "still feels bad" about the last chance she had to say goodbye to Margaret. They were same sex partners for over thirty years, but Tara believes very few people knew then or know even now the nature of their relationship because neither she nor Margaret wanted to declare themselves as a lesbian couple. The nature of their public relationship impacted this SDME and the grief experience for Tara. When Margaret was being wheeled off to surgery, Tara was aware that there was an audience for their goodbye. They had decided that their relationship was not for public knowledge, but that going to the hospital for which Tara works was the best thing to do for Margaret. Their goodbye was altered from what Tara had wanted because of that choice. She stated:

...so I walked out to the elevator with her and I said "I'll see you when you get back"...I mean, our personal life is our personal life and it never has entered into my (name of hospital) life at all...very few people knew the what our relationship was...I just really wanted to give her a kiss you know, going up to the OR, but we're in the hallway and there's a courier...So I gave her a little kiss on the forehead and said "good luck" and you know. But...that, I still feel bad because I thought she'd be back.

Margaret never regained consciousness after her surgery. Tara spoke through tears of how people are reacting to her mourning out of context and not understanding the depth of her loss. Their relationship was unresolved on a societal level. The implications for Tara's decision making were that she had not publicly or legally claimed the moral authority to decide for Margaret.

The audience. It was explicit in seven of the study interviews that surrogate decision makers are aware of an audience watching how and what they decide. This is an added complexity to the relationships involved in the decision-making process because the surrogates were protecting their relationships with respect to a variety of audience responses. Audiences not always known to the health care team.

This audience awareness was described in the examples given above concerning unresolved and resolved relationships and their impact on the process of surrogate decision making. There are other examples described in chapter 4 with regard to whom do SDMs represent the other. The last examples to cross-reference as evidence of an

awareness of audience is described in the section to follow on reconciling SDME memories after the loss. The overwhelming amount of participants (77%) who discussed the desire/need for family unity in decisions and the amount of participants (69%) who discussed the need not to make these decisions alone generates belief in another level of audience awareness that was present, but less explicitly stated.

Overall, whether at the surrogate/patient dyad level, a triad, a family, society, in front of the health care team or not, relationships are the predominant reason memories were orchestrated. At some level, and at various times, the surrogates accept that the patient is not going to survive this experience. That is evidenced in insights such as timing of perceiving the loss being before physical death. It is also apparent in the portrayal of decision-making patterns, validation and resource seeking behaviors, self or other protective behaviors, expressed need for time, and awareness of audiences. There are other relationships that do survive this loss and at times that idea is what the surrogate appears to be thinking about when making their decisions. They appear to be orchestrating memories.

No Solos For Me Please!: Not Deciding Alone

In addition to the influence of individual, dyad, triad, and family dynamics, eleven participants articulated how important attaining family unity was when they were making life-sustaining treatment decisions. Eight participants were explicit about not wanting to make these decisions alone. Therefore, the insight of achieving family unity during the decision-making process to preserve the relationships after the loss was clear in the study

findings. This sentiment seemingly was present irrespective of a formal designation as the surrogate or not. There was a declared need to have someone else that loved the patient agree that the decisions made were the right ones to make.

Camille articulated a good representation of the feelings about family unity when she said, "We didn't really have incongruity in making the decision. That was lucky for us. We were all in agreement. Had we not been it probably could have been very different."

Michelle, a legally designated proxy, said that one of her sisters was particularly helpful to her during the process. Michelle said of that sister, "And she was in it with me. You know. She, we were in agreement and I didn't feel completely alone, but uh, my name was on the paper (laughing)." It was important to Michelle that her family understand what she was deciding and why. That was why she withheld that dose of analgesia as previously described.

Eileen shared a similar need to have her sister support her decisions. Eileen said of her father's deference to her as the decision maker, "The family trusted me, which was kind of hard because what if I made the wrong decision, although they were comfortable, because of her condition." Of her sister's presence to assist with the decisions Eileen said, "I had to bounce it off of her. Yes, I did. I couldn't have done it alone. Well, you do whatever you have to do, but it was helpful to have somebody else there."

Fred said, "It was really important that we (referring to his family members) work together and collaborate and care for each other through our decisions." Similarly, Mary

expressed that she really wished her husband had been present with her in the emergency room when her mother was being resuscitated. When asked what she believed his presence would have meant to her she responded, "Well, I think he would have been, he's a great emotional support to me. Um, he also knew what my mother's wishes were. There was just no question. She told as many people as she could." She wanted her husband's validation that she was doing the right thing.

Tara told of calling Margaret's siblings into the hospital when, "things weren't looking really great." She said of their inclusion in her decision making that:

> ...there was a part of me that although I knew you know that it was really my decision to make, uh, I mean I did talk it out with them because I didn't want to have at some point later. You know, any sort of feeling about they didn't get a chance to give their input or whatever, but it that wasn't the case and it hasn't been at all that way.

Similarly, Buck said he would have waited for all of his siblings to be present when the decision to remove ventilator support was made. Buck replied with, "Yes, oh definitely. You can't do that", when he was asked if he would have waited for somebody if they had been missing.

Paula made sure her stepdaughter came up from a state in the South to be sure that Harry's children were present for decisions. She had the physicians repeat all information in front of Harry's children. It meant a great deal to Paula that her brother championed her

as having made the only decisions possible. Paula said the following about the conference between the physicians and all of Harry's family that she had orchestrated:

> You know, he (referring to her brother) said, "My sister did have everybody take a look at him and see what options he had have. You know she was trying to get either that or a heart donor or a lung donor or both and you know there was nothing more they could do for him." And uh, I told her (referring to Harry's daughter) what my decision was and uh. You know, I wanted their support.

Monica detailed quite a few times when she solicited her mother's feedback about decisions even though Monica was a legally appointed surrogate. She said the following of one specific time:

> And because when she would give me any kind of indication that she wanted me to do it or her, I would remind her that she, this was her spouse and that I was there to support her and help her; but I didn't want to do things that she what she would want only just if it was too hard for her and she wanted to I would step in and help her with her decisions.

She also spoke of great efforts made to include her brother who could not physically be at the hospital as regularly. Of her need to incorporate them Monica said:

> And we said enough in the end to my brother that um, he um, I guess he would've made the decision. We said enough to him that we were comfortable that given the information that we had, that he was on board...so that we were the three of us all on board.

Other examples of the need for family unity have declared themselves in other sections. As previously stated none of the SDME reached a point of intractable conflict. Family unity was achieved for all eleven participants that sought it. The memories were orchestrated to be shared memories.

The Percussion Section: Perceptions Of Health Care Providers In Memory Manipulation

Participants in this study portray health care providers as an important part of the process they went through while making decisions. They are the people from whom clinical information necessary to consider the other insights, for example quality of life or the patients' prognoses, is provided. A beginning understanding of SDMs perceptions of health care providers was presented already in the sections on seeking resources and validation. The SDMs describe health care providers as villains, heroes, and everything in between in their stories.

Health care providers can create either protective memories or harmful memories for SDMs. They maintain the cadence and keep the beat while the strings play the melody. The meaning units and insights that follow support that SDMs want health care providers to: (a) serve as arbitrators if necessary, (b) use their clinical judgment, and (c) control the environment when possible and as necessary. There are findings that suggest communication, compassion, and trust facilitate the SDMs trying to orchestrate and protect memories. Health care providers need to avoid actions that can be perceived as abandonment or neglect. Continuity of care is also something SDMs express as having meaning to them. Afterall, how many providers can the SDM remember?

Arbitration: "...There To Give Clinical Evidence"

One role that health care team providers may be asked to assume is that of arbitrator. In these SDMEs, family unity was deemed essential and fortunately achieved. Participants were asked what they would have done in the event consensus was not achieved. Three participants--Michelle, Monica, and Paula--all specifically said they expected that the health care team would be asked to present the case and decision as theirs.

Michelle talked about giving her family journal articles to read that supported her withholding fluid and nutrition from her aunt. She also stated that the family meetings were very important in providing support to her decisions to stop treatments because as she said, "...And somebody else is saying so. So its not all on me." Monica said, "...although I haven't really thought 'Well what would I have done if he (referring to her brother) had disagreed?'; um, I guess maybe I would have fallen back on the clinicians who were there to give clinical evidence." And Paula specifically scheduled a meeting with the physicians, nurse, her brother, and her husband's children from his first marriage so that the children could hear from the physicians that Paula was making the "right" decisions.

Clinical Judgment: "I Don't Think That Was Fair"

The role of surrogate decision maker exists to support the American value for self-determination. The SDM role is designed to represent the now incapacitated patient's value system and wishes. As portrayed in the legislation or court cases reviewed in

chapter 1, the role of SDM was not intended to replace the health care providers' clinical judgment. Unfortunately, it appeared in six of the study interviews that clinicians asked, or at a minimum allowed, surrogates to make clinical decisions. SDMs appeared to accept responsibility for these decisions in an attempt to orchestrate memories. However, these insights created difficult memories to reconcile after their loved one died.

For example, Michelle decided what medication levels were necessary to manage her aunt's pain. Tara stated that, "They (referring to the physicians) didn't see any point in going on, but they would if I you know, if I wanted them to." Monica was asked to assess her father's labored breathing and determine if morphine should be increased. She was also left responsible for oxygen rates.

In Eileen and Patty's cases, the possibility of clinicians' abdicating their clinical decision making role felt burdensome. Eileen realized during the interview that she was being asked how aggressive she wanted to be about ending her mother's life. Previous discussions felt like they were focused on how aggressive Eileen wanted to be about saving her mother's life. Once decisions to withhold any interventions were made, the health care team asked Eileen how much pain medication she wanted her mother to receive. Through tears Eileen said, "So why should we have to be asked do you want comfort measures? We should be told we are going to do comfort measures."

Similarly, Sammy and Patty had completed living wills that stated neither of them would want to be on a ventilator if there was no hope of recovery. When Sammy came out of a surgery during which it was clear to the medical team there was no hope of

recovery; Sammy's wife Patty was asked if she wanted her husband left on a ventilator. Through tears, Patty stated to the researcher:

> ...I said I don't think that was fair for him to say that. I really don't Carol(yn), I don't think that was fair. He shouldn't have said that to me, "Do you want to see him on a respirator?"...I want to remember my husband lying in that bed and nothing...because he hated the mask on his face...

Embedded in study interviews were situations where perhaps the clinicians could have better prepared the surrogates for what to expect. There were two specific references to how death is portrayed in the media. In these two cases, Paula and Monica, the deaths they were present for were not what they had expected. Monica was concerned that her decision not to provide hydration may be adding suffering. The research on fluid and hydration studies could have been supportive to her at that time.

Paula was surprised that her husband lived, but did not recover when the ventilator was removed. She stated in her interview, "He ended up going into a coma. And its like 'now what?' ...I don't want him to be a vegetable either ... 'what did I do wrong?'" She was not prepared for the possibility that he may breathe off of the ventilator for a considerable period of time. Paula would have benefited from more instruction, more rehearsal time.

Environmental Control: "Landing Peace"

As discussed in the resource seeking section, several of the participants talked about different activities they undertook to manage the environments in which their loved

ones died. The clinicians in several of the stories also controlled varied environments. There were attempts made to secure privacy for dying patients, to accommodate large families, and to minimize interruptions. Unfortunately, there were also examples of situations that needed attention to the environment. These meaning units are bad memories for the SDMs.

The most dramatic example of this is embedded in Monica's experience. Monica described having been present while her father experienced a respiratory arrest and was intubated. The sheets were quite bloody after the intubation. The event was traumatic for Monica who was present during the resuscitation effort and for her father. After transferring him to the intensive care unit, the bed upon which he had been intubated was left in the hallway. Nearly twenty-four hours later, Monica and her mother were sitting on those bloody sheets, on that bed, in the hallway to discuss with the physician the new goals of care. In Monica's words:

> ...it's gross because they pushed the bed that he had been on out into the hall. And they left it there for a long time. And it was soiled. It was stained with this bloody fluid and it was still there when I went the next day. It was still there with these bloody pillows in the hall...a reminder of this episode and she (referring to her mother) didn't know they were his pillows, but I did. We were sitting on the bed because there was no place else to sit while we were waiting for the doctor to come in and make some more decisions and fill us in.

The other environmental issue that should be considered is the issue of the need for a high technological death. Five of the participants told specific episodes that involved technology at the time of their loved one's death. They reported watching numbers on cardiac monitors, ventilators, and pulse oxymeters. Paula stated in her interview that, "...the hardest part was his daughter when the monitor was first going off and before he went into the coma. It was like his daughter actually wanted to go and get help...It was like 'Diane, you know, just let him go.'" Although decisions had already been made not to intervene, the patient remained on a technological assessment tool, the cardiac monitor. When it alarmed it may have been appropriate prioritizing that no clinician quickly responded, but the patient's wife was left to justify inaction to the patient's daughter.

Buck told of the exact moment his mother died in the following description, "Yes for some reason I remember eight minutes. I looked at my watch or something like, right before it. I just thought it was quick for a life and then no life, you know. That was horrible seeing that." Buck did say that he believes they were asked if they chose to have the monitor removed or not. In both cases, the monitor was a source of distraction from the actual patient in the bed and perhaps even a source of added stress for the families.

Patty also watched her husband die while on a cardiac monitor. She stated in her interview, "I kept stroking his head. I said do you hear me. Nobody there...It was quarter after eight when it just went straight line." Patty is still "beating (her) brains" about when her husband "really died". Witnessing the cardiac monitor does not console her that her husband ever made it out of the operating room.

Monica described the difference she felt when she was turning down and then turning off her father's oxygen. The quietness of the room when the oxygen was turned off was described in her statement, "...like when you're on a jet you know and you hear all the noise, but then they cut back the engine...The room is becoming quiet, now maybe peace is coming." For Monica, her mother, and her father, the removal of the technology created a feeling of "landing peace".

Fred described the difference it made to his family that his mother was moved out of the intensive care unit when her death was deemed imminent. He said:

> ...when we felt most cared for as a family was when we were brought up onto that floor and um, given this room and the nursing staff who were able to, periodically, quietly come in without a whole lot of chatter, without a whole lot of interruptions. Just, they created a very caring and quiet important space.

These patients all had restrictions on life-sustaining interventions established before they died. Their deaths were anticipated and deemed imminent. What the patient would experience during their dying process was not clearly presented to families present to bear witness with their loved one. Again, more direction from the conductor may have been helpful.

Communication, Compassion, And Distrust

Eleven participants portrayed the impact communications with health care team members had on their process of making decisions. The other two, Tara and Joe, spoke highly of their overall exposure to members of the health care team. It can be reasonably

inferred that the communication was good in both of those experiences. In addition, specific attention to trust and compassion is described when the SDMs talk about communicating with various health care team members.

Communication. Michelle spoke of the importance of a time when the whole family could meet with the medical personnel and hear the same information. She also spoke of how disconcerting it was to overhear the medical staff speaking of her aunt's diagnosis in ways the family had not yet heard. The following two passages capture Michelle's mixed experiences with communication:

> 1. I'm glad we had the meeting. What helped a lot was that family meeting that we had with the oncologist. He pretty much reassured us all that she was terminal and there was no ifs, ands, or buts and there was no hope...
>
> 2. ... when you are sitting there visiting her and they were making rounds, you could hear them "eighty year old lady with metastatic breast cancer". Everybody presented her like that. Her chart said that. Where was the evidence that she ever had breast cancer? Who knows?

Mary also gave the health care providers who cared for her mother mixed communication reviews. She said the physician was "detached", the nurses were basically absent from communication, and the emergency medical technician (EMT) was her favorite member of the team. The EMT went out of his way to let her know that he had put his full effort into the resuscitation. Mary said of his approach to her in the emergency room, "And I, I remember, and till this day I've wanted to write him a letter to thank him

for that. Because it just, he was the embodiment of all the EMT's tried to do, and all those jobs are so hard."

Monica witnessed a bad team effort during her father's respiratory arrest and intubation. She also perceived that the hospital had fewer than usual staff on because it was a holiday season. Monica said of the team having witnessed the respiratory arrest rescue, "They were short staffed. They didn't know what they were doing. They didn't want to get sued." Conversely, she spoke very highly of her father's primary care physician, a personal friend, and of the nurse present when her father passed away. Monica described the nurse as "God's gift of a nurse". She described both of these two professionals as compassionate and attentive. Monica specifically said that her relationship with the physician was important in her decision making because she followed his recommendations because she needed "cooler heads to prevail." She described in detail how the nurse partnered with her to orchestrate her father's death, including the timing that allowed her mother to be present.

Fred expressed frustration with how the health care team presented what he considered to be too much optimism. He said, "...the medical care providers had a very hard time being straight forward with their answer without putting a uh, 'Well if we did this or that' just some little ray of hope." Fred reported that it was he who initiated a family meeting because he felt it would be important. He was not sure that the medical staff would have done so without his prompting. He expressed distrust in the physician because Fred and other family members believed he had ignored early warning signs of this

illness. Fred said, "He also had not paid attention to these symptoms. He had not. You know he had not done it until, there was a lot of anger towards him."

Eileen felt that it would have been helpful if the health care providers had expressed their opinions more clearly and made her feel less like there was a decision to be made. She said,

> ...maybe, well they did make that suggestion. "Do you agree with the suggestion?". You know what, not having a really big rapport with this doctor, I knew him from working and I thought he was pretty good, but it wasn't like I had like this big relationship with him. So that made it difficult too...So why should we have to be asked "Do you want comfort measures?" We should just be told we are going to do comfort measures.

Eileen did find the nurses supportive of her and her family after a decision was made. Of the nurses' non-verbal communication she said, "...you can just see it in their eyes. They would reassure us that we made the right decision. And that the main goal was to keep my mother comfortable."

In summary, every participant in the study discussed the nature of the relationship that they or their loved one had with the health care providers caring for them during their hospitalizations as an important part of the SDME. They became memories. Six participants described very positive, trusting relationships. Four participants had neutral relationships with the health care team members. Four, one who had also described a very positive relationship, described very bad; antagonistic or non-trusting relationships with

health care team members. The very positive relationships helped guide surrogates toward treatment decisions, the negative relationships appeared to delay decisions because of a lack of trust, and the neutral relationships declared a void in communication and heightened the surrogates' perception of self as advocate. Metaphorically, some health care providers played well and/or conducted the orchestra well, but some did not.

Communicating specifically about the decisions. Not every participant could be very clear when recounting specific surrogate decision-making conversations with health care providers. In fact, the health care provider initiated only three of the thirteen life-sustaining treatment decisions communications. Five other participants reported that the conversations were collaboratively initiated. The last five participants reported that the surrogate initiated conversations themselves. During the interviews four participants--Tara, Monica, Paula, and Eileen--did not consider their withholding of life-sustaining treatments to be part of their experience until prompted to discuss that. They immediately went to the withdraw decisions that they made.

Anne told of how every physician, nurse, and respiratory therapist who came in to see Rachel, also was attentive to Anne. They acknowledged her presence, the strength of her relationship with Rachel, her work as a hospice nurse, and her pain. She stated during the interview:

> ...they were all wonderful I must say. ...I know we've been told you are a very good friend of Rachel's...Oh I'm telling you a better experience...if you can go through that kind of experience...and I never felt we were in an intensive care unit,

never. ...They loved her there. So that love was just there constantly for twelve hours.

She told one particularly poignant moment when one physician said to her, "...you do this everyday and now you have to deal with this now." Anne felt supported by that and other statements that validated to her that the health care team was aware that she was watching someone she loved very much die.

Specifically related to her decision not to resuscitate Rachel, Anne stated of the primary physician:

> ...he knew her whole story and knew what Rachel would have wanted too and he decided not to code her...and we talked about it. You know I said Rachel you know would not have wanted to be resuscitated....he came and sat with me for awhile and we just talked...

This long-term relationship between Rachel and her physician, Anne's knowing him prior to this acute episode, and the support extended during this difficult time all helped Anne reach a decision for Rachel quickly and comfortably.

Conversely, when there were bad communications or relationships with health care providers; then distrust seemed to slow down movement toward the decisions eventually made. For example, Buck spoke of a significant level of dislike for his mother's physician. This dislike appeared to have delayed his family's decision to remove their mother from ventilator support. Buck said the physician did not know his mother well before she had

this catastrophic illness. He described the communication about withdrawal of ventilator support as follows:

> So the doctor was kind of pressuring us to abide by that (referring to an advance directive)...I just didn't want to give up...He brought it up a couple of times and he was pretty strong willed about it...we weren't very fond of him...I thought he was kind of negative and cold.

Buck spoke of his sister-in-law's interventions as a translator as being significant to moving his family toward their decision. She was a nurse and they trusted her.

Camille articulates the dynamics of an non-unified health care team and its impact on the family. Camille experienced both good and bad relationships with the health care team members who cared for her father. Her family could not make a decision not to insert a feeding tube and to stop hydration until the patient's long-term physician came back from a trip to China. Prior to that physician's return the family was conflicted because there were at least two varying opinions about prognosis as stated by Camille below:

> We'd talk to him and there would be some glimmer of hope that we would have him in some capacity. We would talk to the other physician and he would say things that really were not to get your hopes up. Particularly because nothing was improving at all. And this really kind of went on...

Eventually, Camille's father's physician was available to the family. Camille stated:

I think two things helped us make the decision to not put in the feeding tube. One is my Dad had a very explicit living will...And I think also his own physician who knew my Dad over the years, his comments to us were such that "well, this isn't like your father". And that he said..."This would be my choice too, to withhold the feeding."

Knowing that this physician knew her father as a person prior to the catastrophic illness made a difference in how his recommendations were received by Camille and her family.

In the absence of a good or bad relationship with the health care providers, the surrogate's relationship with the patient and knowledge of their wishes became the decision-making framework. That was the case for Michelle, Joe, Eileen, and Mary. For example, neither Mary nor her mother had a relationship with the emergency room physician with whom Mary discussed cessation of resuscitation efforts and removal of ventilator support. In Mary's story, the nurses were not present with the patient's family either. Mary describes that time as if there were no health care provider influence at all. Mary, unlike every other participant in the study, felt the clarity she needed and had came from her mother's expressed wishes; not from prognostic information. Mary describes her decision as advocacy when she states:

...I did take the bull by the horns...The doctor came into a very crowded little room that they had us in and told us that it was very, very serious, no I brought it up. I said you, we, you can't put her, you can't keep her on a life support system because that's not what she wanted. And that I, I guess I did speak of it first.

Trust and distrust. Camille told of distrusting the neurosurgeon for whom her father had to wait over an hour and a half the night of his admission. Conversely, she spoke very highly of her communications with the physician who returned from China in time to help the family with decisions. That trust was based on a lengthy trusting relationship between him and her father.

Paula's entire experience was couched in an uncomfortable level of distrust. She did say there was one physician she trusted. Paula said the following about that physician, "And I really had my faith in him, you know. And he told me 'If there is anything I can do for him, I'll do it.'" Paula also said there were nurses in whom she could trust. When asked what made her trust a nurse she responded, "Um, different nurses. Like the one that had told me. You know, I would leave him with her and stuff like that, but um, different ones that I really knew from the past that he was... He always went to the same hospital." It is clear that Paula's trust was experientially based. She portrayed herself as an information seeker. When asking, after having read information on her own, for an explanation of a drug that Harry was receiving, Paula received the following response from a physician, "Let us do our job." That response to Paula was unacceptable. She wanted more information and that response fostered more distrust.

Patty did not trust all of Sammy's health care providers either. She told of an error made when presumably a nurse took his blood pressure in his arm with his fistula. That error led to an added procedure in a previous admission. She also relayed a confrontation she had had with a physician who challenged Patty in the following passage:

So this girl comes in, a nurse, and she gives him a drink. I said, "What is that for?" She said, "That is Metamucil." I said oh, I said, "I know that controls bowels." Then she comes in with a pill. I said, um, "What's that for?" She said, "That is to bind him up." I said, "Well that doesn't make any sense." I said, "Metamucil is supposed to bind him up right, why give him something to go?" She said, "If he doesn't want to take it he doesn't have to take it." I said, "That is up to my husband, it is not up to me." So he knew I was getting mad, so he said, "Hon, I'll take it."...So I am going out and at the nurses' station is Dr. Smith. So I said, "Dr. Smith, could I see you for a minute?". She said, "Sure." I said, "I'm not questioning your ability, but what is the Metamucil and what is the other pill for?". So she turns around and says to me, "Well, I know what you are going to do when he comes home, you are going to let him do what the, you are going to do what you want to do." I said, "What do you mean by that?"

Both Patty and Paula portrayed themselves as information seekers and caretakers of their respective husbands. The communication histories they had with health care providers in part shaped how much trust was present when making life-sustaining treatment decisions.

Compassion. It may appear obvious that surrogates appreciated compassion expressed by health care team members, but it was also true that lack of compassion may impact decisions. That was evident in the Buck's recounting of his experience. Buck said he and his family trusted their family member who was a nurse. She explained the machines and prognosis to them in a way that made them accept the inevitability of their

loss. Buck admitted he could not trust the same information from his mother's physician because he disliked him a great deal and therefore Buck was not comfortable withdrawing ventilator support. Buck described his mother's physician in the following passage:

> I think doctors out there now a days, the few that I have dealt with, and not all of them, seem to get a cold kind of feeling about them, or that it is just business. It is not, the human factor is not there anymore. If I was going to give this guy a grade I would give him a C.

Chrissy spoke very highly of the level of communication and compassion she and her family received from the health care team members. She expressed an appreciation for the physician's support when she was explaining a decision not to hospitalize her father to her daughter. She specifically used the term compassionate to describe her father's gerontologist.

Continuity Of Care

Three participants specifically spoke of the value continuity of care had on their decision-making process from their perspective. Monica stated that her decisions to increase or not the morphine for her father was influenced in part by continuity of care. She said, "And, it happened because a variety of things that sort of all came together at the same time including that the same nurse came back on the next day and in a very compassionate way was acknowledging that she was surprised that he was still there."

The other three--Paula, Buck and Eileen--all spoke of continuity of care as missing during the time they were processing their decisions. The physician who knew Harry,

Paula's husband, best was himself hospitalized for an appendectomy. Therefore, Paula was being asked by physicians she did not know well and who did not know Harry well, to withhold and withdraw life-sustaining treatments.

When asked what would have been helpful in this process, Buck said:

> You know it's hard when you have someone in the hospital like that for say three weeks and things come up and your primary doctor is not there. But you start to feel like "How come he's not there?", but you realize that he has his own life. There were some decisions popping up here and there and we were thinking "What can we do? Can we do this?". This was before the coma, when she was in the coma. He wasn't there, that kind of irked me.

Eileen spoke of the value of hospice nursing and its approach to care in a favorable manner. However, she also expressed that they should follow the patients into hospital settings as well. According to Eileen this would provide continuity for patients and families. She said:

> I ended up spending three hours with the hospice nurse. Just talking about her experiences. I think that would have been more helpful that there would have been somebody that would have floated in and out to talk. The nurses were more there to kind of, they gave us the compassionate look. I think hospice nurses, someone to have been there to talk, if we wanted to talk about it. Not working their shift having other patients, but the hospice, hospice signs off once they got into the hospital. I think they should stay on and be there.

Abandonment/Neglect

There were examples of clinician behaviors that seemed to border on abandonment or neglect in three of the study interviews. While certainly not a predominant insight (23%), this issue is important enough to report. In addition to those three participants, two other participants, Monica and Chrissy, talked about staffing issues that they believed negatively impacted the care of their fathers.

First, Fred told of the need to hire a private duty student nurse before he and his family could be comfortable that his mother was receiving adequate care. He stated in his interview that, "...we needed to work with this staff, primarily the nursing staff to get good care." He later said:

> I don't know what is physically possible for people. I, what I knew was the hospital seemed to me to have few nurses, lots of paraprofessionals and uh lots of trainees...Even the nurse that I described that I was so angry with um, I think I eventually asked for her not to give care. Um, I just watched her run from one room to another. You know, the hospital was just tapping her out. There was no way she could do adequate care...Clearly, it was very hard and my family vacillated from acting out their anger on the medical staff which obviously then made them resistant to even being in the room.

This family clearly believed that they could not advocate too much for their mother or the nursing staff may retreat from her room. Fred and his family could also have used some

advice upon admission when they felt they were powerless without a formal document designating a health care proxy or executing some advance directive.

Second, Camille, a nurse, reported that the neurosurgeon, "stopped seeing us (the family). It was like she had done her work and then that was it." She also told of how two medical doctors who followed her father's case post operatively had very different prognostic opinions for quite awhile. After the severity of her father's stroke was better established, Camille stated that, "...as you remember one was a little bit more positive thinking and I think maybe when the situation got a little more grim, he maybe, maybe that was too difficult for him." It was Camille's belief that a physician who was present when cure was possible, then stopped seeing her father and the family when the prognosis became grim.

Regarding nursing care she said, "I think he was given ok care, we sometimes had to ask the nurse 'Could you please call a doctor because we think we would like him to get medication for pain?'." She reported that on more than one occasion she felt that she was pushing the nurses to solicit medical attention for her father. She said, "And I don't think they were real empathetic with that or understanding of that. They'd say 'Well, you know what, I'm real busy right now; but I'll get to that when I can.'" Camille rationalized the nurses' non-involvement and lack of acknowledgement of a decision to change the goals of care from curative to comfort in the following statement:

> And I don't know if it really was their role to... I guess because we didn't ask them or initiate the conversation about the decisions we had made, maybe they

didn't feel it was their role to suddenly, you know, maybe they felt it would have been too questioning or prying or intrusive for them to; but it was odd to me that then there was really no discussion about the change in status.

Paula observed that the approach to her and her husband by different members of the health care team had changed. She stated:

> They weren't talking to me as much you know. Um, they wouldn't tell me what was going on and ...Kidding around, they used to kid around with my husband...Respiratory would come in and kid around with my husband and...They weren't doing that anymore. So I knew there was something wrong...

Paula sought resolution to this situation by backing a registered nurse, "up against the wall, though, and I said, 'Hey, I know you're avoiding me.'" The nurse told Paula what Harry's prognosis was and for that Paula was very grateful. Paula believed that the health care team members were pulling away from her because it was uncomfortable for them not to tell her how ill her husband was, but also not their responsibility to tell her. She believed of the nurse who did tell her that, "...probably her job would be on the line because it wasn't up to her to tell me." Paula viewed this nurse's actions as heroic.

The Critics' Reviews: Reconciling Surrogate Decision-Making Experience Memories After The Loss

The SDME as portrayed after the loved one has died is the third and final aspect of Memory Manipulations to be presented. Some insights surrogates portrayed as considerations in the decision-making process were also discussed as relevant to the SDM

when they reflected on their SDME after the death of their loved one. Those insights already reviewed include: (a) substituted judgment meaning units, (b) personal meanings of death, (c) past experiences with loss, (d) spiritual beliefs, (e) meaning of life, (f) not having to make decisions alone, (g) validation of their decisions as the right decisions, and (h) witnessing suffering. Additional insights portrayed as considerations of the SDME after the loss are: (a) sharing the SDME with others, (b) grief responses, (c) emotional responses to the SDM role, (d) projecting to the future, (e) perspectives on death-related themes, and (f) integration of this experience into the SDMs life.

Overall, in the meaning units and insights of the SDME in this study it is clear that there is an effect on surrogates that continues after the patient has died. Metaphorically, there is most definitely a Critic's review.

A Lingering Melody: Guilt, Regret, And Joyous Empowerment

Five of the participants talked about "guilt" as a feeling experienced subsequent to their decision. Those participants were; Michelle, Fred, Tara, Eileen, and Anne. Two participants, Fred and Eileen specifically referred to "voices" they heard after they made decisions. Paula and Eileen also expressed the idea of secondary gain from the loss. The following are examples of that expression of guilt.

Michelle when talking about her aunt's illness spoke of her doubts, her second-guessing, and her subsequent guilt. She said, "I think about her every day. Every day." When asked if that has changed over the course of the year after she died, Michelle said, "I feel less guilt. I think. I think it took me awhile to feel guilt and then later on I felt

guilty." Michelle speaks of feeling her aunt's presence with her now. Michelle says of that feeling, "And I don't know whether that's because she's not happy with the decision. Sometimes I feel her around. I don't know quite why she's around." Michelle not only felt guilt about her decisions, she expressed guilt about inheriting money from her aunt when her aunt had lived such a simple life, and about all the secondary gains Michelle's family experienced from their vigil time.

Anne expressed guilt about how long she waited to call an ambulance and wondered if that would have changed the outcome for Rachel. Anne said reassurances from her brother who has a great deal of knowledge about biology helped relieve that feeling for her. Still Anne did say of her decision not to call an ambulance until Rachel respiratory arrested, "No one ever questioned that...I was waiting for that one person to come out and say, 'Why didn't you bring her to the hospital sooner?' I was just waiting, that was just hanging on my shoulder you know for some reason." Aware of an audience, she was awaiting disapproval.

Paula and Eileen also expressed the idea of secondary gain from the loss. Both of them no longer had caretaker responsibilities. Paula did not speak of guilt. Eileen did feel guilt. She questioned her decisions in the following passage:

> Because what if I made the wrong decision? Although they were comfortable, because of her condition. Sometimes you think (crying) because of um, condition she was in... I question sometimes if I didn't do that just so that I wouldn't be in any more pain. But um, I can't, I can' hold onto that...because I don't think

anybody really knows the pain that you're in. It was a lot of work to take care of my mother. And I did it and you know that. So sometimes the person that has done most of the care taking should be the one making those decisions because they have been there, but when it, I think being human, I say "Did I do that just to put me out of my misery?."

Eileen's reference to a voice is a relief from guilt. Eileen said, "Like I said, now, talking about it more, I am really visualizing her pain and it's making me like, getting the inner voice that 'you did the right thing.'"

Fred said of his grief experience in the following passage:

I think that um, after the fact, and this was something that has been an ache, sometimes it just feels like drama, but um. After the fact for a few weeks, um, periodically, with the waves of grief would come a voice that said "You killed your mother." ...I talked to a couple of people at the, ... you know, it didn't happen over a long period of time, but it certainly came forward.

Fred articulated security of his decision when it was being carried out. He said, "I'm glad it was very clear to me so we didn't have to go with that. For whatever reason it was very clear to me." Yet, in his grieving the decision carried some doubt, some guilt. Again, reconciling the memories took some effort.

Tara reconciled memories about why Margaret consented to surgery in an almost guilt-preventing manner. Of the decision to have the surgery, Tara said:

> I think we both kind of really felt she was gong to come through it, even though for a long time she kept saying she wasn't, and I tried to kind of clarify that with her a bit. You know, she needed to do it because she wanted to do it, and it wasn't for me she was doing it. And although, hopefully it was a little bit for me, it wasn't the main reason.

Tara does not want to consider that she was the one who wanted Margaret's surgery. That would add another layer of accountability.

Haunting Melodies: Grief Responses

Grief was an obvious part of each person's story. Six of the participants incorporated specific information about their SDME into their grieving for the deceased. Those participants were; Michelle, Fred, Tara, Patty, Joe, and Buck. Fred's feeling "waves of grief" accompanied by a voice that says "You killed your mother" is reviewed in the next section addressing guilt. Michelle, Joe, and Buck specifically referenced the additional pain the holidays cause after a loss.

When asked if she believed she made the right decision, Michelle responded the following way:

> Ya, I do. Usually, usually. Oh, when I sit here thinking about her and how she wasn't here on Christmas, Thanksgiving, Easter, you know. I spent every holiday with her my whole life...I have kind of a habit of punishing myself. I have her picture right across from my bed. I think, "Oh my God she's looking at me." And now what must she think. She's probably so mad...I can feel her around me

sometimes. And I don't know whether that's because she's not happy with the decision.

Clearly, Michelle's grief has been affected by the decisions she was asked to make. Recollections of the past with her aunt have a layer of guilt superimposed.

Patty spoke of the added time in her life now that she does not have caretaker responsibilities for Sammy. She said the time provides an opportunity for her to reflect on how unfair she perceived the physician's query of whether or not she wanted Sammy removed from the ventilator. She was speaking of her grief, her inability to get rid of his clothes, and times when her daughter can tell she is thinking about the decisions. Her portrayal of her grief was interrupted by the memory of being asked about the ventilator. So too, her actual grieving is interrupted by that memory. Buck did not directly speak of any connection between his grief and his decisions, but it was clear that the "Catholic thing" was problematic to him and his reflections as previously discussed.

Conversely, Tara reported that reflections on her decisions were not an important part of her grieving. When asked if she believed her grief was any different because she needed to make decisions for Margaret, Tara said:

> No. I don't think having to make those decisions has anything to do with it. That she died suddenly, yes, has something to do with it. Because you don't, I mean I'm not sure, you know you hear these words, and you even say them,... "Well, what the hell does that mean?" You didn't have a chance to put any closure on anything. And I'm not sure you ever do in reality, but the thing is I wouldn't want

her to have suffered one more second than she did. So, to even suppose it could be different, it's the way it was. And I think I'd just rather, just you know, deal with that reality.

Tara reconciled her decisions as ceasing further suffering.

Joe told of his experience as a surrogate decision maker, not from the perspective of decision making as much as from the perspective of his grief. Like Tara, Joe's current emotions are more about the loss and less about the decisions. He projected that "This Christmas is going to suck, and this Thanksgiving is going to suck and everything sucks...its not going to get any better, you know what it is like. You know, doesn't get any better, you just learn to live with it..." Again, Joe was comfortable with what needed to be done as soon as his mother was given her diagnosis and its hopeless prognosis. The role of surrogate decision maker did not compound grief for these two participants.

The absence of the term guilt in the other stories could have multiple interpretations. It may have not been part of their experience at all. Mary expressed feeling "empowered" and "joyous" about being part of her mother's "triumph" not "tragedy". Her story clearly sits on the opposite end of a continuum of guilt as portrayed by Eileen. It may have been that guilt was such a transient feeling that the surrogate decision makers did not think to discuss it. It may have been a reflection of the timing of the interview since guilt appears to come and go in the stories told. Or it may be that they choose not to expose themselves to thinking about it as a protective gesture. They have

reconciled their memories without it and the researcher can not dismiss the fact that she is another audience despite efforts to make it safe to tell all.

Writing The Next Sonata: Collecting Memories For The Future

Three participants, Michelle, Tara, and Joe, incorporated projections of needing to repeat their role as surrogate decision maker into their portrayal of the experience. These three accounts were woven into this SDME as projections versus separated out in response to a query about advance directives. As these experiences are shared, it appears that the SDMs are collecting or aligning memories for the future to help bridge memories of another loved one and a new catastrophic reality.

For example, Michelle spoke of lessons learned that will help her when she needs to make decisions for her parents. She told of an episode where her father was brought to the hospital for an emergency already. Tara also spoke of her parents and how it would feel to decide for them. Joe said with his mother they had never, "sat down and had one of those Northwestern Insurance Mutual Life insurance commercial" conversations; but in preparing to decide for his father, Joe said, "I am going to sit down with him and have one of those Northwestern Mutual kind of conversations." Joe had not had that conversation at the time of the interview. He said he had not done so yet because Joe felt his father needed to write a will to decide what to do about his father's property as a first step.

Songs Of The Heart: How Much Surrogate Decision Makers Share Their Experience

After just three interviews, an interesting insight was emerging. It was centered

on whether or not the surrogate talked about this decision-making experience with others. Those 'others' may have included the people who went through the experience with the surrogates. Participants after the third interview were asked if they hesitated to tell all or any part of their story. As per below, eleven participants responded to that question and/or offered the information without a prompt from the researcher.

Michelle reported that her family has not discussed the decision-making experience since her aunt's death one year ago. She said during her interview that she feels guilt about the decisions she made. When asked if she speaks to her family about that feeling Michelle said she speaks to one sister, "because you know, we're the closest and she's a nurse and ...she was in it with me. You know. She, we were in agreement and I didn't feel completely alone." The other siblings had challenged Michelle during the experience and so after the loss Michelle does not want her memories altered by their views.

Camille was the first participant to be so conscious of withholding parts of her story. She said:

> I will say there are some times with some people that I don't tell them that we had to make this decision. That my father, you know when asked the situation, that my father had a stroke, he lived two and a half weeks and that was it. And I don't always add that. And I think that's an interesting, ... and I ponder that. And I think why is that. And I think possibly its because there still is in my own view different schools of thought about having to make this decision. Is it an ethical decision? Did we, I mean you can even take it, you can take it from the level of

what I think we had to deal with and had guidance from the healthcare personnel caring for my father. But you could take that all the way to the end of the spectrum, all the way to Dr. Kevorkian. And there's issues you know where people feel, nature should have been allowed to take its course and of course you would still give somebody nutrition. And I think because of that or for people who um, maybe haven't had to think through those issues or maybe go through an experience like I had to go through. Maybe in my mind I think maybe there wouldn't be an understanding of the issue. Or maybe, maybe they do have an understanding but they would not have agreed with our decision. That we didn't have the right to make the decision that we did even though as I said, we had the physician support in it. But I think, in my own view I don't think society would look kindly. Everyone in society would maybe look kindly at the decision we had to make. And therefore maybe that's why maybe I keep it a little close to the vest. I think it's one thing if you say, um, "no, don't take him to surgery." Some people would be accepting of that, but to withhold nutrition which is more of a basic need. I don't know, I don't know if everyone would understand that.

Camille had reconciled herself with her decisions, but did not want to allow others to alter that reconciliation. In her story, society at large was a threat to her feelings. They were an audience with whom she chooses not to share her story.

Fred also reported not speaking to his family about what happened during his mother's hospitalization. He said as I left that he may speak to the one person with whom

he felt he had really collaborated on final pain management decisions. He said he speaks to his partner and other friends who he perceives to be a more receptive audience because of their AIDS outreach work and common views on death and dying. Of this non-discussion with his family, Fred said, "...you know just yesterday I said that it was odd that we hadn't gotten together ...we just kind of went back into our lives and our routines." Yet, during his interview Fred also spoke of doubt about his decisions. He, like Michelle, seemed to prefer reconciling his memories without his family, seemingly because they may not agree with his perspective and he needs to reconcile his memories to his comfort level.

Monica spoke of her decision not to share her decisions to increase morphine and remove oxygen from her father. Of those decisions she said:

> Um, when I think it all over if there is any hesitation it's just about the morphine thing. And I said, you know, I decided to just let it be ambiguous, and I can live with that...I feel, he wouldn't have lived even another day, and the question of whether he would have lived for another four or five minutes or whatever. I can't help but to think that the morphine level was high enough that it did affect his respirations and yet I know he didn't want to be euthanized. So, maybe he wasn't. By what, you know, I said I had to ask them, well what do you mean, "labored breathing", is this labored breathing and they're saying his breathing is labored so you need to up the morphine. It's just not going to get resolved. I can live with it. So that would be my only hesitation.

Here, as with Michelle and Camille, the opportunity for dissenting opinions is avoided.

Tara is still choosing not to reveal the nature of her relationship with Margaret. When asked if she shares her decision-making experience with others, she responded:

> I don't say anything to people. I mean all I say, a lot of times at this point, how she died doesn't matter. It just doesn't even matter. So, uh, I don't go into any detail. Someone might say, "you mean she died suddenly" and I'll say, "ya, she went in for a surgery that you know had a lot of potential to be, to have a bad outcome, then she had complications." And that's all I say, you know. I don't feel the need to...Two things I think. I mean it's her privacy and her situation and you know, no one needs to know that information. Secondly, I don't think I want to hold myself to that um, level of uh, emotion and intensity for no particular reason.

The circumstances of Margaret's death are inconsequential for Tara. It is only important that she lost her. Those are the memories she chooses to concentrate on.

Similarly, Buck felt his story was too personal and private to share. When asked if he shared his experience he said:

> I don't think I ever told anyone about us all sitting down and people crying and talking about it. I think it's a personal thing. Other people don't have to know. No one has ever asked me though, besides you...I don't think they feel comfortable with it, with asking someone, it is a personal thing. I wouldn't ask

someone else, unless you were really close like a brother and sister. I don't think I would ask my cousin.

Paula said the only part of her experience she does not always share is the actual moment that Harry died for reasons similar to Buck. Her reason is because, "that's the hardest for me. I try avoiding it sometimes." It is too emotional for her. Yet, unlike Buck, Paula advocated for people to discuss dying, death, and these decisions more openly. She finds her widows support group very helpful.

In a different way, Anne shares her story as requested. She actually believes strongly that sharing is healing. At the conclusion of her interview, she said, "So thank you for letting me talk." Anne seeks audiences for her memories to be shared. Joe said he would not hesitate to tell anyone about his experience because, "it's just a human story." In part because of the clarity of his mother's prognosis, Joe has not second-guessed his decisions at all. That seems to make his memories less vulnerable when exposed to a new audience.

Eileen and Patty lost patients who were chronically ill. The length and awareness of their struggles seemed to impact the surrogates' sense of freedom to share their experience. As Patty said, "I don't think I have to tell anybody because like I say Carol(yn), everybody knows what Sammy went through. What we went through. This is a small town and everybody knows everybody." Eileen said of her decisions:

...because people knew my Mom and knew it wasn't the relationship of nice, easy. They um, they don't question it at all. Like my decision, nobody questioned, I

don't have that, nobody, everybody from acquaintances up to housekeepers would say unequivocally I made the right decision. Like, they are not as hard on me as I am, on myself.

Again, the nature of a chronic illness seems to protect the surrogates' memories from the start.

The other two participants, Chrissy and Mary, did not specifically address what they do or do not share. However, Chrissy did say during the interview that the interview itself had raised questions she would want to ask her daughter. It was clear during Mary's interview that she has shared her story with her husband. The very fact that she was in this study is attributable to her having shared her experience with a mutual friend. Metaphorically, there is an audience for whom the musician does not want to play. They try to protect their memories by keeping them away from Critics. This is reinforced by the seeking validation insight.

Requiems

Memory is defined as: "... 9. Commemorative remembrance; commemoration; a monument in memory in Columbus". (Flexner & Hauck, 1987, p.1199).

It is not surprising that death as a more complete experience than just end-of-life treatment decisions was portrayed by surrogate decision makers in this study. Examples that rituals around death are important, that we predict our own deaths, of people believing that we control the timing of our death, and lastly that there is power in the dying process were all present in these thirteen surrogate decision maker experiences. All of these are to be explored further and to the extent they reconcile or orchestrate

memories they should be attended to during and after the SDME. Meaning units that rituals around death are important, that we predict our own deaths, of people believing that we control the timing of our death, and lastly that there is power in the dying process are all present in all 13 surrogate decision maker experience descriptions. A brief description of each insight will follow.

Death Rituals

Eight of the participants talked about a wake, a funeral, or a visiting a cemetery experience. Overall, the discussions about wakes, funerals, or cemeteries were important to the participants reflecting on their SDMEs. These rituals seemed important to the surrogates for varied reasons. Michelle told of her aunt's wake to reinforce how her own mother was still in denial of the loss. Fred talked about his need to be with his family after his mother died, but before the wake and funeral. Anne was grateful for a memorial service held after Rachel was buried out of state. She described it as healing. Buck was reassured of his decisions when people reinforced that he had no choice at his mother's wake and funeral. Paula visits the cemetery regularly to be close to Harry, as does Patty. Joe spoke of his siblings visiting the cemetery more often than he, but said that he visits, too. Monica reinforced her image of her father's gentility by speaking of what others had to say at his funeral. Tara told a tale of how someone at Margaret's funeral was upset she had opted for an open casket. Again, these are shared memories to be reconciled with the SDMs grief.

Predicting One's Death

Five participants talked about how the now deceased had predicted their own death. The SDMs appeared to use these recollections to comfort themselves after their loss. The comfort was in the belief that if the patient knew they would die, then the death was meant to be. It was a liberating insight.

This was true for Tara's partner, Paula's husband, Patty's husband, Buck's mother, and Anne's best friend. Margaret told Tara, "I don't really want to have the surgery because I know I won't make it." Similarly, Paula's husband was having dreams prior to his death. Paula said, "He was having dreams about different things. You know, angels and so in my heart I think he knew he was going..." Patty's husband was looking in the corner of his hospital room, presumed by Patty to be staring at his deceased relatives. Before he went to surgery that day, Sammy told his daughter, "I'm going to die today." Buck quoted his mother as having said the following to him the Sunday evening before her Monday catastrophic stroke: "Buck, do you think I am going to die...?" Rachel spent months seemingly preparing for her unexpected death. She had her mother buy a cemetery plot and she tried to teach Anne how to drive a standard transmission because that is what Rachel's car had.

Controlling The Timing Of One's Death

Four participants spoke of the timing of death as being within the patients' control. Again, reflecting on these memories on this idea served to comfort the surrogate that their

loved one controlled some part, if not all, of their own death. Fred spoke at length about his mother "not letting go." He implied that that was a choice she was making. He described family members giving her permission to die.

Paula was sure Harry waited for her to be alone with him when he died. She was also angry with him in October when he almost died. Implying he could have controlled that she said to him, "I would want to say good-bye to you." His response to her was, "I would like to say good-bye to you, too." And Paula said he promised, "...he would never do it again, and I think that's what he was doing. He was waiting for me to come back. Because he knew I was taking a shower that morning."

Anne was sure Rachel had waited for her to be present before she died and, similarly to Fred's belief, was waiting for Anne's permission to die. Anne said, "I knew she was there and I knew she must have been waiting for me to come and that it was okay with me." Monica joked that her father who lived past expectations after removed from ventilator support, "...wouldn't be the first CPA to pull himself over the line into the first of the New Year", again implying control over the timing of our deaths.

The Power Of The Dying Process

Lastly, there was a statement about the power of the dying process made in this study. As with the other insights about death, this insight appears to comfort the surrogate after the loss of their loved one. Some of that power has been discussed under vigil activities. There were several meaning units that spoke to the power of dignity and respect for persons as a reflection of the power of dying.

One such example was Fred who said the following when speaking of his mother's final hours of life, the care his family provided her, and the alternative of her having died suddenly:

> ...the ability to engage the care for her body. The sitting, the talking, the feeding each other, the uh, the periodic crying and mourning ...It allowed us as a family to do the work we needed to do...it would have been more shocking. We would have to do a different, we would have had to do our grief work differently...It would not have given us the opportunity to care for her in a different way, it wouldn't have brought us together in the same way...I wouldn't have wanted it the other way, that somebody all of a sudden rushed in.

The intimacy and finality of this experience is something that changed the surrogates.

Moved By The Music: Life Integration Work

There were insights that indicate it was not only the power of dying that appeared to change the SDM. Since many of the participants were nurses, the researcher asked the appropriate participants what impact this experience had on their nursing practice and vice versa. Overall, being a nurse helped with translating medical terms for themselves and for families. However, each nurse-participant also expressed that the SDME was definitely a personal one, not a professional one when it was occurring. Some went on to share that having experienced this profound a loss under these circumstances has had an impact on their practice. This integration of the SDME into the SDMs life after the loss was not

limited to the nurses in the study. Every musician was moved by the music and forever changed.

For example, Michelle said of being a surrogate decision maker that, "You are not a nurse anymore and you're, it's someone you love and you're thinking isn't the same at all." However, Michelle discussed at great length the impact losing her aunt has had on her own nursing practice. She said:

> So I am less sure of everything. And that kind of scientific stuff is not important to me anymore. And working, what I do now, I'm taking care of people who have cuts and broken bones and things like that. And the relationship and the rapport I get with them, it's more important to me now than doing a great job in a code. Like saving a life was ten years ago.

Eileen said of being a nurse-surrogate that she believed the health care providers respond differently to you. Of that concern she said:

> I think we dig deeper into all of this and we can very easily um, I think we are asked to do more decision making because we are nurses. They're afraid maybe they are afraid legally or something or because we use the terminology they forget that they are talking to family and not, because they can use terminology, we are using terminology right back at them so maybe they forget that they're dealing with family.

When asked if she believed it matter to her father that she was a nurse when making decisions for her mother, Eileen said, "...he trusted our judgment and what not.

Um, but towards the end, no it didn't. He knew that we were still just my mother's daughters ...when the tests were over and all the things were over, it doesn't matter what you are." As far as impacting her practice, Eileen feels strongly that nurses should be educated in how to care for the family of a dying patient. She said she sees families of dying patients rarely in her clinical area and that her personal experience has informed that practice, but she believes a deliberate educational effort should be made.

Anne was relieved that the health care team treated her as Rachel's best friend, not a nurse. She was particularly grateful to one physician who very clearly acknowledged this was a personal experience even though she dealt with dying patients regularly at work. Anne spoke a great deal about the impact this experience has had on her nursing practice. She said:

> ...that this incident really changed how I even went back to work and did my work...It sounded so easy, the words but when it happened to me, I saw these people in a totally different light as far as having to acknowledge signing it...Here you are talking about a very important decision in life. If you don't get it on the first visit that doesn't mean that somewhere along the line when you build up a rapport and come to a more trusting relationship about whether the disease is progressing, then they will sign it, but it is not that quick as sign this "piece of paper".

Overall, these sample meaning units present an insight that the SDME is a very personal experience. Furthermore, the SDMs integrate this experience into the lives. The SDME

lives on in their lives long after decisions for others are made and implemented. The SDME is integrated into the essence of the SDMs. These memories linger longer than any musical note could.

Summary

The participants in this study went through a life altering experience when they acted as surrogate decision makers. They had to make cognitive, rational, and permanent decisions under catastrophic, surprising, emotional, and complicated circumstances. They reconciled memories and beliefs not only from their past, but from the patients' past, and in most cases memories and beliefs of multiple audiences as well. They then set out to orchestrate events in such a way that the survivors, themselves included, would have optimized memories. Sometimes sacrificing existing memories was the best way to protect future memories. Those Memory Manipulations were sometimes at the expense of the patient, and/or at the expense of the systems they needed to manage; including health care providers along the way. The SDM accomplished their task with insights such as: (a) advance directives, (b) substituted judgment, (c) quality of life indicators, (d) personal meanings of death, (e) past experiences with loss, (f) spiritual beliefs, (g) prognostic information, (h) considerations of decision-making capacity of the patient, (I) meaning of life beliefs, and (j) age of the patient. They moved through complexities like: (a) established decision-making patterns, (b) resolved and unresolved relationships, (c) surreal time experiences, and (d) with the multiple audiences' responding.

These participants then were left to reassemble this SDME in their minds, in their whole being, after a significant loss in their lives. They had to create protected memories in some cases. In all cases they had to integrate these memories into their grief experience. They had to integrate these memories into their lives. In every case they represented the deceased as they lived, as they died, and as they are remembered.

The health care providers in these SDMEs, predominantly physicians and nurses, at best got mixed performance reviews. They were conductors, fellow musicians, and listeners depending on the number being played by the surrogate or other 'family' members. There are multiple implications for clinical practice, research, education, and policies embedded in these findings. Chapter 6 will address those implications.

CHAPTER 6: IMPLICATIONS OF STUDY FINDINGS

Introduction

The purpose of this study was to describe the experiences and meanings of surrogates' decisions to withhold and/or to withdraw life-sustaining treatments from adults who were rendered incompetent following unanticipated, catastrophic illnesses because the roles of surrogate decision makers (SDMs) in these circumstances were largely unexplored. Based on previously published works, it is known that grief is affected by some of the insights that influence surrogate decision making and it is known that grief may manifest itself physically and psychologically in a bereaved person (Lev, Munro & McCorkle, 1993). Additionally, there are research findings indicating moral decisions can result in feelings of dissatisfaction and guilt (Forsyth & Berger, 1982).

Additionally, research to date has supported that surrogates' decisions for end-of-life treatments are multi-factorial. As outlined in chapter 5, some of these factors were important in this study, as well. However, in some cases, insights about these factors had different meanings in this study than they did in previous studies. In addition, the surrogate decision-making experience (SDME), as portrayed by the surrogates in this study, indicated more complexity than the fixed nature of the factors presented in previous studies.

There are findings that support that having made a moral decision and subsequently experiencing a loss of an important loved one does manifest itself psychologically and physically in surrogate decision makers. The findings from this study

support two major themes in the SDME--Representation of Other and Memory Manipulation. Overall, SDMs' efforts to represent the other and to manipulate memories in this study have strong implications for nursing. This chapter will present implications as they indicate changes or reinforce current standards according to the categories of practice, research, education, and policy development.

Practice Implications

Overview

Study findings indicate there are multiple opportunities for nurses to interact with the SDM as they manipulate memories and represent others. For example, assessments that would clarify substituted judgment statements, spiritual beliefs, and the pertinent relationships could have influenced the SDMEs portrayed. Additionally, findings indicate that nursing interventions of validation, translation, arbitration, environmental control, patient education, and assistance with decision making are sought out by SDMs. Follow-up during the grieving process is something that the SDMs did not receive from nurses, but welcomed when given the chance during the study interviews.

Additionally, there is evidence in this study that nurses did not use sound clinical judgments to care for their patients at optimal levels. Those findings were cited in chapter 5. Specifically, in the sections on self/other protective behaviors, environmental control, "landing peace", high technology deaths, resource seeking, abandonment/neglect, and clinical judgment, there are indications that nursing practice could change to benefit patients at end-of-life and their SDMs. Examples (such as Monica regulating her father's

morphine dose and Michelle determining the amount of analgesia her aunt should receive), demonstrate that clinicians sometimes defer clinical judgment to SDMs. Similarly, there are examples (such as Paula needing to explain to her stepdaughter why no health care team member was responding to Harry's cardiac monitor) that highlight the problems assessment technology can create. These examples indicate a need to question the use of technology at the end-of-life when the treatment plan is not to intervene on the data that the technology collects.

Other study findings indicate a practice imperative to serve as translators for SDMs. When possible, a nurse known to the surrogate and/or the surrogate herself, served as a translator. With only one exception, if there was no nurse known personally to the family, there was very little nursing presence in the SDMs' stories. The one exception was when Paula sought out the nurse to explain what she perceived to be avoidance behavior from the rest of Paula's husband's health care providers. Some of the participants specifically said they needed a resource to sort through all the information they were trying to recall and learn. These findings call for a more active nursing role.

All 13 patients were hospitalized in different settings. This indicates to the researcher that the findings are more a reflection of current nursing practice than a reflection of any one nursing staff or hospital's practice. Hopefully, a heightened sensitivity by nurses to the complexity of the process and the lingering effects may inform nursing practice more effectively.

Reconciling Pre-Catastrophe Memories With A Catastrophic Reality

Surrogate decision makers in this study all experienced trying to reconcile memories of their loved one and/or their loved one's expressed wishes with the reality the respective catastrophic, unanticipated illness/event caused. Findings indicate that the needs of SDMs are complex when trying to comprehend an unanticipated, catastrophic illness and reconcile that reality with what they knew of the patient. The SDMs tried to comprehend the medical terminology and seek clear prognostic information at the same time they were being asked to represent this patient's values and beliefs. During this time, the SDMs also became, consciously or not, aware of audiences for their decisions. Study findings support nursing assessment and intervention practice changes to assist the SDM during this time.

Assistance given to the SDM could be viewed as an extension of their fiduciary responsibilities to the patient. According to the ANA Social Policy Statement (1995), nurses are to assist with decision and choice making, to explore emotions related to the experiences of illness and death, to view the human experience as contextually and culturally defined, and to respect roles and relationships. All of these activities contribute to the logical extension of nursing care to the family members of a dying patient.

There are findings that indicate nurses do practice in this manner. For example, Monica described the nurse who cared for Monica's father during the day he died as "God's gift of a nurse", primarily because she worked with Monica to make sure his wife was present for his death. Another example would be the nurse who responded to Paula's

need for information both at the time of prognosis and when Harry actually died. There are multiple examples of nurses providing privacy once death was determined to be imminent. These examples demonstrate respect for roles and relationships.

However, there are counter examples that culture and context were not considered. One such example is Buck's worry about "the Catholic thing" where there was no attempt to address his needs specific to his religious concerns. Another example is Camille's mother having to come in before seven a.m. if she wanted to get information. There was no attempt to accommodate her needs as an elderly, exhausted woman who required more rest than she was able to get. Nurses could have problem solved another way for her to get the information she needed. Overall, the absence of nursing presence in the SDMEs indicates that nurses were not very attentive to the families.

In addition to implications for hospital staff nurses, advanced practice nurses who are accountable for primary care should assess if their patients have been through a SDME since SDMs report reconciling memories during their grieving and a need for validation of their decisions. Therefore, the SDME may impact their health. Specific study findings regarding memory reconciliation, before and during decision making, and their implications for practice are detailed below.

Substituted Judgment And Advance Directives

Knowledge of advanced directives has been demonstrated by previous research as a factor in surrogate decisions (Ouslander, Tymchuk, & Rahbar, 1989; Pijnenborg et al. 1995; Sehgal et al., 1992). Findings from this study support these previous findings. This

study also indicates that the standards of best interests and substituted judgment are not as distinct in practice as they may be in theory. This was evident in SDMs' attempts to construct substituted judgment statements when none existed because they wanted more than just best interests as a guide. However, this study went further than previous studies by identifying a relationship between substituted judgment and SDMs' grieving that indicates where there are clear statements of substituted judgment, there is less or no guilt compounding grief.

The study findings indicate a clear imperative for clinical practice in that substituted judgment statements from patients should be elicited before the need to make decisions arises. This intervention was not only good for the patient, it proved to be good for the surrogate, as well. This finding is very important for advanced practice nurses who are accountable for primary care. It also applies to staff nurses who interface with patients while they have decision-making capacity. Nurses need to do values clarification work to elicit substituted judgment statements whenever possible. Fred was frustrated that during the first twenty-four hours of his mother's hospitalization she had capacity, but nothing was addressed to designate a formal proxy or to obtain her explicit wishes. This serves as one example of opportunities lost.

Even when nurses interface with an already incapacitated patient, they can work with the surrogates to assist in memory reconciliation. Knowledge that surrogates are consoled by substituted judgments, stated or inferred, should guide nurses toward this intervention. Nurses can assist the surrogates to recall substituted judgment conversations

or life experiences so that the SDMs can know that their decisions represented the patients' wishes as well as possible. That knowledge was consoling when SDMs reconciled SDME memories after a loss.

Nurses should also assess to see if the surrogate has had a similar SDM experience or with a previous loss. Study findings support that past experiences with SDM and/or loss influence current decisions about life-sustaining treatments. This thorough assessment has the potential to impact patient outcomes and may serve to build trust, facilitate communication, clarify priorities, and become a validating SDME memory when the SDMs are left alone to grieve.

Translating The Catastrophic Realities

Clarity of prognoses and translation of medical terminology were two other findings of this study that have nursing practice implications. Specifically, it was clear in the study findings that the element of surprise and the use of confusing terminology distressed SDMs. When that distress was not addressed, it led to distrust and sometimes altered the timing of decisions that were ultimately in the patient's best interests. Nurses should assess the need for necessary translation and be assertive in obtaining as much information as possible if that is what the decision making pattern of the surrogate/family requires. In doing this, nurses should work within the decision-making patterns of the patient/ SDM/family rather than the health care team, advocate for as much communication as possible, and translate as necessary to best support the SDM.

When a clear and definitive prognosis is not possible, nurses should communicate their understanding of its importance to the family. If SDMs are asked to make a decision, then there is enough clinical data available to generate doubt in the minds of the health care providers about what to do or not do for the patient. Study findings indicate that acknowledging ambiguous prognoses to the surrogate may prove beneficial to their decision making and to their grieving because they are important components of the memory reconciliation work SDMs do leading up to their decisions and subsequent to their loss.

Orchestrating Memories

There are nursing practice implications for SDMs' activities when orchestrating memories just as there are with SDMs' efforts to reconcile memories with a catastrophic reality. Some of the finding in chapter 5 concerning factors considered in end-of-life treatment decisions, specifically: (a) health of the patient, (b) spiritual beliefs, (c) personal meanings of death, (d) quality of life and (e) age, have significant implications for practice. Additionally, findings presented about: (a) time, (b) relationships, and (c) perceptions of the role of health care providers indicate a need for practice changes.

Health Of The Patient

Health of the patient is another factor that had been identified in previous studies as important to consider in end-of-life decisions (Hanson et al., 1994; Hare & Nelson, 1991; Sehgal et al., 1992; Uhlmann, Pearlman, & Cain, 1989). In this study, clarity of prognosis and quality/meaning of life insights combined to partially address that factor.

However, the study was purposefully designed to capture unanticipated illnesses. Therefore, study findings about the element of surprise and normalizing chronicity in the SDME are new dimensions of the patients' health. The element of surprise has moral and practice implications to be detailed when discussing time. Normalizing chronicity is something clinicians should consider when assisting SDMs performing their role.

For example, Eileen was clear that people did not see her mother the same way she did. She believed her mother's quality of life was far better than the clinicians could see. Paula and Patty were both surprised that their husbands were as ill as they were. The discrepancy between the clinicians' assessments and the SDMs' assessments should be explored whenever end-of-life care and life-sustaining treatment decisions are being made. The SDM may need more information than expected based on the patient's past medical history because family members do not see patients and health in the same way that the clinicians do.

Spiritual Beliefs

Spiritual considerations have been identified in previous studies as important in end-of-life treatment decisions (Hare & Nelson, 1991; Sehgal et al., 1992). One limitation of this study was that the participants and surrogates predominantly identified with one religion, Roman Catholic. However, despite that common religion, the participants expressed varied beliefs about the role of religion at end-of-life, treatment decisions, and other spiritual considerations. That variance is informative to clinicians because the label "Catholic" did not serve as an accurate predictor of what SDMs believed.

For example, Patty was very assertive in finding priests to be a resource to her while Buck did not use this resource even when in the physical presence of a priest. Anne and Tara experienced the presence of clergy as positive, but did not have to seek them out themselves. The clinicians had called for the clergy's response. Mary felt conflicted about the need for a priest's presence given an experience she had with her father's death. In conclusion, each individual had a different need and perspective on the presence of chaplain support despite being a member of a common religious group.

Seemingly even more important was Buck's experience that reinforces the need for health care providers not only to consider spiritual beliefs during end-of-life care and its decision making, but also to actually initiate the conversation about concerns and offer clarifications whenever they exist. Buck would have welcomed a priest explaining Catholic doctrine about withdrawal of life-sustaining treatments, but he never would have solicited it on his own. Buck was very relieved when the researcher clarified his misconceptions.

The study findings indicate that using a religious group label is a potentially hazardous way to assess a person's spiritual beliefs. To reinforce that potential hazard was Anne's SDME in which Rachel, the one Jewish patient in the study, was consoled most by a Catholic nun even though the clinicians offered a Rabbi. Rachel had a long term, personal relationship with Sister Claire and did not know a local Rabbi. The label "Jewish" was not the guide to the best spiritual support for Rachel.

Overall, not assuming that a given religious label defines an individual's beliefs is an important practice imperative. Additionally, initiating the use of resources when it is

known that end-of-life treatment decisions have associated spiritual, cultural, and moral beliefs, is in patients' and SDMs' best interests. There are findings in this study which hospital chaplains and other clergy should be made aware of, as well. For example, a priest provided last rites for Buck's mother, but the priest did not initiate a conversation about the Sanctity of Life Doctrine. When life-sustaining treatment decisions are being made for a patient identified as Catholic, then chaplains should take the initiative to relieve any potential concerns. Additionally, Mary was quite clear that the priest present when her father died was not a therapeutic presence for her. Sensitivity to end-of-life care should be part of pastoral training for hospital chaplains and ongoing support of the chaplains.

Personal Meanings Of Death

Personal meaning of death has been present in several studies about fear of death, death anxiety, and others (Neimeyer, 1994). It appears in the findings of this study as well. The implication for nursing practice is that the nurses should assess for any information that the SDM or the patient is using to make decisions. An example can be found with Michelle's aunt who was afraid to die. Michelle needed validation and support to reconcile memories of her aunt's expressed wishes to live with the catastrophic reality. She ultimately used a contrived substituted judgment statement inferred from a childhood memory she shared with her aunt. Nursing could be instrumental to facilitate this type of processing that SDMs do when confronted with incongruent personal meanings of death and decisions to be made.

Quality of Life

Another factor researched prior to this study was quality of life (Sehgal et al., 1992). Findings from this study reinforce that quality of life matters not only for decision making, but also for memory reconciliation work after the loss of the patient. Combined with the witnessing of suffering and the need for prognostic clarity, some sense of what the patient would experience if they lived is a very important aspect of their grieving process. There are no findings that specifically indicated nurses understood the value SDMs placed on quality of life, but there are no findings to indicate the nurses were not sensitive to this factor.

Age

Perhaps age of the patient is assumed to be a factor in surrogate decision making because age is the cause of death Americans consider acceptable. Age of the patient had appeared in previous studies as a reason to treat patients less aggressively (Hare, Pratt, & Nelson, 1992). In this study, age is not a very prevalent consideration during decision making. That may be in part because of the unanticipated nature of the illness from which the patients in this study died versus other studies that have focused on elderly or terminally ill patients. There is little to learn from this study about age as a factor, except maybe to highlight that although it is a measurable number, people still respond to it in the context of quality of life.

Time

Time also was established by previous studies as an important element in end-of-life treatment decisions because patients use "time left to live" as part of their reasoning (Hare et al., 1992, Tomlinson, Howe, Notman, & Rossmiller, 1990). Time is also an important aspect of unresolved grief when the loss is associated with a brief illness in the person who died (Parkes, 1975). Time also plays a role when assessing the autonomic symptoms during grief, the more time lapsed the less the symptoms (Higginson, Priest, & McCarthy, 1994; Parkes and Brown, 1972). Time as it is present in this study affects the SDME is at least four ways.

First, by study design the SDMs in this study experience grief subsequent to brief, unanticipated illnesses. Second, the study participants were six to 18 months into a bereavement process. There are no practice implications inherent in these statements, except possibly increased sensitivity to the difference it makes to the SDM when reconciling their SDME memories during their grief work. Therefore, the recommendations for practice changes during the memory orchestration efforts are reinforced by the impact duration of illness has on the survivors.

Third, time has a surreal nature in the findings of this study. The implications of asking for cognitive, rational, reasoned responses under these circumstances needs to be further explored. This finding needs more research before any new knowledge can be implemented into practice.

Last, there are strong indications that surrogates need time to make these decisions. Time allows for orchestration of memories that are relatively invisible to the health care provider. From that perspective, it is possible to feel a moral imperative of time being declared as something every clinician should consider. If health care providers are asking that people make life and death decisions for people in their personal lives, then should they also be provided the time to make those decisions in whatever manner they feel necessary, in a manner that minimizes their future memory reconciliation efforts. If there is no time for the decision, then maybe health care providers need to wonder if there is really a choice to make. Have clinicians abdicated clinical responsibilities beyond what is reasonable to support autonomy? If it would feel that wrong to the clinician to treat or not to treat a patient, then is there really a choice? These are the questions the "problem" of time posed.

Relationships, Protective Behaviors, And Family Burden

Relationship to the patient is another previously researched factor that is portrayed differently in this study than in previously reported studies. In previous studies this variable was identified in a fixed manner (Fulton, 1987; Ouslander et al., 1989; Tomlinson et al., 1990; Ulhman, Pearlman, & Cain, 1988, 1989). These past studies detail relationship to the patient in terms of relationship labels such as "daughter", "son", "wife", etc. Grief research supports the nature of a relationship in this context alters what can be expected after a loss (Parkes, 1972).

Findings of this study also support that the wives and same sex partner appear to be grieving differently than the children, niece, and best friend. However, in this study "relationship" has a descriptive, dynamic, qualitative nature versus being a static label. The implication for practice is that this variable is not fixed, it is something that needs to be thoughtfully assessed and addressed. It may even be a reason to question the capacity of the surrogate to perform in that role.

The study findings presented as memory orchestrations indicate a need to explore relationships beyond the patient/surrogate decision maker dyad. The fact that the SDMs had other loved ones to represent and protect was evident in the study findings. The need to be sensitive to the nature of these relationships was obvious in the self/other protective behaviors and in the validation seeking that the surrogates did. These self or other protective decisions/acts highlight that surrogate decisions are made in complex contexts that include multiple family members and other audiences as well.

The 'right' decisions are not obvious unless there is knowledge of all the people potentially impacted. Only the surrogate has that knowledge. However, nurses should assess who the audience members for decisions may be so they can better care for the patient and the SDM. Nurses need to realize they also are an audience and act accordingly by validating/not validating that the SDM is fulfilling their role appropriately.

Another way to view these relationship findings is that surrogates are asked to represent their loved ones but the health care team asking them to do so is perhaps assuming they have no other relationship concerns other than the dying person. The

assumption that the surrogate can/will prioritize the patient over any other people in their lives should be explicated in these situations. The health care team can not assume the patient, the only person to whom the health care team has fiduciary responsibilities, is the only person the SDM considers when decisions are being made. The fact that SDMs did not always make decisions based on what was best for the patient in question was evident.

Clinicians should be clear about their expectations of the role the surrogate is to enact. The clinicians, if aware of these choices, would be faced with possible dilemmas. One issue for the clinician would be to consider basic tenets of respect for persons where the individual (the patient) should not be used as a means to an end for the other person(s). "Harming" or not placing the patient first when making decisions because of a competing need to benefit another person is an inherent conflict with the fiduciary relationship the clinicians have. However, the individual nurse may argue it is respectful of the patient as a whole. That idea was articulated by Monica when she said:

> And I was uncomfortable at that time because I felt like my father needed me to up the medication because he's laboring, my mother needed me not to do that because she needs to be here. So, what do I do? So I said "Well, I know my father would do that for my mother." I know he would breathe hard for a long time so that my mother could be at peace.

In support of choosing the SDMs' priorities, the ANA Social Policy Statement (1995) states nurses consider the person in a holistic framework that includes roles and relationships. This idea may be what guides nurses in these situations. Clinicians should be

aware when they are agreeing or disagreeing with the prioritization chosen by the surrogate. In that decisions were made that were protective of self or other in 69% of the SDMEs in this study, it is a potential ethical dilemma that clinicians may encounter. These self or other protection decisions also reinforce an awareness of audience in the surrogates' experiences.

Another relationship variable presented by other studies as significant in life-sustaining treatment decisions is "family burden". While family burden has appeared as significant in other studies, it is really minimally present in the findings of this study (Hare et al., 1992; Sehgal et al., 1992). However, family burden did appear as explanations for why the deceased completed advance directives. It was also presented by SDMs in the form of guilt. The question for the SDM became, was release from a caretaker's burden part of their decision to let the patient die without intervention?

An example of this occurred when Eileen questioned her decisions to let her mother die without intervention. Eileen questioned if her decision was partially because caring for her mother was burdensome to her. Eileen's fear was that idea had a part in her decisions. Interestingly, Eileen realizes nobody else would say that about her. The implications for practice here speak to selection of surrogate decision makers. Perhaps it would have been kinder not to let Eileen perform in this role because of the possible conflict of interest. However, it most likely would not have altered what care Eileen's mother received. It may have a positive impact on Eileen's abilities to reconcile those memories and grieve if she had not been the actual surrogate decision maker. This

example highlights the need to do deeper explorations about roles and relationships if health care providers are going to assist SDMs beyond getting the decisions they need/want to care for the patient.

The ethical implications of causing harm (emotional/psychological) to one individual to protect the autonomy of another needs to be considered in cases like Eileen's where she is left with guilt because of her role as SDM. The role was established to protect her mother's right to autonomous wishes, but Eileen is left harmed by enacting the role.

The decisions made by surrogates to benefit themselves or another (emotionally/ psychologically/legally) at the possible risk of perceivable harm (physiological) to the patient also need to be considered from that perspective. An example here would be Anne resuscitating Rachel to avoid any litigious action or Michelle withholding analgesia from her aunt to avoid conflict with her siblings. In basic terms there is reason to believe people are being used as a means to an end for another, a violation of respect for persons. Yet, that is exactly what all parties involved are trying to avoid. Some protection from added burden and suffering may be necessary. Additionally, more concerted efforts to work with the surrogates may be helpful when they go to reconcile their SDMEs with their grief.

Perceptions Of Health Care Providers/Communication

Communication during the decision-making process has been identified in previous studies as a factor in life-sustaining treatment decisions (Higginson et al., 1994; Ouslander et al., 1989). However, the phenomenological approach to this research study adds

considerably more information to these previous findings. Health care providers in this study, predominantly nurses and physicians, played significant roles in the timing of decisions and the acceptance of decisions after the patient died. In some cases, it is the absence of communication that dominates the story. Additionally, some surrogates stated, if necessary, they would have used clinicians as arbitrators to achieve family unity or override other family members as needed.

A role for the registered nurse in end-of-life care and specifically, in decision and choice making is supported by professional documents and statements (ANA, 1992, 1995). However, in this study, the absence of a nursing presence in decision making and in pain management was a difficult finding for the researcher. The portrayal of nursing even when the participant thought he/she was being positive about nurses was not very impressive in the study. The lasting impression for participants in this study is that nursing did not fulfill its contract with society as stated. Closer analysis of possible causes for this absence of a nursing role needs to occur. Perhaps, the expectation or the reality of nursing practice should be further evaluated.

Abandonment/Neglect And Clinical Judgment

The activities presented in chapter 4 when SDMs advocated for better, more, or different care for their loved ones indicate that nursing practice as experienced by these surrogates had areas for improvement. Findings indicate that health care team members were perceived as pulling away from the patient and/or the family and that SDMs made clinical judgments instead of the clinicians caring for the patients.

Abandonment. For example, when Paula was describing avoidance by clinicians because she was not informed about her husband's condition, she described what she believed to be risk-taking behavior on the part of the nurse who told her what was wrong with Harry. Was the nurse in this story really taking risks or was she practicing good nursing? Was she doing both?

Paula's perception was that talking to a wife about a patient's condition was not within the scope of nursing practice. Therefore, Paula thought the nurse who did tell her Harry was gravely ill was a risk-taker and a hero. The scope of nursing practice for Paula was something she experienced throughout multiple hospitalizations and visiting nurse care at their home for Harry.

The question to be asked is, what do patients and families need from clinicians at end-of-life? Paula wanted information, but she felt that nurses were avoiding her. Were nurses' avoidance behaviors manifested because of their discomforts with the prognosis or because of the non-communication between the physician and Paula? Arguments against health care professionals' avoidance behaviors can be made regardless of the etiology. Bok (1996) states:

> ...clinicians can serve the dying person by being present. We may not have answers for the existential questions of life and death any more than the dying person. We may not be able to assuage all feelings of regret or fears of the unknown. But it is not our solutions that matter. The role of the clinical team is to

stand by the patient, steadfastly providing meticulous physical care and psychological support, while people strive to discover their own answers (p.251).

While it is not a nurse's responsibility to give prognostic information to a patient, it is a nurse's responsibility to be truthful and caring with their patients. This scenario could be analyzed in terms of Chambliss's (1996) beliefs about nursing and the social organization of ethics. Chambliss depicts nurses as subservient professionals who are not accountable for decisions made at end-of-life, but rather are accountable to care for the patients through the decisions made by others. Others may argue the examples of surrogates advocating for improved nursing care may be a reflection of the current workloads assigned to hospital staff nurses. As a discipline nursing should analyze the scope of nursing practice and what may be preventing nurses from connecting at an optimal level with patients.

Neglect. In other SDMEs there is no apparent barrier between the nurse and the patient to whom they were to provide nursing care, but the surrogates perceived gaps in care nonetheless. Such was the case for Camille who felt the nurses did not care about her father because she had to ask more than once for a nurse to call the physician. Camille's father was experiencing pain and the nurse responded to Camille that the physician was asleep. Fred seemed willing to excuse a great deal of non-attention by the nursing staff because of perceptions of excessive workloads. Other participants did as well. Perhaps findings from this study could prompt an assessment of the plausibility of allocating more resources to our dying patients. An argument could be made that clinicians should be

impacting the health of the surrogates while tending to the dying patients' comfort and dignity.

Clinical judgment. There are also examples in the findings to indicate that nurses and physicians are deferring clinical judgments to family members. While it is part of the system design to abdicate decisions to patients and surrogates out of respect for autonomy, those decisions were meant to be value-based decisions. The amount of morphine necessary to maintain a comfort level for a patient is a clinical judgment. There are clinical signs and symptoms of pain and discomfort. Nurses have the education necessary to assess for those signs and symptoms. No family member should be asked to make those decisions. Even if SDMs were willing to accept responsibility for clinical decisions when asked to do so, these decisions clearly were problematic for the surrogate when reconciling their SDME memories during the grieving process.

Lastly, there are SDMs, some of whom were nurses, who were not prepared for what it would be like to watch somebody die. Examples include the references to how dying is portrayed on television and Monica's second-guessing her decision to withhold hydration. There is a practice implication here that nurses should be preparing family members for what they will witness.

Goetschius (1997) suggests nurses do the following for families at end-of-life care:

1. Be present;

2. Assess knowledge of the process of death;

3. Supply family members with a role and provide feedback on how they are performing in that role; and

4. Supply families with as much information about what will happen after their loved one has died.

All of those suggestions are supported by the study findings here and by Viney's (1991) research findings which state being able to anticipate events minimizes negative feelings during bereavement. There are examples of goof nursing practice as recommended by Goetschius (1997) and Viney (1991), but overall these recommended standards of practice were not met.

For example, there was a nurse present with Paula and Harry when he died. The nurse helped guide Paula through confusion about why Harry's eyes opened after he died. Unfortunately, earlier Paula had not been prepared for Harry becoming comatose. She believed he would either begin to recover or die immediately when the ventilator support was withdrawn. Another example would be Fred speaking of the value his family held for taking care of their mother's physical needs. Unfortunately, prior to that time Fred and his family felt nursing care was absent.

Perhaps establishing standards of practice that are similar or the same as hospice nursing standards of care in this regard would serve acute care nurses well. The National Hospice Organization articulates the organization's difference from other types of healthcare to include consideration of the entire family, not just the patient, as "the unit of care" (1998). Hospice offers support to their patients and families on a 24-hour-a-day,

seven-days-a-week basis. Hospice works with patients and families to anticipate events. This could potentially avoid the stress Paula felt when Harry did not die or recover, but rather became comatose. She queried at that time if she "had done something wrong." Informing her that that was a possibility ahead of time would have alleviated that concern.

High technology deaths and other environmental controls. Related to clinical judgment findings were issues of environmental control and high technology deaths. Participants of this study appreciated interventions such as finding private space and being there with family members if desired and not there if not desired. As previously cited, Paula was grateful her nurse-hero was with her when Harry passed away. Fred was glad the nurses were not intrusive when he and his family kept their vigil. Monica felt the nurse caring for her father was an ally with whom she could strategize to make dying as peaceful and meaningful as possible. These are examples of good nursing care at end-of-life.

Unfortunately, there are bad examples of environmental control and presencing as well. Camille's attempt to get a nurse in to see her father when he was in pain and Monica sitting on bloody sheets were clearly not standard nursing care. Therefore, these examples hold no implication for practice change. They were just bad practice.

In addition, the issue of patients dying on assessment technology was a recurrent finding in this study. Buck reported he thought he was asked if he wanted his mother to stay on a cardiac monitor even though there would be no interventions performed when she inevitably went into asystole. Conversely, Paula told of how she had to explain to her stepdaughter why nobody was responding to the monitor when it alarmed. Patty watched

the cardiac monitor go flat line as well. Monica described a sense of relief like "landing peace" when the noise was reduced by the lessened oxygen for her father. These technologies, once deemed non-beneficial, should perhaps be assessed for the possibility that they are harmful. At a minimum, they distract the family members from concentrating on the patient. At worst, they can add a tension because of the non-response. Individual preferences should be assessed, but the option of removing these technologies should not be overlooked.

Reconciling Surrogate Decision Making Experience After the Loss

Memory Manipulation efforts conclude with reconciling SDME memories after the loss of the loved one. Here, the SDM has left the health care system. However, what the SDMs are reconciling are thier grief with memories of their experiences while in the health care system. To the extent that the memories can be influenced by nurses, there are implications for nursing practice.

Vigil Time And Witnessing Suffering

Some of the most compelling findings from the study come from the SDM depictions of their family vigil experiences and having witnessed the now deceased patient suffer. Van Hooft (1998) reviewed ancient, Christian, post modern, and Nietzschean conceptions of the meanings of suffering and concluded, "Perhaps all the meaning that suffering can have is that it teaches us to care for others" (p.19). That sentiment is resonated in the findings of this study.

The findings from this study would reinforce that surrogates have empathetic responses to the patient because of suffering. Witnessing suffering has two obvious effects on SDMs. First, it appears to have an impact on the timing of the decisions. For example, Eileen quickly decided to turn to comfort measures instead of aggressive treatments because her mother was suffering. The impact that witnessing suffering may have on the timing of decisions could be viewed as a means to improve patient outcomes if processed with the SDM appropriately.

Second, findings also support that witnessing suffering is consoling when reconciling SDME memories during the SDMs grieving. This knowledge of the positivie possibilities of witnessing suffering may inform nursing practice. This finding is reinforced by Berns' and Colvin's (1998) study findings that conclude families and friends want to be present at death and want to give their loved one permission to die. Families and friends want to be present with the dying person they love.

Being a witness to suffering in this study has the double effect of being difficult, but also beneficial when making decisions and reconciling those decisions with the loss of a significant person in their lives. The difficulties, in part, can be lessened by communicating to the SDM and other family members what they can expect. Knowledge of this double effect on surrogates can guide nurses who are caring for SDMs going through this experience. Nurses should pause before protecting families from journeying with their family member through suffering. It may be helpful to the SDM on a long-term basis. As Newman (1994) states:

> To be open is to be vulnerable, an important characteristic of humanness. To be vulnerable is often to suffer. We tend to avoid suffering, and yet avoidance of suffering may deter movement to higher levels of consciousness. Suffering offers us the opportunity to transcend a particular situation. Vulnerability, suffering, disease, death do not diminish us. What does diminish us is trying to protect ourselves by binding ourselves off from those experiences. The need is to let go, embrace our experience, and allow the expansion of consciousness to unfold (p. 142).

Seeking Resources

The findings from this study also include an expressed desire to have been guided through the SDME by an expert clinician. The Principal Investigators for the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) (1995) reported that the presence of a specially trained nurse did not have an impact on the outcomes of care as measured by timing of resuscitation limitation orders. However, the study did not measure the impact this resource had on the surrogates' perceptions of support and memory reconciliation after they experienced the loss.

In light of the clearly expressed desire for a clinician to support the surrogate during decision making in this study, perhaps the SUPPORT study can be interpreted as expressing the same void in the SDME as this study portrays. Researchers who were involved in the SUPPORT study recently conducted secondary analyses of that study. Hiltunen, Medich, Chase, Peterson, and Forrow, (in press) conclude, "The SUPPORT

study shows that judgment and mutual human support are required at many levels. For the involved clinicians, persistence and patience, time to be available when needs arise, excellent communication skills and an ability to be present to all involved in the process are crucial." Those findings are reinforced by the void expressed in the findings of this study.

Grief

As previously cited in chapter 2, studies that directly examined the surrogate decision-making role and/or process and the aftereffects of the SDME for the SDM were virtually non-existent. Viney (1991) found that when faced with their own imminent death or likely death of a loved one, people experience major changes in their reality. Viney found that negative feelings occur when people are not able to effectively interpret and anticipate events. The findings from this study portray the surrogates' inabilities to effectively interpret and anticipate events. The element of surprise, the portrayals of resource seeking behaviors, the expressed need for a translator, and the surreal nature of the SDMEs all describe an inability to interpret and anticipate events.

There are important practice implications drawn from findings that indicate that SDMs needed good communication and validation for their decisions. More than likely, health care providers described in these experiences were not aware of their impact six to 18 months after one of their many patients had died. The expressed need for validation from the health care providers stands out as something that nurses could address at the

time that would have meaning for the SDMs when reconciling those memories with their loss.

In this study, the surrogates also sought validation from others. The audiences for their decisions were apparent. Some participants overtly asked the health care providers what they would have done, but others sat in silence. The ends of the continuum are anchored by Joe aggressively seeking a neurosurgeon out of the system and a test only available in another state, while Camille passively waited for a "thumbs up" acknowledgement from the nurses that decisions had been made and the goals of care altered. Additionally, some of the participants told the person who had referred them to the researcher that the interview itself was a positive experience for them. It was evident at the conclusion of other interviews that the participant had answers they had been seeking and a welcomed chance to share their experiences.

The implications of these findings establish a need for health care providers to facilitate surrogate decision making in a manner conducive to maintaining their overall well-being as well as obtaining desirable patient outcomse. It also speaks to advanced practice nurses accountable for primary care. Nurse practitioners need to ask their seemingly healthy patients if they have had these experiences. Grief should be assessed anytime a patient loses a significant person in their life. However, this surrogate decision maker role adds another dimension to explore. The SDM, now in the patient role, may need validation of his or her decisions.

Higginson et al. (1994) found that there is strong evidence to support that a family member's perceptions of the patient's death experience alters during a bereavement period. These findings are also present in the SDMEs portrayed in this study. As previously discussed in chapter 3, the six to 18 months after death timeframe had merit for capturing the SDME. Several SDMs mentioned how their grief has changed over time. Just as Fred said grief comes "in waves", so too did Eileen's doubts and Michelle's difficulties with different memories of her aunt's life ebb and flow.

Impact Of Moral Decision Making

In previous studies it was found that a person's ethical ideology may not affect their decisions, but self-satisfaction and guilt are different for individuals who endorse different ethical ideologies (Forsyth & Berger, 1982). The findings from this study do not differ from those findings since all of the SDMs decided not to intervene to stop death, but they did differ in how they felt about their decisions. The level of accountability expressed by the SDMs, the second-guessing, and the guilt expressed all concur with the findings of earlier studies. The implication for nursing practice is found in what assuages those feelings during memory reconciliation of SDMEs after the loss. In some of the SDMEs shared, there appeared to have been almost no decision to make. Perhaps nurses and physicians could consider making that fact more explicit in order to prevent needless guilt. At a minimum knowledge that these feelings do occur should encourage validation efforts.

Research Implications

Overview

This study was intended as a beginning effort to describe the SDME. The research question was answered, but new or evolved questions are raised by the findings. Therefore, there is a need for further research. Specifically, because context was so critical to the essence of the SDME, factors and circumstances that affect the context need to be studied with more variability to more completely understand the phenomena. Factors such as: (a) cause of death, (b) culture, religion, and socioeconomic differences, (c) the grief trajectory, (d) SDM selection, (e) continuity of care, and (f) hope and denial need to be further researched. Additionally, more research on surrogate aftereffects, evaluation of any practice changes, and death themes needs to be conducted.

Cause of Death

The study sample was purposefully restricted to sudden, unanticipated illnesses. Further research on SDM for chronic and terminally ill patients must be done to capture the SDME that is not subject to the same timing and element of surprise issues. Additionally, it is reasonable to assume the SDME is altered when the illness is not as sudden since substituted judgment is clearly an important factor for this experience and there is more opportunity to elicit expressed wishes when deaths are anticipated.

Culture, Religion, And Socioeconomic Differences

This study researched predominantly Roman Catholic Americans of Western European decent although it was not designed to do so. Clearly, because death and dying

is value and culturally laden, attempts need to be made to research other cultures and other religions. Hern, Koenig, Moore, and Marshall (1998) call for ethnographic studies at end-of-life decision making as well. There are also socioeconomic issues that could be researched. Wolder Levin and Glick Schiller (1998) argue that the relationship between social class and medical decision making is a neglected topic in bioethics. The findings of this study which highlight trust and communication as important factors in the SDME reinforce the need to research the SDME, specifically as socioeconomic differences apply.

Grief Trajectory

The inclusion criteria for this study also limited the grief period that was studied. Therefore, the shorter-term and long-term effects of the SDME should also be researched. To do so the researcher would seek participants who experienced a death more than 18 months ago and seek participants experiencing the more acute grief, less than six months. These research efforts may yield different findings. While the findings from this study indicate there are negative aftereffects from the SDME, it is not known how long those effects last. Individual SDMs should be researched over time. Additionally, if the recommended changes to practice occur, then the SDME as researched in this study would need to be repeated to evaluate their impact.

Surrogate Selection Issues

Perhaps not every person should be asked to be a SDM. Consideration of that idea is present in the memory reconciliation efforts after the loss that were portrayed in this study, in Forsyth and Berger's (1982) earlier findings, and in what is known about grief

responses. However, Reckling (1997) found that situational factors appeared to be more important in determining which stances SDMs took during their decision making experience than the individual characteristics of those who made decisions regarding withholding/withdrawing. Reckling concluded that "context-dependent research is needed to more fully understand how organizational culture and professional role expectations for physicians and nurses affect end-of-life care" (p.44).

Research on what personal characteristics facilitate positive memory reconciliation during grief may inform SDM selection processes. Findings which may indicate which are the "right" people to be asked to represent the patient may minimize aftereffects of the role. After all, not wanting to be a burden was a reason that advance directives were completed and health care proxies were designated. Given the low number of people formally designated, this knowledge could be used by clinicians caring for these families just as the physician working with Camille's father was careful to pay special attention to Camille's sister's needs.

Continuity Of Care And Long-Term Relationships

There does not appear to be an easy way to assure that the physician caring for the patient at the time life-sustaining treatment decisions are being made is a physician who has a long term relationships with the patient. Neveloff Dubler (1995) "argues for a conscious focus on the ethical duties, emotional supports, and guidance owed by physicians to health care agents" (p.289). Findings from this study support a need to develop a system to provide that support. There are findings that suggest it may be

important, especially with the timing of decisions. To that end, more research that specifically investigates outcomes dependent on continuity of care and length of physician or nurse practitioner relationships should be completed.

The impact of continuity of care for the acute care nursing staff also needs to be researched. Understanding the complexity the SDME requires that the nurse be present to the patient, SDM, and other family members on a consistent basis. Hiltunen et al. (in press) reinforce this idea from the SUPPORT study findings.

Hope And Denial

There is an interesting relationship between hope and denial that should be researched. This is a difficult distinction to make when in context. Perhaps research could help distinguish when health care providers are fostering therapeutic milieus and when they are supporting denial. This would require phenomenological inquiry of both health care team members and family members simultaneously.

Evaluate Practice Changes

Evaluation research on any intervention put into place as a result of the previously described practice implication recommendations should be completed. Impact on interventions such as additional expert resources, translation efforts, validation of choices, guided witnessing to suffering and death, and family participation should all be completed if the interventions are altered. Staffing also appeared as an issue for SDMs. As such, perhaps assessing for differences based on skill level and ratios may have interesting results for administrative audiences.

Health Status Of The Surrogate Decision Makers And Others

It is also important to research the health status of SDMs versus others experiencing grief without having made any decisions. This should be done for more than one reason. First, it is possible that even though being a SDM has some aftereffects, it may be worse if you are not asked to make decisions for your loved one. Many surrogates described losing sleep thinking about their decisions, Tara was clinically depressed, some expressed guilt, and all of them described grieving. However, the finding that Representation of Other was an important part of the SDMs healing could support the possibility that not having decided would be worse.

Second, it may be important to assess changes in health status of the multiple members of a family to see if it is the overall experience or the added accountability of the SDM role that impacts the survivors. Given the multiple other dramas and relationship work portrayed in the study findings, it may be important to research the health of the family as a unit after this experience.

Death Themes

Lastly, there were additional findings about various death themes that present as asides to the SDME. There are opportunities to research these areas as well. Perhaps of particular interest is the question of the differences among when the SDM experienced the loss, when clinicians perceive the patient is 'gone', and when the patient physiologically died.

Education Implications

Overview

It is difficult to discern from the perspective of the SDM which aspects of nursing practice were a reflection of individual practitioners' abilities, or nursing knowledge about the phenomenon of concern, or staffing/systems failures of health care in the late 1990s. The fact that all 13 patients were treated in different patient care institutions, three of them outside of the Commonwealth of Massachusetts, appears to indicate that education of nurses on death and dying is needed. Still, another possible analysis could be that there exists a consistent failure of current health care trends to allow for sound clinical nursing practice at end-of-life.

Clinical Judgment

The sense of abandonment experienced by some during their SDME, the environmental control and high technology death scenes, the clinical judgment about pain management/palliative care, and the potential impact this experience will have on the SDM all need to be discussed with nursing staff. Additionally, nurses need to learn how to do values clarification work. Practice standards need to be established and taught to practicing staff nurses and nursing students.

Witnessing Suffering And Death

There also seems to be a need to educate nurses on how to guide families through witnessing suffering and death. Being able to anticipate events reduces grief (Viney, 1991)

and helps reconcile memories after the loss. Nurses need to be aware of how to guide family members through this process.

Cultural/Spiritual/Values Clarification Assessment

Assessing culture and spiritual beliefs and personal meanings of death is another area for nursing education. There are a lot of assessment needs presented in this chapter. Understanding cultural and spiritual meanings of death and dying is an area of practice that requires broad education as evidenced by the variety of spiritual responses in this study.

Advanced Practice Nurses

Advanced practice nurses who are accountable for primary care need to be educated to do values clarification work with their patients. They also need to learn how to assess grief and recognize when a former SDM is having difficulty with a protected memory or painful SDME. Some participants in this study did not get specific with their family members about all of the decisions they made and why they made them. Perhaps they would be more willing to discuss their wishes with their primary care providers.

Policy Development

The SDM role is a legally recognized role. The Patient Self-Determination Act (1990) and the President's Commission (1983) generated policies that describe the role as necessary to protect the constitutional right to privacy. The intention of the role is clear, but the findings from this study raise some questions on a philosophical level, macro policy level, and micro policy level. Philosophically, as a nation we need to decide if we treat patients only or do we feel obligated to the entire family, specifically the SDM. We also

need to ask if we are committed to follow-up with SDMs and grieving families, or is our work completed when the patient dies.

Macro Level

On a macro level we need to examine if the SDM role is viable over an extended period of time. Findings of this study point to more research needed to assess if advance directives serve the purposes for which they were designed. Do we need to have a public health campaign to initiate conversations instead?

If we remain committed to autonomy and families of dying patients, then can we afford the resources and time necessary to support this process? Should we resource a task force to develop standards of care when working with SDMs as we have for other nursing phenomena such as pain? Do we need experts, specifically trained, designated, and available to families making end-of-life decisions?

Given the concerns, Eileen in particular, raised about secondary gain when a caretaker decides to withhold and/or to withdraw life-sustaining treatments, we need to ask if we should allow caretakers to be SDMs when there are other options. Is it in the patient's best interests and is it "fair" to the caretaker turned SDM? Is it fair if they are not the ones asked? More information is needed.

Micro Level

On a micro level we need to research the impact of continuity of care, continuity of nursing care and of primary care. As we move into our next wave of managed care, are we going to facilitate the best patient/primary care relationships or are we going to move

patients through in the most time efficient manner? Findings from this study indicate there are hidden costs when a primary care provider does not have a positive relationship with their patients. It may cost more money in end-of-life care and in SDM future health needs to disrupt these relationships.

Summary

In summary, the SDME is a complex process with ramifications for the patient, the SDM, and multiple others. Those others include health care professionals asked to be present, to witness suffering, and to witness death along with the people who cared for the patient prior to any catastrophic illness. There are multiple findings in this study that indicate that health care professionals have much to learn about this time for families.

The practice changes recommended by this study would lead to a stronger nursing presence in helping SDMs with their decision making and memory reconciliation work. Practice changes may include adding resources with expertise to guide SDMs through this experience. The health care providers need to respect the SDMs' efforts to represent the other as a whole, prior to a catastrophic illness. Health care providers also need to demonstrate patience when present with these family members and help them control the environment as much as possible, in an individualized way which respects their patterns of decision making and is also respectful of their cultural and spiritual beliefs.

This study was a beginning effort to describe the SDME. Much research needs to be done to examine the experience in varied participant populations and patient situations.

In addition, the role of the health care team members should be researched for impact. The health of the SDM needs to be researched to assess the viability of this role and to advocate for resources if deemed necessary. The policy implications of added resources and effect on the health of SDMs should also be explored when more research is completed.

Lastly, educational efforts need tooccur on several levels. Health care providers need to be educated on the findings of this study as they direct a stronger role in validation, presencing, symptom management, and resource acquisition. Patients and surrogates need to be educated by their primary care providers, ideally before the loss of capacity. Society as a whole needs to be educated on aspects of dying, on the SDME, and on substituted judgment conversations. Perhaps then, SDMs will not feel they can not share the SDME with what they fear to be a potentially unsympathetic audience.

Education can create a bridge from current reality to the hope and expectation that nurses can make this poignant journey with the SDM and the patient. The nurse can work to transition the patient with respect and dignity to the end of their life. At the same time, the nurse can validate and guide the SDM, manipulate the environment, and provide anticipatory information so that the SDMs grief experience will include reconciliation of memories of having represented their loved one well. Therefore, the nurse will have impacted positively on the health of the surrogate.

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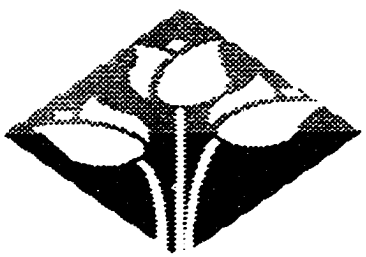
APPENDIX A

THE FLYER

- **Have you recently (six to eighteen months) lost someone you loved?**
- **Was their illness sudden or unexpected?**
- **Did *you* have to decide not to start or to stop medical treatment(s) for that loved one?**



If your answer to these questions is yes, then I want to hear about **your experience**. I am a registered nurse & doctoral student researching the effects this loss has had on you. You would be asked to participate in a private interview that would take approximately **one hour in your home or another location you find agreeable.** *Please pass this flyer along if you know someone else who could be part of this study.* **I need your help now to help others in the future. Thank you.**

For more information, please call:
Carolyn Hayes, Ph.D.(c), RN
(xxx) xxx-xxxx

Deciding to withhold/withdraw life-sustaining treatment from incompetent adults following unanticipated, catastrophic illnesses: A phenomenological study of surrogate decision makers' experience. BOSTON COLLEGE SCHOOL OF NURSING

APPENDIX B

BEREAVEMENT GROUP LETTER

Ms. Carolyn Hayes
[redacted]

July 24, 1998

Ms. [redacted]

Dear Ms. [redacted]

I am a registered nurse, currently employed at Massachusetts General Hospital, and a doctoral candidate at Boston College researching the surrogate decision maker role. I was referred to you and your organization by a recent widow who attends your meetings. It is my understanding that some of the participants at your meetings may meet the criteria for inclusion in my research study. I am writing to ask your assistance in accessing these potential subjects.

My study is intended to better understand and describe the experience people have when asked to make life-sustaining treatment decisions for loved ones in unanticipated circumstances. I am interviewing surrogate decision makers six to eighteen months after they decided to withhold or withdraw a life-sustaining treatment(s) for a loved one who subsequently passed away. The study is not intended to be of direct benefit to the participants, however I have completed six interviews and all six participants have been glad they took the opportunity to share their story. The interviews average one hour in length and are conducted at a location determined by the participant. Usually, the interviews are conducted in the participant's home.

Personal networking has led me to all six participants to date and a few more that I have scheduled for August. Predominantly, they have been children who made decisions for their parents. Based on previous research and my study findings to date, I believe the relationship the surrogate has with the patient contributes to different experiences. Therefore, I am hoping to represent varied patient/surrogate relationships in my study. Specifically, at this time I hope to recruit more spouses as participants. Enclosed are documents related to my doctoral dissertation research. Please consider letting your group participants know about my study. I would appreciate any assistance. If you have any questions, then please call me at [redacted]. Thank you for considering my request.

Sincerely,

Carolyn Hayes, RN
Doctoral Candidate, Boston College

Enclosure 3

APPENDIX C

TELEPHONE SCREENING TOOL

Telephone Screening Tool/Verbal Consent

Thank you for calling to participate in this study. I would like to start by introducing myself and the study to you. I will need to ask you some questions to see if your situation matches the circumstances that I am studying. Any information you give me on the telephone today and later if we meet will be strictly confidential.

My name is Carolyn Hayes. I have been a registered nurse for 15 years and am currently a doctoral candidate at Boston College. This research study is hoped to obtain a better understanding about the experience you went through, having to make life-sustaining treatment decisions for a loved one who passed away. This better understanding that we learn from you and the other participants in this study will hopefully help health care team providers better care for others in the future.

I am going to make a notation on a sheet of paper that I have discussed the study with you (*as per above*) and that you gave verbal permission for me to ask the following questions (*read questions to participant*). We can stop the telephone call if at any time you do not wish to continue.

1. How long has it been since your loved one passed away?

(*if not between 6 and 18 months, then stop*)

2. How old was your loved one? (*use name of love one once it is known*)

(*if the deceased was not 18 or over, then stop*)

3. What happened to your loved one that caused their death?

(*if not unanticipated, then stop*)

4. Did you have to make decisions for your loved one?

(*if no, then stop*)

5. What decisions were you asked to make?

(*if not related to life-sustaining treatments, then stop*)

6. What did you decide?

(*if they didn't decide to withhold or withdraw, then stop*)

I am going to mail a letter and formal written consent sheet to you so that you have it before we meet. (*Arrange time and location of the interview meeting*).

Date of telephone call

Participant's name

Carolyn Hayes

APPENDIX D

CONSENT FORM

CONSENT TO BE A PARTICIPANT IN A RESEARCH STUDY
Boston College, School of Nursing, Chestnut Hill, MA

Investigator: Carolyn Hayes, RN, Ph.D. (c)
Boston College School of Nursing
Chestnut Hill, MA

You are invited to be a participant in a study which will explore the experience you had when making decisions for your loved one at the time of their last hospitalization. The purpose of the study is to increase health care providers', nurses in particular, understanding of this experience to help guide their practice in the future.

If you choose to participate in this study, then you will be interviewed in the privacy of your home or another agreeable location. The interviews will all be done by Carolyn Hayes, a nurse and doctoral candidate at Boston College School of Nursing. The interview will take approximately one hour, and no longer than two hours. More than one interview may be requested. The interview will be tape recorded.

Minimal risk, stress or discomfort is anticipated as a result of participation in this study. Some questions may be considered personal and may be emotional. All interviews and responses are kept confidential and anonymous. You will select a fake name for me to use when writing about your experience. In other words, no one will be able to identify you. If you do become uncomfortable or do not approve of any specific questions, you do not need to answer them and the interview can stop anytime at your request.

This study may or may not be of direct benefit to you. It has not been designed to be of benefit to you. Rather, it is hoped that the knowledge gained from this investigation will enable health professionals to better assist others asked to make health care decisions for a loved one in the future. A possible benefit to you may be the opportunity for you to reflect on your decisions and feelings.

The identity of each participant who chooses to be in this study will remain confidential. Names will not appear in or on the taped interviews. A master copy of all participants will be kept in a locked file in Carolyn Hayes' home office. Only she will have access to this list. Your name will not be used in any scientific reports of the study.

You are free to choose not to participate in this study. In addition, if you do choose to participate; then you are free to withdraw at any time. That includes withdrawing even in the middle of the interview. Whether you choose to participate, or not to participate, it will not affect you in anyway.

Please feel free to ask questions after reading this consent form. Consider this research form and the consent form carefully before you agree or decline to participate.

Authorization: I have read this form and decided that I will participate in the project described. Its general purpose, my degree of involvement, and possible risks and inconveniences have been explained to my satisfaction. My signature also indicates that I have received a copy of this consent form.

Signature: _____
Date: _____

_____ _____
Signature of Principal Investigator Telephone

If you have any questions about this project or your rights as a research participant, please contact Carolyn Hayes at (xxx) xxx-xxxx.

APPENDIX E

HUMAN SUBJECTS APPROVAL

BOSTON COLLEGE

CHESTNUT HILL, MASSACHUSETTS 02167-3812

SCHOOL OF NURSING 617-552-4922/3123
Center for Nursing Research 617-552-0745 FAX

TO: Carolyn Hayes, PhD (c), RN [redacted]
FROM: Mary E. Duffy, PhD, FAAN
Director, Center for Nursing Research
RE: Expedited IRB Approval for Dissertation Research:
DATE: January 26, 1998

Your dissertation research proposal, ***Deciding to Withhold/Withdraw Life Sustaining Treatment from Incompetent Adults Following Unanticipated, Catastrophic Illnesses: A Phenomenological Study,*** has been reviewed under the expedited IRB review category. The purpose of the study is to describe the experience and meaning of surrogate decision makers who have decided to withhold/withdraw life-sustaining treatment(s) from incompetent adults following unanticipated, catastrophic illnesses. The results of the study, although not intended to have a direct benefit to participants, may provide an opportunity for them to reflect on their experience.

Subjects in the proposed study will be 20 adults who have served as surrogate decision makers for now deceased, incompetent adults who suffered an unanticipated life threatening catastrophe illness/event and for whom they made a decision to withhold or withdraw life-sustaining treatments two to eighteen months prior to the study. Subjects who volunteer to participate in the study will be interviewed one or more times by the researcher either in their homes or in mutually agreed upon sites for one to two hours. Interviews will be tape recorded. Subjects will be assured confidentiality and anonymity of their responses. Each subject will select a fictitious name for the researcher to use when writing about his/her experience. Subjects will be assured they do not have to answer any question asked by the researcher and can stop the interview at any time.

Because of the nature of this phenomenological study of a volunteer group of surrogate decision makers, there will be little known risk to these respondents. The proposal description contains the methods for accessing subjects, data collection, and a letters informing potential participants about the conditions for participation in the study.

This study has been approved under the expedited IRB review category on January 26, 1998. This IRB approval is valid for a period of one year. Any proposed changes to the use of human subjects in the project must be submitted in writing to the Center for Nursing Research for review and approval prior to initiation. Please contact me if you have any questions or need additional assistance. Good luck with your project.

cc: Joanne Scibilia, Chair, BC IRB Committee
Sara Fry, PhD, FAASN, Dissertation Chair

APPENDIX F

DEMOGRAPHICS

Demographics

Participant _____

DEMOGRAPHICS:

Participant's age: _____

The deceased's age at the time of their death: _____

Participant's relationship to the deceased : _____

Participant's religious affiliation: _____

The deceased's religious affiliation : _____

Participant's cultural group identification (the name of the culture with which the participant most identifies): _____

The deceased's cultural group identification (the name of the culture with which the deceased one most identified): _____

Participant's gender (circle one): Male Female

The deceased's gender (circle one): Male Female

APPENDIX G

INTERVIEW GUIDE

Interview Guide

1. Demographic questions. See appendix F.

2. Please tell me what happened to (insert name of the deceased).

3. How did it come about that you were asked to make a decision for (insert name of the deceased)?

4. What was it like for you to make that decision?

5. What does having made that decision mean to you now?

6. Tell me if you feel/think anything is different as a result of having had this experience that would not have happened if (insert name of deceased) had died without you having had to make a decision for him/her?

Added by interview process insights:

7. Do you have a health care proxy for yourself?

8. Tell me what was or what would have been helpful to you when you were making decisions for (the deceased's name).

9. Is there any part of this story you do share or hesitate to share with others?

APPENDIX H

SUBSTITUTED JUDGMENT

Surrogate	Substituted Judgment Meaning Units (from a formal document *, explicitly stated, or inferred by the surrogate)
Michelle	(Referring to Michelle and Michelle's aunt visiting Michelle's great aunt in a nursing home) ...she was the one to go see Auntie May, nobody else did...and she used to say like, "Oh that's never going to happen to me...I never want to do that, I just don't want to do it".
Fred	...when she was told in one of her lucid moments that she was more than likely suffering from cancer, her response was, she just said "Call Dr. K. I don't want to, I don't want my children going through this.
Camille*	Dad had a very explicit living will...Very. And he wanted no extraordinary means...when they would be in church and somebody would come in let's say maybe in a wheelchair and be pushed and somebody probably who had had a stroke or somebody that they had known. And my Dad would say, "Oh please, don't ever let that happen to me and don't wheel me into church and just let me be at home".
Mary*	Mom had it in her will that she wanted no form of resuscitation at all.
Tara	I mean she was very clear that she did not want a whole lot of extraordinary things done. She was very clear, um, but we were able to talk about what happened to her in that sudden unexpected situation (referring to a previous episode) and realized that if they felt it was some sort of septic thing and a metabolic reaction and uh, it was reversible. And it was reversible within a week.
Monica*	(Referring to a formal advance directive completed by her father and discussed with her). I had it in my hand and I did bring it to the hospital, when we were actually making those decisions; but I knew what it said. I knew what he wanted. I knew that I didn't agree with it, but I didn't need to look at it in the end. I knew what it said.
Paula	I didn't want him to live like that and he didn't want to live like that either. I knew he didn't want to. We talked about it before.
Patty*	...a piece of paper saying he didn't want to be on a respirator, he didn't want to be on life support or anything like that....
Joe	Jokingly she would say "Oh God and you would hear stories about people or see something on t.v. and she would say that is no way to live. I think we all feel very strongly about that...my mother loved life too much that she would want to have...to go on living the way she was in the end.
Eileen	And my mother did say at that point that she was okay with this...on Monday she just seemed to succumb.
Buck*	You go over it and over it in your mind right after and kind of come to a comfort zone with it, saying hey, listen that this was the only thing that I could have done and that was my mother's wishes anyway.

Surrogate	Substituted Judgment Meaning Units (from a formal document *, explicitly stated, or inferred by the surrogate)
Chrissy	...knowing his life, knowing where he was at, what were some of the satisfiers, what made him happy, how he viewed things...And I thought is he just giving us a sign, that like I just don't want this anymore and he cannot say it. Again, the articulation of it, but that I'm done. I just don't want this anymore.
Anne	...But Rachel didn't want to live that kind of life...and we (referring to MD) talked about it. You know I said Rachel ...would not have wanted to be resuscitated...So he knew that prolonging her life if this was what her life was to be like forever, that was not the kind of life she would want.

APPENDIX I

QUALITY OF LIFE

Surrogate	Quality of Life Meaning Unit
Michelle	She couldn't have tolerated life as less than the way she lived it. And she would have done any kind of effort or work that she could to make herself better, but it wasn't going to make her better.
Fred	My understanding was that, it was, there was very little hope for her to recover and have a quality of life afterwards...
Camille	And at that point we thought, knowing a person was that brain damaged, you know although he would sometimes follow us with his eyes in the room, not all the time. He thought there was some there, but you just didn't know how much understanding there was. But we felt that that wasn't probably a life. If he couldn't communicate, he couldn't squeeze your hand and he couldn't eat.
Mary	Real grief would be if they had somehow revived her whatever, resuscitated her and she was in a nursing home now with a feeding tube and 84 years old and um that would be grief that she would never have wanted to inflict on us.
Tara	...I mean, we're looking at things that are not ok. Besides the fact that I'm not sure what would have happened if she was...you know without blood pressure a long time...I finally said that I didn't see any point in going on. They didn't see any point in going on...
Paula	And if he can't live on oxygen, just on oxygen like he's been; then what's the sense of living, you know. Uh, that's what made me make my decision...
Joe	It's it's a terrible thing and it was the most heartbreaking thing, because no way in hell you would want to keep...if somebody you love is in that kind of condition you would want them to die at that point.
Eileen	Yes, but I saw that her quality of life was different from mine and she accepted that, so that's why. Like in the past we would have this discussion and my sister would get flabbergasted because my mother wanted everything done when she was already stroked. And my sister couldn't understand it. I had to give her credit. God she's a fighter. She is happy in her life; it is perception I guess. You know it is not for me but she made the most of her disability.
Buck	I'd want people to take me off, if there was nothing else they could do. If I wasn't going to get better or I couldn't go fishing. ...if I was alive just from tubes and wires and electricity, you know, I would want to be pulled.
Chrissy	...I think he could have said something that might have been his reasoning. Like I lived long enough and friends are gone, family's gone, his immediate sisters and brothers...heard him make comments increasingly...there is nothing to do, I'm lonely with you people gone all day. You know, its just time ...
Anne	I couldn't take away the fact that she didn't have the quality of life...

APPENDIX J

PROGNOSTIC CLARITY

Surrogate	Participant Meaning Units About Prognostic Clarity
Michelle	What helped a lot was that family meeting we had with the oncologist. He pretty much reassured us all that she was terminal and there was no ifs, ands or buts and there was no hope for any kind of rehab that would be more than sitting in a chair kind of thing.
Fred	...after the operation we had a clearer picture of what we were really talking about and literally everything was perforated. There really wasn't any hope for her to, you know, survive.
Camille	...but they could tell by the cat scan that there was tremendous damage up there. But they just really didn't know how much was paralysis, how much was brain damage. But I think probably the biggest deciding factor at we had wonderful physicians that counseled us, a lot, during the time..
Monica	...and I asked him that question every couple of days as we went through this and as I said to you he said on Christmas eve "I'm not sugarcoating this Monica, I still believe he'll get better. Our best information is that he will recover from this". He did sort of modify it a little bit once we got into like ten days.
Paula	The doctor, he didn't tell me much...I just and finally I just asked this nurse you know everybody's avoiding me you know what's the story? You know. And, this was um two days before Christmas I asked her and she said it was the end stage emphysema. You see I didn't know there was an end stage to it...I wanted to know my options before I even pulled him off this, you know. There was no option. There were none. There was no option. As far, either, if he went through the operation his heart wouldn't take it or his lungs wouldn't take it.
Joe	It's one of those things where you kind of hope, we were getting to the point where we were really hoping they would find something. Like it was definitely a stroke or it was definitely, uh, so you can deal with it at that point, not knowing for three weeks and watching her steadily decline and not knowing, feeling helpless that was the worst part of it as far as that goes.
Eileen	I struggle with it. Now that I am talking about it again, like, when he mentioned peritoneal abscess I just felt like oh my God why did I jump can't right into and I remember...There was absolutely nothing, they must have done labs...I can't imagine that I would be that powerful to direct everything...my God is there something I could have done, to point this out. Because it was definitely the pain med that caused her to fall. Did she suffer a subdural? I don't know by the time she got to the hospital she wasn't even able to drink the contrast to do, that's what they were going to, she wasn't even able to drink so we could be conclusive as to what it was...
Buck	He explained exactly the condition of my mother and the progress that was going to be made which was none, and by actually pulling the plug she would die. There's nothing keeping, she is, her brain was dead and there was nothing keeping her alive.

Surrogate	Participant Meaning Units About Prognostic Clarity
Anne	My brother said it would not have mattered because her immune system was so depleted as it was from her illness no matter when they would have instituted the antibiotics or even needed to put her on a respirator then because her ABG's would have been probably totally out of whack even when she was conscious. Um, they would have intubated her and put her on antibiotics and he felt the same course would have taken place. So that was reassuring for me.

APPENDIX K

WITNESSING SUFFERING

Surrogate	Meaning Units About Suffering
Michelle	How can I watch her go through this pain? You know I tried to look at every, you try to look rationally, at everything...I just couldn't take it. I couldn't take one more day like that. And that's when we said just we need to keep giving her stuff. She's, she's just say "I, my head hurts so much...And she stopped saying "I don't want to die"...And she started saying "Help me"...And that's when I just, you know, paged her doctor right from the room and said she needs medicine. She needs something.
Fred	She was, you know her face was all raw. She was emaciated. All kinds of different things and there was no hope for recovery...Just really flailing around and being very, very angry. Her face, her whole being felt angry. And even when she wasn't coherent, she was just angry.
Camille	...because he would grab his leg at one point, he would grimace with his face. This was when he was not communicative and it's just hard to see your loved one make a grimace like that.
Mary	...and she was thrashing. Really, really thrashing. Her color was very, very bad.
Tara	So she was so swollen. I mean it was just. That's the thing that I still you know. I mean I can see her real face and I can, but I also can remember looking at uh, it was so grotesque kind of you know...And I thought, no she doesn't need to suffer anymore.
Monica	I mean his skin was spread taught over his bones. His facial bones. AN uh, he was unrecognizable from that. I would not have known that that was my father. An um, you know, you just say to yourself, well, you just keep going because you're so immersed in this, this difficult stuff. It did, make a deep impression on me, but it didn't stop me, it didn't drive us away from the bed or stop us from that sort of presencing that we were involved in at the time. ...So by Friday morning he was very mottled. And, I, um, that was an advantage because you don't see that kind of mottling and have any question as to whether death is imminent.
Paula	You know his private area was swollen and it was just so sad seeing that. Um, so he had and you know he didn't suffer because they were giving him morphine and stuff like that. ...And uh, but in the back of my head I say well he's not suffering no more either.
Patty	I don't dwell on it, was he or wasn't he. So, but he didn't feel any pain because he was in no pain, just like his stomach was bloated that day.
Joe	Geez and each day that I went in there and I would notice a deterioration from the previous day and in her symptoms, in her actions, and in her whatever...Like I said at the end of it there, I thanked my lucky stars that she went as quick as she did because I saw some of the people that had been on that floor at that nursing home, for years, literally years and I just felt so sad for them, so bad for them.

Surrogate	Meaning Units About Suffering
Eileen	Like I said now talking about it more I am really visualizing her pain and it's making me like, getting the inner voice that you did the right thing.
Buck	The only good thing was that she wasn't in any pain.
Chrissy	...because the focus of his life was meals that to watch him drink a cup of coffee with thick it in it. I can remember this vividly and thinking this is gross...We really I think were in sync with the decisions and that was good, so there wasn't conflict around that. Uh, he didn't suffer and that was a big, big part.
Anne	I'm thinking I wonder if I delayed the decision for knowing what she would have to go through once I did call an ambulance. I know what would have been because of my medical background...Rachel didn't suffer emotional pain. You know she loved life and loved it all the way up to the end. She loved it all the way up to the end.

APPENDIX L

TIME

Surrogate	Meaning Unit About The Need For And/Or Value Of Time
Michelle	Her aunt needed time to prepare to die ...but I guess I believe n my heart that you know she had a lot of visits from priests and a lot of signs that she felt a little better about...or maybe it gives you time to sort out what's important to you and reflect upon your life or I don't know. I guess I believe you can do that even though its at the end of your life and I'm sure she did plenty of that.
Fred	Needed time for other family members to reach the same conclusions ...there were a few people that just weren't ready and weren't prepared to make that kind of decision and that at that time...I think that the decisions, although I might not have made them, I think they opened up, they gave us enough time because it was such a difference from a week before to then.
Camille	Needed time for a trusted health care provider to return I think he wanted to be very clear that we understood what was happening...my Dad's doctor who my Dad loved dearly was coming back from China. We said, could we do you think we could hold. I think it was two more days, and he said of course and maybe you would like to talk to this Doctor Beach and get his opinion. We said we would, that would be comforting for us...
Camille	Needed time to decide to withhold and withdraw That you don't give up on the person the night that they have the stroke. That you decide, that your own decision making can change in the course of all these...
Tara	Needed time to decide to withhold and withdraw ...in retrospect she was probably bullshit at me that I let them work so hard. You know. Really, truly. Um, but I could, it was such a shock that I just like couldn't say well don't do anything. And I don't think anyone asked me to say that at that point. I mean, I think they were all equally in shock.
Monica	Needed time for her mother to return to the hospital And fortunately for me, um, nobody was saying, there was no push on that. I mean if he had died, well he died; but there was no need for us to institute the decisions that were made about upping the morphine and withdrawing the oxygen until after she came back.
Paula	Needed time to be sure she had no other options I wasn't ready to let Harry leave me because I didn't know what was wrong with him...

Surrogate	Meaning Unit About The Need For And/Or Value Of Time
Joe	Needed time for everyone to reached the same conclusions I mean I think it was one of those things were again some of us arrived at conclusions quicker than others or at least the inevitable. Yes, some of those things I wanted to do quicker to get to that point where we knew exactly what we were dealing with and then we could take the steps towards what we could do to attack it or just help us prepare ourselves for the inevitable and get to that next phase.
Buck	Needed time to decide to withhold and withdraw So the doctor was kind of pressuring us to abide by that and we, ...I was against it...I just didn't want to give up, you know. ...I don't know to make sure that there was nothing else that we could do, that we did everything possible.
Chrissy	Needed time for her daughter to accept decision not to treat I think she really did understand and you know then she could see where he was coming from and would say that, which is good. And she had a little bit of time.

APPENDIX M

VIGIL EXPERIENCES

Surrogate	Vigil Experience Meaning Units
Michelle	The benefits ...we were having like a vigil...Actually I have to admit that those two months, or less than two months, six weeks the whole process. We became close as a family, closer as a family...I learned way more about them than I had ever expected.
Fred	The benefits I personally came away from that experience feeling closer to my family. Understanding them somewhat more... not regretting the decisions...even the part about whether or not we should have done something earlier...It allowed us as a family to do the work that we needed to do...It (referring to a death without a decision) would not have given us the opportunity to care for her in a different way, it wouldn't have brought us together in the same way. The harms (referring to a sister-in-law)...she was so frightened and emotionally drained. It had been a couple of days since she had slept.
Camille	The benefits So, after the surgery was completed by this time we had many family members who had joined us...it was a very loving time though because we would go in and spend uh quite a bit of time with him and just talk to him... The harms It was a very stressful time for my mother because my sister, my sister's response through all of this was, um, what would you say, uh, kind of churning up the family emotions...I think we needed to emotionally take care of ourselves too. This is going to be a long haul, could be a long haul, it could be you know days; but it could be you know more than a week.
Mary	The benefits Noone, the grandchildren, they seized upon that, that I said we have no regrets and they all said "Ya, we don't. We have no, we were good grandchildren and we" and it was just a great moment. The harms Because I think some of my sister's kids probably wanted to comfort me and be comforted by me, but they saw the need was elsewhere (see section on unresolved issues).
Tara	The benefits Sister Joan, a friend and she's become much more of a friend over the last year. But um, she's on the pastoral staff here and she's um, I don't think she hardly ever left my side for those two days that this was all going on. Between her and Anna one of them was always there.

Surrogate	Vigil Experience Meaning Units
Tara	The harms I probably needed to keep busy. I had some things that I had already set up with patients and um, that I thought that that's what I'd do. I mean, uh, I don't think I was thinking too clearly.
Monica	The benefits ...you could see what people are made of. You could see what living and dying means, you could see what suffering and stamina and enduring and all that stuff we saw. The kind of thing that epic novels try to have you see. I saw in the members of my own family at that time.
Paula	The benefits I stayed with him through the whole thing and through ICU because there was a shutdown anyway at work. And, I slept in ICU...He was waiting for her (referring to Harry's daughter) to come up because he saw everybody else. He was waiting for people to come and that's how I knew he was going to go. The harms I didn't sleep at all, just doze... And I would only leave him with certain nurses that I really trusted after that had happened (referring to incident with nurse detailed in another section).
Joe	The benefits We had a very close family and um we were all helping each other through this thing. Its one of those things where we always have been close and my mother was always, kind of like, without a doubt, the ring leader of everything...like I said we were always there, we were always their together every night, pretty much every night we were all there at various times. We would have conversations about what was going on, what they did, what the issues are, what do we think and stuff and we really didn't disagree on too much of anything else. The harms ...its an emotional drain. You end up spending pretty much every waking hour there, um, sleeping there on the floor in the room and you know then you have to get up and go to work in the morning or stay until 1 o'clock in the morning and go home and get a couple hours of sleep and then go to work. Go to work and then repeat the same thing the next day.
Chrissy	The benefits ...my nieces and nephews and the impact , but I think again they took cues from the family structure as to how we were responding and um the importance of that and watching you like "if she is upset, then I'm going to be upset. If she is okay, I'm okay". It isn't like we didn't cry together, when we were all in the room and looking, but it was kind of like a happy cry, or a comforting cry. That this was okay

Surrogate	Vigil Experience Meaning Units
Anne	The benefits I would have rather have it over rather than prolong it, but then as I sat back and looked at it, I was not the only person involved in her life. It was almost like a selfish thing because it was me. But after watching the people that were important grew that, it, it watching them come in and out...It was good for them, but then it was so good for me to hear people do that. And since she couldn't be waked this was a time for people to get the opportunity to express how they felt about her...It was a good testimony to her and one she deserved, one she deserved.