

**SURROGATE DECISION MAKING FOR THE CRITICALLY ILL
INTENSIVE CARE UNIT PATIENT**

by

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A thesis submitted to the Department of Nursing

In conformity with the requirements for

the degree of MSc

Queen's University

Kingston, Ontario, Canada

(April, 2008)

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Abstract

Background Although the technological complexity of the intensive care unit (ICU) is often focused on saving lives, creating consumer confidence in miraculous recovery, it is more frequently becoming a place to support the dying. Because of the serious nature of critical illness, patients are unable to communicate their needs and desires, leaving their families to make decisions for them. Although family members are often called upon to communicate the critically ill patients' wishes, values, and views, many report feeling anxious, unprepared for, and burdened with the task of making decisions for their family member (Azoulay et al, 2001; Chambers-Evans & Carnevale, 2005; Murphy et al, 1992; Sjokvist et al, 1999; Swigart et al, 1996). The distress which surrogate decision makers describe, may lead to difficulty mobilizing appropriate coping mechanisms, which may affect their ability to make appropriate decisions for their family member's care. Hence, a more in depth understanding of the surrogate's experience is critical to plan effective interventions and provide anticipatory guidance to support the process of making decisions around end of life care.

Objective The purpose of the study is to describe the surrogate decision makers' appraisals of the demands of decision making for a critically ill adult intensive care unit patient and the coping strategies employed by them during this experience.

Method A descriptive study design using a qualitative interviewing approach extracted perceived stressors and coping strategies used during the decision making process using systematic focused thematic analysis guided by Folkman and Lazarus' Stress and Coping Paradigm.

Findings Respondents appraisals identified the following perceived stressors: doubt of self efficacy, unknowns, impingement of real life in the process, and problematic relay of information. The surrogates' perception of their ability to manage the decision making process required their awareness of the decision making role and magnitude of illness, their realization of

their need to form partnerships with others, to have time to reflect to make the right decision, reflections on prior discussion and experience, and their appraisal of the patients' suffering. Participants described emotion and problem based coping strategies they employed during the task of making end of life decisions for the incapacitated critically ill intensive care patient. To emotionally justify their decisions, surrogates' referred to their understanding of patient wishes. They also sought solace and comfort from the health care staff. In addition, surrogates used strategies to solve problems encountered. These included dealing with others, employing strategies to decrease their uncertainty and mobilizing time to process the events unfolding.

Conclusions End of life decisions in the intensive care are complex and demanding. A better understanding of the process may guide health care professionals in developing focused interventions to assist surrogates through a painful process with as little scarring as possible.

Acknowledgements

The support and expert guidance of many individuals helped make this thesis possible.

Thank you to Dr. Cynthia Baker for her unwavering commitment and support to a graduate student set on changing the world with her first research project in a clinical environment which was initially foreign to her. Dr. Baker's flexibility, willingness to partner with other disciplines and commitment to education and research made this project possible.

Thank you to Dr. Daren Heyland & the CARENET group who provided insightful feedback and continuing encouragement through this process. The passion this research group demonstrates as they strive to improve end of life care for their patients as well as support junior researchers is inspirational.

To the members of my thesis committee; Drs Cynthia Baker, Daren Heyland and Marianne Lamb, each of them did not hesitate to provide unlimited time and support.

Thank you as well to Naomi Jones for wading through many hours of interview transcripts and struggling with me to accurately portray surrogate perceptions.

A special thanks to the staff of the Kingston General Hospital Intensive Care Unit, in particular the clinical nurses who recognized this research as important and did everything they could to facilitate the interviews no matter what time of day or night.

To my family and friends for their encouragement, love and support which did not waver, even when forced to talk about end of life for two years straight.

Most of all, my heartfelt thanks goes out to the surrogate decision makers, who in the midst of making life and death decisions took the time to share their experiences.

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Chapter 1

Introduction

Although the technological complexity of the intensive care unit is often focused on saving lives, creating confidence in miraculous recovery, it is more frequently becoming a place to support the dying. Because of the serious nature of critical illness, many patients are unable to communicate their needs and desires, leaving their families to make decisions for them.

Although family members are often called upon to communicate patients' wishes, values, and views, they report feeling anxious, unprepared for, and burdened with the task of making decisions for their family member (Azoulay et al, 2001; Chambers-Evans & Carnevale, 2005; Murphy et al, 1992; Sjokvist et al, 1999; Swigart et al, 1996). The distress which surrogate decision makers describe, may lead to difficulty mobilizing appropriate coping mechanisms, perhaps decreasing their ability to make appropriate decisions for their family members' care. Hence, a more in depth understanding of the surrogate's experience prospectively is critical to plan effective interventions and provide anticipatory guidance to support the process of making decisions around end of life care. Both the protection of patient autonomy and improved health outcomes for surrogates depends on a more sensitive engagement with decision makers in the process (Meeker, 2004).

The thesis is presented in manuscript form. The manuscript is comprised of three major components, guided by three main research questions.

Chapter One: Introduction and Background

Chapter Two: Surrogate Decision Makers for the Critically Ill Intensive Care Patient: Appraisal of Ability (Manuscript 1 to be submitted to The British Journal of Nursing Research following thesis defense).

Chapter Three: Surrogate Decision Makers for the Critically Ill Intensive Care Patient: Perceived Stressors (Manuscript 2 to be submitted to The Journal of Critical Care Nursing following thesis defense).

Chapter Four: Surrogate Decision Makers for the Critically Ill Intensive Care Patient: Coping Strategies. (Manuscript 3 to be submitted to The Journal of Palliative Care following thesis defense).

Chapter Five: Summary and Implications for Practice and Future Research.

Background

Over the last 50 years, advanced life support technology has improved care delivery and patient outcomes, including the ability to prolong life. Unfortunately, idealistic perceptions of the technological advances lead to higher expectations for life sustaining treatments than ever before, often with unrealistic goals of recovery. Therefore as more patients are dying in intensive care, families understandably report shock, disbelief, and feeling overwhelmed with information, and paralyzed by emotions, affecting their ability to hear or think straight (Chambers-Evans & Carnevale, 2005; Curtis et al, 2001). Family members' uncertainty, separation from the patient, distress, anxiety and fear have been found to contribute to inaccurate expectations, compound fears, foster misassumptions and increase family stress (Coulter, 1989; Williams, 2005). For health care professionals, the goal for patients and their families is a new state of wellness or a peaceful, dignified death. The apparent disconnect between health care professionals and surrogates making decisions for the critically ill patient makes achievement of these goals becomes tremendously difficult when expectations do not match reality (Yeager, 2005).

It is not only surrogates' emotional state that influences the process of making end of life care decisions. Numerous health care professionals are involved in end of life care in the intensive care unit, often contributing to the complexity of the process (Azoulay et al, 2004; Ho et

al, 2005; Hunter, Dean, & Gowan, 2006). Health care professionals often find it easier to continue treatment than to enter into emotionally charged conversations around end of life care, possibly for some because death is still perceived to be an unacceptable outcome in the intensive care unit (Cassell, 2003; Lang & Quill, 2004; Le Claire et al, 2005; Moreau et al, 2004; Simmonds, 1996). Further difficulties in decision making may result from disagreement between multiple family members magnifying surrogate anxiety. In order for health care professionals to be able to move from curative to comfort oriented care, a consensus among all parties involved in the decision making process must be reached (Badger, 2005). Without such a consensus, surrogate decision makers may be at risk for ongoing emotional distress and long term non acceptance of the decision (Azoulay et al, 2004; Jacob, 1997; Boyle, Miller, & Forbes-Thompson, 2005).

Since the late 1970's, the needs of family members visiting a critically ill intensive care patient have been identified, providing some guidance to health care professionals to help family members cope with a loved ones' critical illness (Delva et al, 2002; Molter, 1979; Mendonca & Warren, 1998). The ability of the intensive care unit to meet family needs has been evaluated through family needs and satisfaction surveys (Azoulay et al, 2001; Chavez & Faber, 1987; Dodek et al, 2004; Heyland et al, 2002; Johnson et al, 1998; LeClaire, Oakes & Wienert, 2005; McDonagh et al, 2004; Myhren et al, 2004). The most commonly identified area for improvement is communication – most often between physician and surrogate (Boyle, Miller, Forbes-Thompson et al, 2005). As a result, communication frameworks have been developed to guide physicians in end of life discussions. Information brochures in waiting rooms assist surrogates' to understand diagnoses and team focused communication improvement strategies have been implemented to assist families in making decisions for the critically ill intensive care patient (Ahrens et al, 2003; Curtis et al, 2002; Medland et al, 1998; Prouchard et al, 2001; Verhaeghe et al, 2003). However, the limited success of these interventions in alleviating surrogate decision

makers' stress over the longer term, indicate that caution must be taken when implementing improvement projects based on survey results alone. Success or failure of interventions requires further understanding of the patients' (families') perspective of care and treatment in the midst of the process (Bailey et al, 2005; Dowling et al, 2005).

Recent studies have reported that as many as one in five hospitalized patients die in the intensive care unit, many with no previous discussion of their wishes regarding life sustaining treatment (Angus et al, 2004; Booth et al, 2004; Heyland et al, 2000). The nature of critical illness means that the patient is unable to make the decision and where a surrogate decision maker has not been appointed, the next of kin is approached to make these decisions. Many families of critically ill patients have expressed a desire to make treatment decisions on behalf of their relatives in consultation with the physician, even if they have had no prior discussion with the family member concerning desires or wishes in the event of illness (Booth et al, 2006). Furthermore, health care professionals are required to consult the next of kin in a health care system where autonomy is valued. Even though families making these decisions have been found to have high levels of anxiety, inability to remember the discussions, to misunderstand the prognosis and to feel burdened with the responsibility, they still want to be part of the process (Baylis et al, 2004; Jacob, 1998; Mendonca & Warren, 1998; Meeker, 2004; Prendergast & Puntillo, 2002).

End of life decision making is a highly subjective process for surrogate decision makers who integrate information from health care professionals into their own knowledge of the patients' preferences and interpret and decide using their own values and perceptions of the situation (Catalano, 1997). Because end-of-life care decisions emerge from a complex and largely unexplored personal domain of experience, health care professionals require an in-depth understanding of decision makers' perspectives for improvement (Jacob, 1997). Questionnaires,

surveys or one point in time retrospective interviews, may not capture this, leaving unidentified, perhaps amenable, sources of stress and responses to the demands of the decision making process. Furthermore, little literature to date recognizes that end of life care decisions often occur sequentially over several days (Faber-Langendoen & Bartels, 1992). After decisions have been made mental processes such as repression of an uncomfortable stressful experience may distort recollections of the decision making experience (Baggs & Schmitt, 2000). For instance, stress examined in intensive care family members was found to be highest at the time of intensive care admission and plateaus at day 6, suggesting different coping strategies are essential to allow the family to function at different points in time in the decision making process (Halm et al, 1993). Emotional and psychological responses may interfere temporarily with the family's understanding, however over time the responses may change (Young, 2000). A fuller understanding of the surrogates' perceptions of this complex process as it unravels over time, is important for health care providers to provide family surrogates with supportive and effective care (Jacob, 1997; Shidler, 1998).

As the number of critically ill patients who may require comfort rather than curative care in the intensive care unit increases, surrogates' involvement in the decision making process is an important area for study (Heyland et al, 2000). Although recent studies have documented decision making as a stressful experience, they have not fully described the surrogates' perception of this stress, nor recognized that life or death decisions are very rarely instantaneous but occur over a period of days or weeks in the intensive care unit (Azoulay et al, 2005). To date, research has revealed portions of the surrogates' decision making experience retrospectively using structured questionnaires with limited fixed alternatives, there is no certainty that the stressors and coping mechanisms of surrogates during the actual decision making process have been captured (Azoulay et al, 2001; Chambers-Evans & Carnevale, 2005; Heyland et al, 2002;

McDonagh et al, 2004; Swigart et al, 1996; Pouchard et al, 2001; Wiegand, 2003). Because interventions must be delivered in real time not in retrospect and must address problems as they occur, they should not be designed solely on the basis of what persons remember of the experience (Baggs & Schmitt, 2000).

As health care professionals, it is important to grasp surrogates' perceptions of the complexities of the process decision making around end of life care in the intensive care in order to effectively support them during this difficult time. Without this understanding, it is difficult to assist surrogates appropriately in this process, and may lead health care professionals to infringe on the rights of surrogates making decisions.

Background to Thesis Study

The thesis topic was initially chosen because of my interest in critical care and observation of family members participating in difficult decisions for an unresponsive, non-participatory intensive care patient. Although new and emerging literature document surrogate decision maker post traumatic stress three to six months following participation in the process of making decisions, it reveals very little focused research on surrogates in the midst of decision making. Understandably, clinical practice revealed few guidelines to assist surrogates through this process.

This thesis was undertaken to describe the decision making process from the surrogates' perspective, gaining a better understanding of the demands as identified by surrogates, their ability to cope and appraisal of ability to participate in this process.

Research Purpose

A descriptive study was undertaken to generate knowledge about the decision making process from surrogates' perspectives. The purpose of the study was to describe the surrogate

decision makers' appraisals of the demands of decision making for a critically ill adult intensive care patient and the coping strategies employed by them during this experience.

Research Questions

The following research questions guided the study.

1. What are surrogates' appraisals of their ability to make serious treatment decisions for a critically ill, intensive care adult patient?
2. What are the stressors perceived by surrogate decision makers when making serious treatment decisions for a critically ill, intensive care adult patient?
3. What coping methods are used by surrogate decision makers to manage or modify stress related to making decisions for a critically ill, intensive care adult patient?

Sensitizing Theoretical Framework

Lazarus and Folkmans' stress and coping paradigm was used as a sensitizing theoretical framework to guide the researcher in examining and analyzing surrogate decision maker's perceptions of their experiences. This framework addresses the ongoing, reciprocal relationship between a surrogate decision maker and the intensive care environment, including the influences of situational and personal factors. These factors are recognized as influential in the process during stress appraisal and may be regarded as antecedents to the response. The paradigm identifies stress as a dynamic phenomenon (Lazarus, 1984) based on individuals constantly appraising and reappraising environmental demands in light of their perceived effects on them and on their perceived ability to respond to them.

Clear definitions related to appraisal, stressors, and coping derived from this model are central. Stress is defined as a state within resulting from the interaction of the organism with noxious stimuli or circumstances, including personal characteristics and nature of the

environment (Lazarus, 1984). The stress and coping paradigm acknowledges there are important differences in stress response. Performances are not uniformly impaired or facilitated by a given potential stressor and therefore one cannot predict performance simply by reference to stressful stimuli; to predict performance outcomes there is required attention to the psychological processes that create individual differences in reaction (Lazarus, 1984).

The paradigm suggests the appraisal of a situation is a two step process. The primary appraisal is the process of categorizing an encounter, in its various facets, with respect to its' significance for well-being. It is here the individual registers the meaning of the situation, begins an evaluation of perceived stressors, and their possible consequences. It is evaluative, focusing on meaning or significance which takes place continuously. Stressors are those factors that the person appraises as actually or potentially harmful or an actual or potential loss. Secondary appraisal follows, and refers to individuals' assessment of their ability to manage the stressors involved (Lazarus, 1984).

The person responds to stressors through coping, choosing a specific manner in which to deal with the perceived harm or loss. Coping is the process of restoring balance (equilibrium) between excessive demands and inadequate resources (Lazarus, 1984). Coping resources include individual and social network characteristics available and that may mediate or moderate the individuals' response to a stressor. People use a variety of strategies to cope with stressful situations, although individuals may have a preference for one type. Two main categories of coping are identified: problem oriented coping and emotionally focused coping. Problem oriented coping refers to adjustments that are deliberate actions by the individual directed at the cause of stress. Emotion focused coping describes the adjustments made by the individual that are focused on altering the person's emotions resulting from the stress-inducing situation.

Methods

A descriptive study design using a semi-structured interview schedule was employed to collect and analyze qualitative data regarding primary and secondary appraisal of ability in end of life decision making, perceived stressors and coping strategies at two points of time in the decision making process. The first was during the period when the patient was at risk for having to make an end of life decision and the second during the period of end of life decision making. The goal was to capture as much of the decision making process from the surrogates' perspective as possible. Such an approach acknowledges that individuals may identify different stressors and engage in different coping strategies at different points in time in the decision making process (Karlavish, 1996; Young, 2000). Therefore more than one interview was completed to capture as much of this process as possible.

This methodology was also responsive to the subjectivity of human experience. By collecting qualitative data the researcher was able to provide intricate details about thought processes and emotions which are difficult to extract through other research methods. Systematic thematic analysis was used to identify perceived stressors, perceived ability to manage the decision making, and coping strategies employed by the surrogate decision maker facing end of life treatment decisions.

Participants

A convenience sample of 19 surrogate decision makers of critically ill adult patients at risk for making end of life care decisions participated following consultation and recommendation by Intensive Care Unit staff including registered nurses, intensivist and social work.

The following inclusion criteria were used in the selection of study participants. The patient for whom the surrogate was making decisions must be an adult (over the age of 18), admitted to the intensive care unit, incapable of making treatment decisions necessitating the

potential role of an identified surrogate decision maker in the decision making process. The patient's risk of mortality must be assessed as greater than 50% by the attending intensive care physician after 24 hours of admission. In addition to patient characteristics, the surrogate for the critically ill patient must be over 18 years of age, speak English, be literate and have visited the patient they are making decisions for at least once in the intensive care during current admission. The surrogate approached to participate must be identified as the decision maker on the patient's medical chart. Participants must be aware of their role as potential surrogate decision maker.

Surrogates were excluded if the relative they were making a decision for was hospitalized because of attempted suicide.

Recruitment Process

Recruitment relied on recommendations from the registered nurse in charge, attending physician, or critical care fellow of patients for whom an estimated probability of death in intensive care exceeded 50%. Research indicates that physician estimates of a low probability of intensive care survival are more strongly associated with intensive care mortality than baseline illness severity, evolving or resolving organ dysfunction, and use of inotropic agents or vasopressors (Rocker et al, 2004). In addition, the patient and surrogate met the inclusion criteria as outlined above. Surrogate decision makers were initially approached by the investigator after verbal consent to approach was obtained from the surrogate by a member of the health care team. The researcher invited surrogates to participate in the project after consultation with and agreement of attending medical staff.

Research Milieu

The medical-surgical unit is a closed 21 bed unit in an academic teaching center. Attending physicians rotate through in pairs on a weekly basis, nursing staffing ratio is most often

1:1, social work, and pastoral care are available during the week with on-call availability after hours and on weekends.

Data Collection

Three instruments for data collection were used. The first was a patient profile used to collect the medical history of the patient requiring a surrogate decision from the patients' chart (Appendix C). The patient profile information provided data about the patient's medical condition that may influence the decision making process such as; cause of intensive care admission, previous illness history, and illness course. The second instrument was a brief, one page socio-demographic questionnaire completed by the surrogate decision maker at the first interview (Appendix D). The data collected from this questionnaire provided background information about variables previously identified in the published literature that may influence the surrogate in the decision making process. These included gender, education, age, previous experience with the intensive care unit, and relationship to the patient. Finally, surrogates were interviewed using a semi-structured interview schedule with broad open ended questions and probes designed to encourage surrogate decision makers to identify perceived stressors, appraisals of their ability to manage these demands, and coping strategies employed (Appendix E). Interviews are an essential means of eliciting information about human processes and provide a rich source of data about complex, emotionally laden topics (Dilman, 1978; McCauley, 1987; Morse, 1995). This interview schedule was developed from the literature and personal experience. The questions were reviewed by a group of interdisciplinary healthcare professionals familiar with the decision making process including a registered nurse, medical doctor and intensive care unit social worker (Appendix E). No assumptions were made, however regarding the nature of stressors or coping strategies, allowing the subjects to describe their experiences.

The patient profile was completed following surrogate consent and a time to meet the surrogate in a private room near the intensive care unit had been arranged. The first interview took place after a potential surrogate had been informed by the intensive care unit Medical Co-Director that the patient was critically ill. The patient was at risk for an end of life care decision and unable to make decisions for him or herself. The investigator approached the potential surrogate no earlier than 24 hours after patient admission to the intensive care, allowing time for the surrogate to become more familiar with the intensive care unit environment itself, potentially decreasing the amount of new environmental stress (Halm et al, 1993). This also allowed for the attending physician to determine mortality risk of greater than 50%. The first interview took place within 24-72 hours of admission to the intensive care. The socio-demographic questionnaire was administered at this time.

In order to capture the decision making process over time, a second interview was conducted. It took place after the patients' prognosis had deteriorated necessitating discussion with the health care team and the surrogate regarding change in therapeutic treatment goals. These treatment options included but were not limited to, use of mechanical ventilation, inotropes, antibiotics, and dialysis. Each of the two interviews were audio-taped using a Sony digital voice recorder in a private room with a closed door near the intensive care unit.

In the case of three patients' who survived the intensive care stay, following a decision making process, the patients' surrogate was interviewed within 24 hours of discharge from the intensive care unit.

When the patients' surrogate was unable to be interviewed between limitation or withdrawal of treatment after discussion regarding treatment goals, the follow-up interview was not conducted. Three patients expired quickly after a decision was made to limit treatment and the second interview was not completed.

Data Analysis

Tape-recorded interviews were transcribed verbatim by the researcher. Notes made by the researcher such as environment, perceived emotional state of surrogate, and observed interactions were made within one hour of the interview to contribute to the analysis of the data collected.

Content analysis for time one and time two was performed using NVIVO 7 software to identify the following:

(1) Perceived ability to make a surrogate decision around end of life care (primary and secondary appraisal).

(2) Factors perceived as actually or potentially harmful or as actually or potentially a loss for the participant (stressors).

(3) Problem based or emotionally based methods used (coping) by surrogate decision makers to manage the process of making an end of life decisions (Lazarus, 1984; Polit & Beck, 2001).

The first step of the analysis involved a line by line review of each transcript extraction and classification of interview items into the following categories: perceived harm, perceived loss, ability to handle stressors, emotion based coping, or problem based coping. In the second step, the items in each category were coded and then collapsed into major themes for time one and major themes for time two. The categories of items and the reduction of items into themes were validated independently by a graduate student in epidemiology with expertise in qualitative methodology. After comparison and discussion, revision and consensus was reached. If there was disagreement on an item, a third rater, the thesis supervisor was consulted. The numbers of participants for each theme, in each category at time one and time two were compiled and examined.

Ethics

The severity of patient illness and the vulnerability of potential surrogates who participated in this study were recognized. Similar studies have examined both family members and surrogates during the process of making end of life care decisions without added burden to families (Reckling, 1994; Swigart, 1994; Swigart et al, 1996; Wiegand, 2003). In fact, many participants reported that their participation in a study at this time was helpful to them as it gave them a chance to talk about what was happening and many reported feeling better doing so (Wiegand, 2003).

All potential participants were approached after consultation with the attending intensivist or fellow primarily responsible for the patients' medical care. When the attending physician confirmed expected mortality, a health care professional (registered nurse, social worker, medical doctor) approached the surrogate asking if they would be willing to speak to a nurse doing research around their stress during the decision making process. After verbal consent, potential participants were approached by the researcher, given time and privacy to consider participation, and the voluntary nature of participation was explained. All participants were given both written and oral explanations of the study before a signed consent was obtained (Appendix B). Participants were assured that confidentiality and anonymity would be maintained and of their right to withdraw from the study. They were assured that this withdrawal would not affect clinical care in any way. The registered nurse conducting the research was not working in the intensive care unit during the data collection phase of the research project.

Confidentiality of information obtained during the interview was maintained. In the event of emotional distress requiring intervention during the interview process, a social worker was available for notification however this intervention was not required.

The thesis proposal was approved by the Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board (Appendix A).

The findings of this research will be presented in three manuscripts. Each manuscript reports on one of the research questions.

Chapter Two: Surrogate Decision Makers for the Critically Ill Intensive Care Patient: Appraisal of Ability

Recent literature reflects continuing controversy across nationalities regarding the competency of surrogates participating in decisions for the critically ill adult intensive care patient. The section describes the surrogates' perceptions of their ability as they participate in the process of making end of life care decisions for the patient.

Chapter Three: Decision Making Stressors in the Surrogate Decision Maker for the Critically Ill Intensive Care Unit Patient

While having a family member in the intensive care unit is stressful in itself, surrogates participation in end of life decision making for patients has been found to compound this stress in retrospective studies and to be associated with post traumatic stress disorder symptoms three to six months following patient discharge from intensive care (Azoulay et al, 2005). This section describes the surrogates' perception of decision making stressors as they participate in the process of making end of life care decisions for the critically ill adult intensive care patient.

Chapter Four: Surrogate Decision Maker for the Critically Ill Intensive Care Patient: Coping Strategies

In order to move through the process of making end of life decisions for a critically ill patient, surrogates employ a variety of coping strategies. This section describes surrogates' perceptions of the ways they coped with the process of making decisions for a critically ill adult intensive care unit patient.

Chapter Five: Summary and Implications for Practice and Future Research

Contribution to Knowledge

This thesis contributes to the understanding of end of life decision making in the critically ill intensive care patient. The descriptive study design employing a conceptual sensitizing framework was a focused way of eliciting surrogate perceptions of appraisal, stressors and coping for the purposes of informing health care professionals' interventions through this process.

Given the small, one site, sample of this study the results are not intended to be generalizable to all populations, but to provide the groundwork for future, intervention based research in this population. This addition to current knowledge will aid in developing and testing focused interventions to assist surrogates during the process of making decisions at the end of life for the critically ill adult intensive care unit patient.

Statement of Authorship

Jeanette Suurdt is the first and primary author on all three manuscripts. Contributions of the committee (Drs Cynthia Baker, Daren Heyland and Marianne Lamb) are acknowledged through co-authorship statements on the proposed manuscripts. Cynthia Baker, Daren Heyland, Marianne Lamb and Naomi Jones made contributions to the conception and study design, data analysis and critically reviewed and suggested revisions to the drafts of the manuscripts.

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Chapter 2

Surrogate Decision Making for the Critically Ill Patient in the Intensive Care Unit: Appraisal of Ability

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Abstract

Background: As the number of patients dying in intensive care increases, there is a proportionate rise in surrogates participating in end of life care decisions for the incapacitated patient. Recent studies have found this produces significant psychological distress lasting long after the patient has expired. A better understanding of the process that intervenes between the demands of surrogate decision making and the stress reaction is essential for health care providers to provide appropriate support.

Methods: A qualitative descriptive study was undertaken to capture surrogate decision makers appraisal of the demands of their role and their ability to make end of life decisions for a critically ill patient. Thematic analysis guided by Folkman & Lazarus' Stress and Coping Paradigm was used to examine surrogates' perceptions.

Findings: Surrogate decision makers perceived a need for a clear understanding of their expected role, supportive partnerships, time to process events and reflect on prior discussion or experiences in order to make end of life decisions for the critically ill patient.

Conclusions: Understandings gained from surrogates provide direction for appropriate intervention during this stressful process. Health care professionals must clarify roles, decision making expectations, and enhance partnership opportunities.

Key Words

Intensive Care Unit, Critically Ill, Surrogate Decision Maker, End of Life, Decision Making, Appraisal of Ability.

Key Points

In order to protect the intensive care unit patient's autonomy while critically ill and incapacitated, a surrogate decision maker must be approached to communicate the patient's values and beliefs about end of life treatment. Surrogate decision makers for the critically ill adult intensive care patient are often unexpectedly placed in a role they are not prepared for, although many have reported a desire to participate in this role. Health care professionals engaging surrogate decision makers' in sensitive discussion about end of life treatment have a responsibility to explore, guide, educate and inform surrogates throughout the decision making process.

Surrogate decision makers appraisals of the demands of this role indicate that they require a clear understanding of the expectations of their role, supportive partnerships with health care professionals, family or God, time to process events and reflect on prior discussion and experience with the patient.

Introduction

Although the complex technology of the intensive care is focused on saving lives, it is frequently a place to support the dying. Recent studies have reported as many as one in five hospitalized patients die in intensive care, many with no prior discussion of their wishes with others about life sustaining treatment (Heyland et al, 2000; Angus et al, 2004; Booth et al, 2004). Because of the serious nature of critical illness, patients are often unable to communicate treatment preferences, leaving others to make life and death decisions for them.

Health care professionals operating in a health care system which values patient autonomy are required to approach a surrogate decision maker to obtain a reflection of the patients' values, beliefs and wishes about end of life treatment. Although many surrogates express a desire to participate in decision making for a critically ill patient the role is often unexpected (Heyland et al, 2000). When placed in this role, many report feeling anxious, unprepared for and burdened by the responsibility of making end of life decisions for their family member (Murphy et al, 1992; Swigart et al, 1996; Sjokvist et al, 1999; Azoulay et al, 2001; Chambers-Evans & Carnevale, 2005). Furthermore, as a result of being involved in end of life decision making, a large percentage of surrogate decision makers have been found to manifest post traumatic stress disorder symptoms three to six months following their involvement in this process (Azoulay et al, 2005). The health care team's responsibility to support and protect must extend beyond the critically ill patient to the surrogate decision maker. It is imperative to design focused interventions that can be used by health care professionals to assist and support surrogates through this difficult process.

Background

Recent studies reveal that a large portion of surrogate decision makers who participate in end of life decision making for an intensive care patient experience anxiety and stress following

the event (Azoulay et al, 2005). Although the decision may result in the patient's suffering ending, the surrogates' clearly does not. Research to date has been primarily retrospective and has focused mainly on the family experience with the decision making process, their satisfaction with care, and on communication with the health care team (Heyland et al, 2002; McDonagh et al, 2000; Curtis and Engelberg, 2006; Swigart et al, 1996; Wiegand 2003; Chambers-Evans and Carnevale, 2005). Although one study has examined families' experiences prospectively, the patients had an existing diagnosis of cancer and therefore had been sensitized to the suggestion of a shortened life span (Swigart et al, 2003).

Retrospective studies of the end of life process attribute the burden of surrogate decision making to a number of factors. Family members' uncertainty, separation from the patient, and inaccurate expectations of intensive care increase family anxiety (Coulter, 1989; Williams, 2005). Families of critically ill patients report shock, disbelief, feeling overwhelmed with the information presented to them, and paralyzed with emotions, affecting their ability to hear or think straight (Chambers-Evans & Carnevale, 2005; Curtis et al, 2001). Research has also found that families tend to put themselves in second place, not caring for themselves while someone close to them is critically ill, which adds to their vulnerability during and following the decision making process (Engstrom and Soderberg, 2004; Tracey and Ceronsky, 2001).

Contributing to the complexity of the end of life decision making process are the numerous health care professionals representing different specialities involved in end of life care in intensive care units (Azoulay et al, 2004; Ho et al, 2005; Hunter, Dean, & Gowan, 2006). In addition, some of these health care professionals may find it easier to continue treatment rather than enter into emotionally charged conversations around end of life care, possibly because death may be perceived as an unacceptable outcome in intensive care (Cassell, 2003; Lang & Quill, 2004; Le Claire et al, 2005; Moreau et al, 2004; Simmonds, 1996). This contributes to the

potential for differing opinions and misunderstandings about treatment and prognosis to be communicated to the surrogate.

The most commonly identified area for improvement in previous studies is communication, primarily between the physician and surrogate decision maker (Boyle, Miller, Forbes-Thompson et al, 2005). In response, communication frameworks have been developed to guide physicians in end of life discussions with family members. Information brochures in waiting rooms assist surrogates' to understand diagnoses and team focused communication improvement strategies have been implemented to assist families in making decisions for the critically ill intensive care patient (Ahrens et al, 2003; Curtis et al, 2002; Medland et al, 1998; Prouchard et al, 2001; Verhaeghe et al, 2003). However, the limited success of these interventions in reducing the longer term effects of stress, indicate the need for further study in this area.

Despite the complexity and emotional drain of the process, studies have found that families of critically ill patients wish to make treatment decisions on behalf of the patient in consultation with the physician, even when they have had no prior discussion with the patient concerning desires or wishes in the event of serious life-threatening illness (Booth et al, 2006; Jacob, 1998). The process may be even more complex however, for those who have not previously discussed end of life decisions with the patient. Surrogate decision makers provided with prognosis and disease information from health care professionals, must integrate this into their own knowledge of the critically ill patient's preferences, and interpret it using their own values (Catalano, 1997). In some cases, surrogate decisions lead to disagreement amongst other family and friends, magnifying the level of anxiety (Prendergast, 1997).

Consensus among all parties involved in the decision making process has been identified as important for health care professionals to successfully move from curative to comfort oriented

care (Badger, 2005). Without such a consensus, surrogate decision makers may be at greater risk for long term emotional distress (Azoulay et al, 2004; Jacob, 1997; Boyle, Miller, & Forbes-Thompson, 2005).

As noted, most studies of surrogate decision making have been conducted retrospectively. However, in order to effectively support surrogate decision makers, health care professionals must know more about surrogates' perceptions during the complex and emotionally charged process of making end of life decisions in the intensive care unit. The surrogate's perceptions in a new and foreign environment under stress may change their view of the events, placing them at risk. The gaps in research to date of the surrogate decision makers' appraisal of this role and their ability to carry it out leaves health care professionals with an incomplete guide to support the surrogate while making serious life limiting treatment decisions for an incapacitated patient. Because interventions must be delivered in real time not in retrospect, supporting surrogates as needs occur, they should not be designed solely on the basis of what persons remember of the experience (Baggs & Schmitt, 2000). Therefore the purpose of this study was to describe surrogates' appraisals of the demands of having to make serious treatment decisions for a critically ill, adult, intensive care patient during the process. This is part of a larger study exploring appraisal, stress and coping during the end of life decision making process.

Sensitizing Framework

The study was guided by Lazarus and Folkman's model of stress as a dynamic phenomenon based on individuals constantly appraising and re-appraising environmental demands in light of their perceived effects on them (Lazarus, 1984). In order to understand the process of surrogate decision making for the critically ill, health care professionals must take into account this cognitive appraisal process that intervenes between the demands of the surrogate decision making role and the persons' response to these demands (Lazarus & Folkman, 1984).

Surrogates' appraisals of their role in end of life decision making involve the unique and changing relationship that takes place between a person with certain distinctive characteristics (values, commitments, styles of perceiving and thinking) and an environment whose characteristics must be predicted and interpreted by that person. This cognitive appraisal process is largely evaluative, focused on meaning or significance and takes place continuously throughout the decision making process, mediating the person's reaction as encounters are categorized with respect to their well-being (Lazarus, 1984). Given the long term impact on surrogate decision makers, an understanding of this interplay is critical in developing strategies to mediate the strain.

There are two non sequential components to evaluative appraisal, primary and secondary. Primary appraisal involves the decision maker processing the encounter, registering the meaning and significance of the situation. It is here that surrogates begin to evaluate potential stressors, possible consequences and the situation's relevance to their own well being. Surrogates ask themselves "What is going on here?" "What is my role in this process?" "What does this mean to me?" "Am I in trouble now or in the future?". This form of appraisal focuses on the meaning or significance of the situation and takes place throughout the decision making process.

Secondary appraisal involves the decision maker's evaluation of what might and can be done about this situation. This component of appraisal focuses on possible ways of coping with the situation and evaluates the extent of resources available for dealing with the situation before them (Folkman & Lazarus, 1984). They are asking "How can I manage this situation?" "What resources are available to me?" "What do I need?" The primary and secondary evaluation of what is at stake interact with each other, shaping the degree of stress and the strength and quality (or content) of the surrogates' emotional reaction (Lazarus & Folkman, 1984).

Together, primary and secondary appraisal determine both the nature and intensity of the surrogates' emotional reaction. It is vital to examine surrogates' appraisals in the midst of end of

life decision making in order to develop interventions to support them through the process (Folkman and Lazarus, 1984). The study, therefore, examined the following research questions:

1) What are the primary appraisals of end of life decision making for a critically ill intensive care patient among surrogates? 2) What are the secondary appraisals of end of life decision making for a critically ill intensive care patient among surrogates?

Methods

In depth interviews were conducted with nineteen surrogates participating in the process of making end of life care decisions for a critically ill adult intensive care patient. Surrogates were interviewed twice during the patient's admission to intensive care to capture their appraisals of the demands of making end of life decisions for a critically ill adult intensive care patient. The first interview took place between 24 to 72 hours after patient admission to intensive care and the second interview occurred after a decision to limit or withdraw treatment had been made.

Over a period of seven months, potential surrogate decision makers were approached for every intensive care patient in a 21 bed unit of a large, university affiliated hospital who were incompetent to make treatment decisions, were estimated by the physician to have a mortality risk of >50% and at risk for life limiting treatment decisions. The surrogate decision makers of all patients who met these inclusion criteria were approached between the first twenty four and seventy two hours of the patients stay. This provided data from surrogates at greatest risk of having to make an end of life decision for a patient with a predicted short stay. It excluded the longer term intensive care unit patients, who were treated for weeks or months before a surrogate was approached for a serious treatment decision. Following consultation with the attending physician, the person identified as a potential surrogate decision maker was asked by a member of the health care team if he or she would be willing to be approached by the researcher to participate in the study. Once participants consented to this, an information sheet and a brief

description of the process were given to them by the researcher. Written consent was then obtained and interviews were conducted by the researcher in a quiet, private room close to the intensive care. All interviews were audio recorded with a Sony Digital Voice Recorder and transcribed verbatim by the investigator.

Surrogate characteristics were collected at the time of the first interview. Patient characteristic data and admission diagnosis were collected by the researcher through chart review during the decision making process and following the patients' death (See Tables 1 & 2).

Participant Characteristics

Twenty surrogate decision makers were approached after screening, one refused and nineteen surrogate decision makers were interviewed over a period of six months (Table 2: Surrogate Characteristics). The mean age of surrogates was sixty nine years with fourteen women and five men. A range of socioeconomic groups were represented. Five participants were retired, ten were employed and four were unemployed. Although the highest level of education achieved varied among participants, two thirds had a post secondary education. One completed post graduate education, ten had a college/university education, five completed high school, and one completed elementary school. The majority, eleven, of the surrogate decision makers lived with the patient, one surrogate visited the patient daily, and the remainder visited the patient weekly or monthly. Fourteen of the surrogates had no previous experience with the intensive care unit.

The median length of stay of the critically ill patient in intensive care before the first surrogate interview was thirty eight hours. Sixteen of the patients died shortly after a decision was made to limit treatment, three survived the intensive care stay.

Ethics approval was obtained through both the Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board and the Kingston General Hospital.

Data Analysis

Lazarus and Folkmans' (1984) stress and coping paradigm was used as a sensitizing framework for line by line thematic analysis of thirty seven interviews (Lazarus & Folkman, 1984; Miles & Huberman, 1994). NVIVO 7 computer software aided line by line extraction of the surrogates' appraisals of ability which were coded first as either primary or secondary appraisals. The extraction of primary and secondary appraisal items were then coded and further reduced into thematic categories.

To enhance trustworthiness of the analysis, a second independent analyst reviewed the categories of items and the reduction of items into themes for a random third of the data set. After comparison and discussion, revision and consensus were reached. To ensure confirmability coding was completed using computer software, leaving a clear audit trail of coding. Finally, transferability refers to the degree of applicability of these findings to other contexts. To enhance this, the characteristics of participants and sampling are described in detail. In addition, participant statements are used to illustrate the themes and subthemes identified in this study.

Findings

The study presents a thematic analysis of data relating to participants' primary appraisals of the meaning and significance of the environmental demands of their role as surrogate decision makers for a critically ill adult intensive care unit patient and their secondary appraisals of their ability to function in this role. Lazarus and Folkmans' Stress and Coping Paradigm (1984) was used as a sensitizing framework to guide analysis and identifies two categories of appraisal, primary and secondary. Although these categories are presented sequentially, with reduction of codes into themes, the appraisal process was non-linear. In addition, participants' appraisals of their role as surrogate decision makers were often intermingled with their appraisals of other, related environmental demands.

Primary Appraisal

Two major overlapping themes were identified as the surrogate decision maker registered the meaning and significance of the situation at hand. The first involved their awareness of the fork in the road ahead of them and the second, their anticipation of the demands of the role of default decision maker (See Figure 1.0).

Awareness of Fork in the Road

As surrogates were anticipating having to take on the role of end of life decision maker, they were developing an awareness of a fork in the road, the possibility that death was at hand for the critically ill patient, in spite of life sustaining therapy. These appraisals involved intense scrutiny of the patients' unfolding condition and a recognition of the magnitude of the patient's illness.

Surrogates observed the patient's condition very closely looking for indicators of decline, improvement, suffering, and future quality of life. They assessed the patient's physical condition and degree of suffering. For example, in the midst of making a difficult decision one patient's wife tearfully concluded "*he's suffered enough*". Another participant stated: "*why prolong it? It is inevitable that she is going to go, she has suffered enough*". Surrogates' also watched and listened to health care professionals, carefully trying to appraise the situation. One surrogate commented: "*We don't want to hurt her anymore than she has been hurt you know? We don't want to put her through any more pain or discomfort here*". They observed the patient, staff, and equipment to determine what would be best for the patient, weighing potential for improvement with perceptions of suffering and poor future quality of life. Reflecting on her observations, for example, a participant noted "*he has no quality of life and he won't*". Another participant said, "*She is just a vegetable right now and we don't want to prolong if it's going to hurt her so there is no point*".

Mixed in with their observations of the patients' condition was a recognition of the magnitude of what they were seeing and the realization that a decision about end of life treatment would soon have to be made. For instance, a participant's observations of the support equipment led her to conclude: *"there's nothing there, just the machines."* Another noted that the staff had said, *"you have a very sick man on your hands, a very sick man."* Another reflected, *"He has no quality of life, and he won't, he will be having less than my uncle...and knowing that, that he can't be any better than that..."*

A major concern for surrogate decision makers as they observed the situation and recognized the severity of the illness was the amount of pain the patient was experiencing and the quality of life that lay ahead. Most commented on their desire to protect the patient from further harm and suffering. For instance, one participant stated: *I don't want to put him through pain"*. They described their reluctance to prolong life if a patient was in pain or there was a strong potential for poor quality of life. As one spouse when considering the decision to limit treatment noted, *'what's the point of keeping her going in pain with a tube back in her, that's not worth it. It's not helping any, it's just prolonging the inevitable and I'd just as soon not prolong it.'* Similarly, another said, *"we don't want to hurt her 'cause we figure it's not going to help, it's just going to prolong the situation as it is"*.

Default Decision Maker

As participants were experiencing an awareness of the fork in the road ahead/the decision facing them, they were also recognizing that they were the person the health care team turned to when the patient was unresponsive and that the decision making role would fall to them. As one stated, *"I have to make the decision, there is nobody else to be in this role"*. Another commented, *"I realized that I have to do it and I'm not keen on it"*. Indeed, most surrogates

began to anticipate surrogate decision making from the moment the patient was admitted and incapable of communication.

Acknowledgement that they were the default decision maker prompted participants to appraise the possible consequences of a decision to maintain or terminate treatment. For some surrogates, a decision to limit treatment would mean committing murder. For others it would mean an end to suffering or what the patient wanted. For example, a participant reflected on her fear of both her own and her families' perceptions of a decision to terminate treatment, *"it's too hard – later on they'll say well you are the one who killed our brother"*. Another explained, *"we don't want to kill her cause there is life"*. In contrast, one participant noted *"the way he is right now is not the way he wants to be"*. Similarly, another said, *"I don't think that he would want to be on life support"*. Yet another surrogate shared, *"we have not discussed death but he (patient) would say if someone is in the position shoot me first"*.

The primary appraisal process of determining the meaning of being decision maker for the patient prompted some to consider what sustaining treatment would mean for their own lives. One said *"Maybe I'm selfish but I don't want to be committed to her to do that, changing her diapers for the next five years, sit there and feed her pablum"*. They also thought about their own preferences at the end of their life. For example, a participant considered someone being a decision maker for him, *"taking somebody off life support. Yeah, I'm 62 now and one day someone is going to have to do that for me. I think about that...we're talking about that"*.

Secondary Appraisal

One of the stressors participants faced as they appraised their ability to manage the decision making process was self doubt about making the right decision. In appraising their ability to make end of life treatment decisions for the patient, participants identified the resources they required in order to manage this role. Four themes emerged related to this: their need for

partnerships, prior knowledge or discussion of the patient wishes, prior experience in this role, and time to process the events at hand. (Figure 1.1).

Partnerships

Surrogates described feeling able to manage the decision maker role with the help of significant partnerships. One surrogate adamantly stated: *“I don’t want to be the sole decision maker here. They need to help”*. Another surrogate said *“I told his sons that they need to be there. That they need to make decisions with me”*. The partners identified included health care professionals, family, friends, and God.

Each of the significant partnerships had specific character traits deemed important in assisting in management of this role. All surrogates placed high value on honest, caring, competent, and information giving health care professionals. For example, one participant noted: *“Oh yes. It’s the same one that’s been. He’s giving us, feeding us information that is vital for us to make a decision that we need to know”*.

Another commented, *“the surgeon that was there was not blunt because that’s what he had to do but he was honest. Honest. Which I appreciated”*. While surrogates highly valued supportive information from health care professionals, information gathering from the health care team was often identified as problematic and the cause of considerable stress.

Most surrogates also referred to the need for the presence of friends and family members, for dialogue with them about the decision and for agreement in order to manage their role. A surrogate noted *“I want us all to get to be a part of this here, I want the family to help make the decision...”*. Another commented: *“Yeah having them all here. I wouldn’t want to be here by myself. You couldn’t do it”*.

Some surrogates also required a sense of support from a higher power through prayer and consultation with spiritual advisors. For example, one surrogate said: *“So, it’s a decision you have to make, basically put your faith in God, really, that He will help you make the decision”*.

Prior Knowledge/Discussion

Another resource surrogates identified as important as they contemplated the role of surrogate decision maker was prior knowledge of the patients’ wishes. While appraising the situation, surrogates struggled to recall prior discussions with the patient around end of life treatment preferences and to reflect on their knowledge of the patient. One surrogate commented: *“Thankfully this is something we discussed a long time ago ’cause he was a very sick man.....and he didn’t want to suffer and didn’t want anything invasive”*. Another surrogate noted: *“I said lookit, he told me many times he don’t want to live this way and I’m going by his wishes”*.

Prior Experience

A few surrogates had prior experience in the role of surrogate decision maker. This inspired their confidence in their ability to manage the process. For instance, one explained: *“Yeah. That experience I think you learn from these experience and you take something away from that experience and use it in this experience.*

Another commented *“We’re prepared to have to do it again which doesn’t sound nice but it’s good because I know now that we can make it. We can make it. Like you know you think I can’t have another thing on my plate but we know that we can do it and the choices that we make are going to be for the best”*.

Surrogates reported prior experience prevented them from “playing ostrich” and ignoring the decision before them. For example, one surrogate noted *“Some people just like to play ostrich. We can’t because he was sick before.... and we all had to get our things in order at some point and we lost our parents when were young so we know these things”*. Another surrogate reflected:

“We had to make decisions. He had to tell them to unhook his mom. So I wouldn’t know what it’s like not to know what he wants. I would assume it’s harder for someone, people who have had no idea. But I was there. I was the one who had to tell the doctors to give the last shot of morphine to my mother”. Prior experience assisted surrogate awareness of their role and the expectations that come with it.

Time

Lastly, surrogates’ reported time as an essential resource in the decision making process. For example: *“if that is in fact looks like where things are going ...everything to decide at once, we need time”*. Another participant noted she required, *“..time to sit and think things over and ask for help”*. Surrogates felt they needed time to assimilate the situation, make sense of what was going on, consult others, and get some much needed rest, enabling them to think clearly. One participant reflected: *“In fact I could have made the decision today, but my brother is out of town and I wanted some time to discuss with him”*.

Discussion

This study found that surrogates facing the demands of making end of life treatment decisions for the critically ill patient were actually assessing the meaning of this situation and its’ relevance to their well-being. They were simultaneously appraising the nature, extent, and availability of resources they required to manage the demands of this situation.

This study supports previous research findings which indicate that the surrogate decision maker role for a critically ill intensive care patient is an intense and demanding experience (Azoulay et al, 2005; Delva et al, 2002; McDonagh et al, 2004; Tilden et al, 1999; Wiegand, 2003). Findings also indicate that surrogates begin to grapple with the end of life treatment decisions early on in the intensive care stay. This suggests that the health care team should offer guidance to surrogates early on in the process. Anticipatory guidance of surrogates as they

appraise the demands of the situation and their ability to meet those demands would reduce some of the stress of the decision making role.

As participants of this study appraised the situation at hand, they developed an awareness of the magnitude of the patient's illness through their perceptions of the patient's suffering, and negative condition. This made them feel more prepared for end of life decision making and suggests the importance of ensuring surrogates' have the opportunity to be physically present in the intensive care unit to process the patient's condition. Patient observation also provided surrogates with a better understanding of the implications for the critically ill patient when maintaining or terminating life sustaining treatment. In addition, the participants' watchfulness of intensive care health care professionals in their struggles to interpret the patients' illness trajectory indicates the importance of self awareness among health care professionals. Health care professionals need to be open and honest with surrogates, clear in discussion and careful with language when communicating potential patient outcomes as this is crucial to the surrogates' perceived ability to act as a surrogate decision maker.

Surrogate decision makers described partnerships in decision making as non-negotiables to be able to function in their role. These partnerships included the health care team, family, friends, and God. It is vital that the health care team caring for the patient are aware of the surrogate need for their honest, caring, and competent partnerships in the decision making process alongside the surrogate. Expert health care professionals must be careful not to burden surrogates, but empower them in their role. As other studies have also found, it is imperative that the health care team provide clear information about the patient and expectations of the surrogates role to prevent misconceptions or placement of undue burden on the surrogate (Prendergast & Puntillo, 2002). Strategies of the health care team should also include clear discussion and definition of a shared decision making process early on in the patient stay, decreasing opportunity

for misunderstanding and providing an open forum to clarify the role in the midst of experts familiar with the process. Besides providing support, such an approach offers surrogates more time to reflect on patient preference and their own values regarding end of life decisions, a key factor identified by participants in their appraisal of ability.

Education of health care professionals caring for the patient and surrogate should encompass the established benefits of family and friend partnerships to empower surrogates to facilitate their own support networks early on. This provides opportunity for dialogue, physical support, and agreement in decision making. As well, recognition that surrogates may need access to spiritual care support should prompt the health care team to make this available.

This study supports previous research indicating that prior discussion of the patient's preference assists surrogates in their role as decision maker (Jacob, 1998; Swigart, 1994; Swigart et al, 1999; Tilden et al, 2001). However, health care professionals must recognize that often this discussion may not have occurred and that they may need to facilitate exploration of patient values and beliefs with the surrogate to inform the decisions at hand. By providing opportunity for dialogue and guidance in the surrogate's responsibility and role, the health care team can facilitate this process. Ideally, future interventions designed to facilitate this process would include early discussion among patients, families and their primary health care provider, perhaps in the form of written advanced directives.

While surrogates reported prior experience in this role increased their confidence in their ability, most are unexpectedly placed in this role and require both support and education to function effectively in it. Although the intensive care health care team hopes that the end of life conversation does not begin in the intensive care with an unresponsive patient and an ill prepared surrogate, the unexpected nature of admission can often result in this situation. Therefore, the

intensive care team must be keenly aware of surrogates' appraisal of their ability and support them by providing a clear explanation of the role.

Limitations

As this study was exploratory, a convenience sample was recruited from a single site and data were collected through in depth interviews. The limitations of this study include a non probabilistic sample of mainly female surrogate decision makers for a predominantly white, adult male, patient population. All participants recruited were making end of life decisions after a short stay in the intensive care and the study did not include surrogates making decisions over a long period of time.

Conclusion

This study indicates that the surrogate decision makers begin to assess the demands of this role early and experiences a continuous appraisal process. The health care team must be aware of the surrogate need for support in this role, clear information about the patient and the treatment goals and time to reflect on the patient's past and the patient's future. This awareness will assist them in guiding surrogate decision makers through the process and hopefully decrease surrogate stress during and after their interaction with the intensive care unit. This knowledge enables the well coordinated health care team to educate surrogates on a shared decision making model, clarify the process, facilitate key partnerships with the surrogate and improve the end of life experience in the intensive care.

Figure 1.0 Primary Appraisal

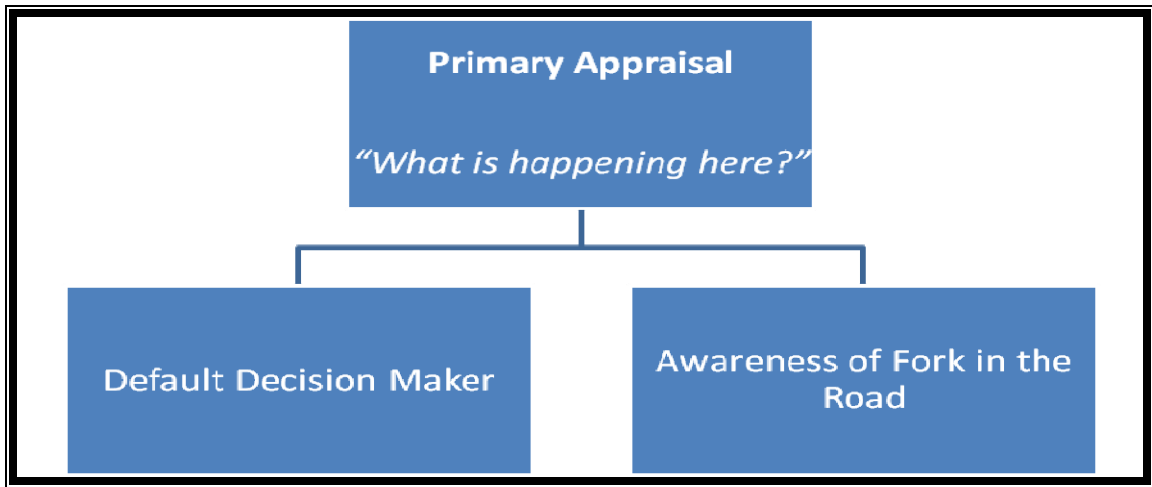


Figure 1.1 Secondary Appraisal

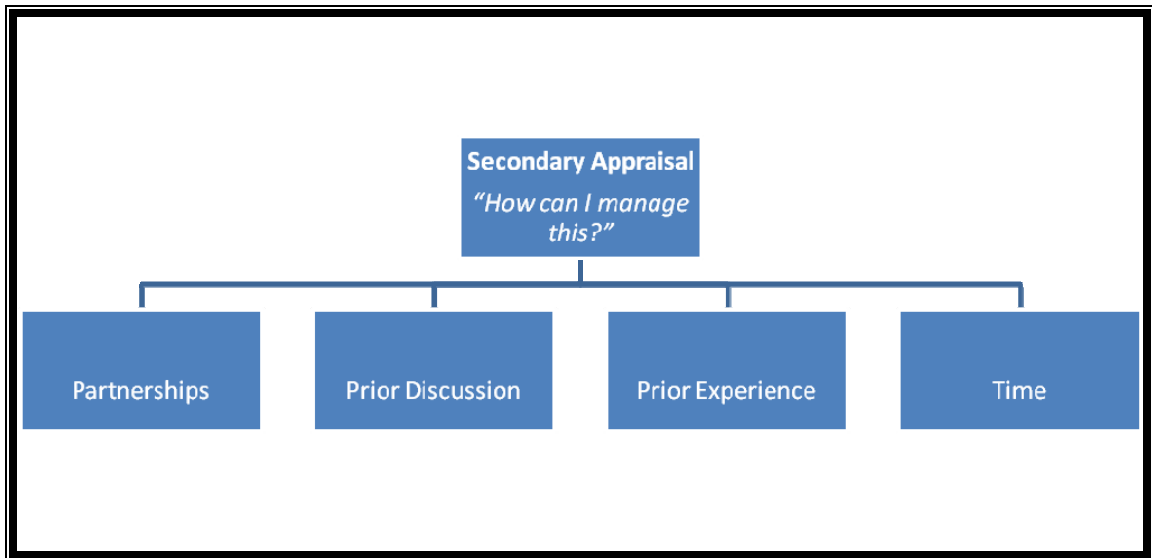


Table 1: Patient Characteristics (n=19)

Diagnosis	No. of patients
Neurological Events	4
Cardiac Events	6
Respiratory Events	4
Hepatic Events	1
Sepsis	4
Age (years) <ul style="list-style-type: none"> • Median Range 	69.94 (44-86)
Gender <ul style="list-style-type: none"> • Male • Female 	16 3
Marital Status <ul style="list-style-type: none"> • Married/Partnered • Divorced/Widowed • Single/Never Married 	16 2 1
Previous ICU Patient <ul style="list-style-type: none"> • Yes • No 	3 16
Advance Directive <ul style="list-style-type: none"> • None • Written 	17 2

Table 2: Surrogate Characteristics (n=19)

Relationship to Patient	
• Wife	9
• Husband	3
• Son	2
• Daughter	1
• Sister	2
• Grand-niece	1
• Niece	1
Gender	
• Male	5
• Female	14
Highest Level of Education	
• Elementary	1
• High School	5
• College/University	10
• Post-Graduate	1
• Not Available	2
Previous Experience with ICU Surrogate Role	
• Yes	5
• No	14
Time Spent with Family Weekly	
• Lives with	
• Daily	11
• Weekly	1
• Monthly	2
	6

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Chapter 3

Surrogate Decision Making for the Critically Ill Intensive Care Patient: Perceived Stressors

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Acknowledgements: The author is grateful for the support of CARENET
throughout this project.

Submitted to Journal of Critical Care
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Abstract

Background It is estimated that as many as one in five hospitalized patients die in intensive care. The majority of deaths occur after a third party has made a decision to limit treatment. Recent research indicates many of those participating in end of life decisions find it a stressful process that may negatively impact their longer term well being. A more in depth understanding of the surrogate's stressors during the decision making experience are critical for health care professionals to effectively plan interventions and provide anticipatory guidance and support during the process.

Objective The purpose of the study was to describe the stressors as perceived by surrogates' during involvement in making decisions for an incapacitated, adult, intensive care patient.

Method A descriptive, qualitative study design was used. Thematic analysis guided by Folkman & Lazarus' Stress and Coping Paradigm was used to examine surrogates' perceptions.

Findings Nineteen surrogate decision makers were interviewed twice during the decision making process. Stressors identified by the surrogate included doubts regarding their self efficacy in this role, facing situational unknowns, the impingement of everyday life on the decision making responsibility, and problematic relay of information during the process.

Conclusions End of life decisions in the intensive care are demanding and complex. Key sources of decision making stress could be addressed with focused interventions to modify stressors and assist surrogates to manage stressors making decisions at the end of life.

As the number of incapacitated, critically ill patients dying in intensive care increases, surrogate involvement in the decision making process has become an important area of study (1-3). Although recent studies indicate decision making is stressful for surrogates and reveal portions of the surrogates' experience retrospectively, or through fixed choice questionnaires, they have not described the surrogates' perception of stressors encountered during the actual process (4-10). Interventions to support surrogates must address problems as they occur and should not be designed solely on the basis of what persons remember of the experience (11).

It is important for health care professionals to grasp the complexity of surrogates' perceptions of the stress of decision making around end of life care for an intensive care patient in order to effectively support them when carrying out this difficult role. Without an understanding of their experience, it is difficult to assist surrogates appropriately in this process, and may lead health care professionals to infringe on the rights of surrogates making decisions.

Background

Although technological advances in critical care medicine over the last 50 years have increased the critically ill patient's chance of survival, admission to the intensive care does not guarantee restored health. In fact, as many as one in five patients admitted to the intensive care will die there, with a significant number expiring after a decision has been made to withdraw or limit life sustaining therapy (2, 12). Due in part to the unplanned nature of intensive care admissions, as many as 90% of patients have had no prior discussion of their wishes regarding life sustaining treatment and are too incapacitated to provide this information to guide treatment decisions (1-3,12,14-15). Life and death discussions, therefore, fall to a surrogate decision maker and the health care team.

In a health care system where respect of patient autonomy is an understood value, both the patient and health care professionals must depend on a surrogate to accurately represent the incapacitated patient's values, beliefs and wishes in order to determine direction of treatment. In the province of Ontario, unless otherwise designated by the patient, the legal next of kin is given the responsibility of surrogate decision maker, based on the understanding that the person closest to the patient will be the most able to reflect his or her wishes. Families report a desire to participate and be included in the decision making process for the critically ill patient, even if they have had no prior discussion with the patient concerning his or her wishes and find the experience is overwhelming, anxiety provoking and burdensome (5, 16-17). The difficulty of surrogate decision making is further compounded by the unexpected nature of many admissions to intensive care and lack of prior discussion with the critically ill patient. Family members' uncertainty, separation from the patient, distress, anxiety and fear have been found to contribute to inaccurate expectations, foster misassumptions and increase family stress (17-19). Furthermore, a number of studies indicate that more than 80% of surrogates participating in end of life discussions for a critically ill intensive care patient have symptoms associated with post traumatic stress disorder at three months after their participation (13). Yet, the health care team must involve surrogates in this process to preserve the patient's autonomy in treatment options. Therefore, health care professionals must be aware of and sensitive to surrogates perceptions of stressors to assist them with the process.

The decision making process at the end of life is further complicated by the multitude of health care professionals and other family members involved. Numerous health care professionals such as intensivists, primary care physicians, nurses, social workers and clergy provide end of life care in intensive care, often contributing to the complexity of the situation (3-6, 20-24,26-27). Some health care professionals find it easier at times to continue treatment than

to enter into end of life conversations, possibly because death may be perceived as an unacceptable outcome of the intensive care (22-24). Difficulties in decision making sometimes occur because of disagreement among family members which may magnify the anxiety of the surrogate decision maker. In some cases, there is a lack of congruence among health care professionals regarding prognosis of the critically ill patient (25). Without a consensus, the surrogate decision maker's risk for ongoing emotional distress and long term difficulty with their decision may increase (6-7,13, 24, 29-30).

Since the late 1970's, the needs of family members visiting a patient in the intensive care have been investigated through family needs and satisfaction surveys (2-4, 6-7, 24, 26, 28). Findings of research studies have provided health care professionals with a guide to help family members cope with a family member's critical illness (4-11). The most commonly identified need is for better communication between physicians and surrogates (27). As a result, communication frameworks have been developed to guide physicians in end of life discussions. Information brochures are placed in some waiting rooms to assist surrogates' to understand diagnoses. In addition, team focused communication improvement strategies have been implemented to assist families in making decisions for the critically ill patient (16,21,31). However, the limited success of these interventions in reducing long term stress indicate that caution must be taken when implementing interventions based solely on survey results scores. Questionnaires, surveys or one point in time retrospective interviews, may not comprehensively capture sources of stress during the decision making process. In addition, after decisions have been made mental processes such as repression of an uncomfortable stressful experience may distort recollections of the decision making experience (11). Furthermore, little literature to date recognizes that end of life care decisions often occur sequentially over several days and stressors may change during the process. For instance, the level of stress examined in a sample of

intensive care family members was found to be highest at the time of intensive care admission and to plateau at day 6, suggesting stressors and strategies are dynamic (32).

The process of end of life decision making is a highly subjective experience for surrogate decision makers. Information provided by health care professionals is integrated into their understanding of the critically ill, incapacitated patients' preferences, and interpreted using their own values and knowledge (33). Because end-of-life care decisions emerge over time from this complex, largely unexplored personal domain of experience, supportive interventions require an in-depth understanding of the perspectives of the decision makers (26).

A fuller understanding of surrogates' perceptions of the stressors associated with end of life decision making for an incapacitated patient can enhance the development of supportive interventions to assist them during the process. Therefore, a descriptive, qualitative study investigated the stressors perceived by surrogate decision makers while participating in decision making for a critically ill, adult, intensive care patient. This was part of a larger study to generate knowledge about the decision making process from surrogates' perspectives. The purpose was to describe the stressors perceived by surrogate decision makers' while participating in decision making for a critically ill, adult, intensive care patient.

Sensitizing Framework

Lazarus and Folkmans' stress and coping paradigm was used as a sensitizing theoretical framework to guide both the interview schedule and analysis of the surrogate decision maker's experience (34). The framework addresses the ongoing, reciprocal relationship between a surrogate decision maker and the intensive care environment, including the influences of situational and personal factors. Within this paradigm, stress is defined as a "particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being". The paradigm

acknowledges stress as a dynamic phenomenon based on individuals constantly appraising and reappraising environmental demands in light of their perceived effects on them and on their perceived ability to respond to them. Stressors are demands perceived to be either potentially or actually harmful or to represent a potential or actual loss.

Method

Twenty surrogate decision makers participating in the process of making end of life care decisions for a critically ill intensive care patient were recruited as part of the larger project which also explored appraisal, stress and coping during the end of life decision making process. One, however, declined participation. Nineteen surrogates were interviewed in depth twice during the process of making end of life care decisions for a critically ill intensive care patient were recruited for in depth interviewing as part of the larger project which also explored appraisal, stress and coping during the end of life decision making process. Surrogates were interviewed during the process of making end of life decisions for a critically ill, adult intensive care patient. All patients were incompetent to participate in treatment decision making, were over 18 years of age, and were identified at risk for end of life decisions by an intensive care physician, with an expected mortality in intensive care of greater than 50%. Patients had been admitted to intensive care for a minimum of twenty four hours and a maximum of seventy two hours. The intent of interviewing participants within this time period was to provide opportunity for the surrogate to adjust to the unit prior to the first interview, and to capture the stressors associated with decision making for the critically ill intensive care patient, rather than for the longer stay patient. Following consultation with the intensive care unit physician for suitability, surrogates were asked by a member of the health care team if they were willing to be approached. Participants who consented to this were given an information sheet and a description of the process. All participants provided written consent to take part in the study. Following consent, in depth

interviews were conducted by the investigator twice during the decision making process using a semi structured interview schedule in a quiet, private room close to the intensive care. The first interview took place within the first 24-72 hours of patient admission to the intensive care unit. The second interview took place after the surrogate was asked by the health care team to make an end of life decision. Patient acuity made a second interview difficult for all participants. In three cases, one interview was completed but quick death of the patient prevented a follow up interview. All interviews were tape recorded using a Sony IC Recorder and transcribed verbatim by the researcher.

Sample Characteristics

Surrogate characteristics were collected at the time of the first interview for surrogates. Patient characteristics and health history were collected through chart review during the decision making process and when necessary, following the patients' death. The mean age of patients was 69.94 years with a range in age from 44 to 86 years (See Table 1). The majority of patients were admitted for cardiac, renal or respiratory failure (See Table 2).

Ethics approval was obtained from both the Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board and the Kingston General Hospital.

Data Analysis

Lazarus and Folkmans' (1984) stress and coping paradigm acknowledges stress as dynamic, changing with re-appraisal and mediation. This definition of stressors provided a sensitizing framework to extract the decision making stressors through line by line analysis of thirty seven surrogate interview transcripts during participation in the decision making process. The data were coded and codes were collapsed into themes and sub-themes. NVIVO 7, qualitative computer software, assisted the line by line analysis to extract statements representing surrogate perception of decision making stress.

To ensure trustworthiness in qualitative research, Lincoln & Guba (1985) suggest that dependability, confirmability, and transferability be used as criteria of trustworthiness in qualitative research. Dependability is the degree that another investigator having the same data would come to similar conclusion. Therefore to ensure dependability, a second independent analyst reviewed the categories of items and the reduction of items into themes for a random third of the data set. After comparison and discussion, revision and consensus were reached. To ensure confirmability coding was completed using computer software, leaving a clear audit trail of coding. Finally, transferability refers to the degree of applicability of these findings to other contexts. The characteristics of participants and sampling are described in detail. In addition participant statements are used to illustrate the themes and sub-themes identified in this study.

Findings

In the process of making end of life care decisions for a critically ill, adult, intensive care unit patient, surrogates consistently identified four major decision making stressors (Figure 1.0). These stressors included doubts about their decision making self efficacy, the problematic relay of information, the impingements of real life in the midst of decision making, and the unknowns they faced in the process. Each major category of stressor will be described using surrogate comments to illustrate both main stressors and sub themes.

Doubt Self Efficacy

In the midst of the decision making process, surrogates attempted to balance the impact of the decision on the patient, the patients' family and themselves. All expressed doubt about their ability to come to a decision that would not have a negative impact on the patient, the patients' family, or themselves (Figure 1.1). Some worried about making a decision that they would blame themselves for because the outcome worked out poorly. One commented for instance: *"Our main stress is if we take out the breathing tube and she lives like this"*.

They shared their fears and uncertainties about how their decision would impact on the patients' present and future suffering. One surrogate noted: *"She cannot talk at all she can hardly even open her eyes, she can open her eyes a little bit we don't know what she sees.....we don't want to prolong that if it's going to hurt her"*. Another reflected: *"I didn't want to be the one who had to make a decision but I did know that he could not go on like that. So who knows how long he would stay this way before he would, you know, go on to be with the Lord I don't know and I can't let him suffer like that any longer"*.

Surrogates also worried about the impact of their decision on the patients' quality of life. For instance one surrogate noted: *"... if one of the options is that for the next several weeks or months he lay there with that, you know machine making him um breathe and live, you know it's like why. I mean what's the point"*. Surrogates experienced a significant amount of self doubt as they considered the patients' future quality of life, as they weighed short term suffering in the intensive care unit against a longer life but longer suffering as well.

Balancing what seemed to them to be the best decision for the patient with family members' needs contributed to their self doubts. Surrogates described the difficulty they would experience when facing family members who were not present during the process of making end of life decisions who therefore might not understand the events as they unfolded. They were also worried about feeling guilt far into future relationships with others close to the patient. They also expressed distress contemplating the impact of the patients' death on those close to the patient, such as other family members or close friends of the patient. For example, one said: *"Yeah, yeah, because when we go back home we'll have to go and see the kids and explain to them"*. Similarly, another surrogate expressed concern about the affect of the decision on the family saying, *"...my kids, my grandkids. They don't know any other grandfather but this grandfather. And, he's been so good to them and they are very close"*. On the other hand, after reflecting on

the size of the patients' extended family, a surrogate commented on the harm of prolonging the decision saying: *"Well they're going through it too and by putting it off I'm putting them through it...I'm worried about them"*.

Problematic Relay of Information

A second major stressor was problematic relay of information (Figure 1.2). Three subcategories were identified within this large stressor: inadequate information, exclusion from information, and difficulty relaying information to key participants.

Surrogates perceived gaps in communication as a significant stressor. They expressed concerns with about inadequate amounts of information and difficulty in receiving information from health care professionals. Sources of communication gaps as perceived by surrogates included health care professional busyness, length of daily patient assessment by the multidisciplinary care team, numerous consults to other medical specialties continually in progress, and technical language. From their perspectives, this fostered misunderstanding. One surrogate stated: *"Like if you... yeah we want life support if it's going to benefit, but, how do we know? Like sometimes they explain stuff to you, they don't talk to you in laymen terms"*. Another surrogate relayed a source of his anxiety and said: *"...there were definitely doctors that were conflicting. And that was, that's difficult"*. Yet another surrogates reflected: *"..we are hearing two different things...and then here comes happy go lucky and don't give up on him yet..."*.

A second information related stressor identified was not being approached when treatment decisions were made after having been asked to participate in end of life decisions. One surrogate reflected on the perception of feeling excluded and said: *" Well, we came in and the dialysis machine was off and I asked the nurse how come it's off and she said well the filter went in the middle of the night and the attending said that is okay they are limiting treatment in the morning anyways. And I'm like WHAT? So you ask us to make a decision like that but then you*

take matters into your own hands?... ”. Another surrogate shared: “... I’m not sure that we really made the decision...but you know we were in agreement and we understood where we were going along and basically this is what is going to happen. He didn’t say and is that okay with you?”.

Finally, many surrogates found the demands on them to provide information to key participants such as other family members and friends tremendously time consuming, often repetitive, and ultimately draining. For instance: *“But after a while, you just get tired because you are repeating yourself. Repeating myself sounds like a record, I should have a little CD player and tape it and plug it in and I can just play it back”.*

Impingement of Real Life

In the midst of crisis surrogates continued to feel pressure from other parts of their lives, which did not come to a stop with the patient’s admission to intensive care. This major stressor was titled impingement of real life (Figure 1.3).

Surrogates’ struggled with families, friends, employers, and pets who still had needs that had to be met. For instance, a surrogate stated: *“and this one sounds a bit selfish but I think for all of us our whole life is on hold while this process goes on and um you know it’s kind of like we’re not in a hurry to get rid of my dad but it’s like you know everybody is just living on the edge”.* Another surrogate reflected on the stress of home life and said: *“We’ve got two cats. I mean I know that you know that I can leave them food but they still have to eat”.*

Financially, surrogates struggled with wanting to be with the patient however, for some not working meant not eating or not paying the car fuel to visit the patient in intensive care. One surrogate was unable to pay the mortgage and said: *“the financial end of it has been very, very stressful”.* Another surrogate said: *“I’m trying not to think about work. But we all know what that is like. You know especially in my, well I have 30 voice mails right now from clients”.* The

stress of the competing interests for their time added to the surrogates' experience of stress, with reports of feeling overwhelmed with their role as decision maker.

Facing Unknowns

The final, large category of decision making stressors encompassed the unknowns surrogates faced and perceived as crucial to their role (Figure 1.4). For several surrogates the unknowns were associated with an unplanned, unexpected admission of the patient. An important stressor stemmed from not having discussed the possibility of this situation with the patient prior to admission. For instance: *"But it's just...he's a very young man, he's a very healthy 43 year old guy. Very healthy"*.

Another unknown for many was their uncertainty about the patient's prognosis. Surrogates described their concerns about the lack of guarantees around prognosis, however, still wanted to know prognosis and said: *"You know that he's, that the situation is you know not as good as I would like it to be...even though it's hard to hear you know"*.

Surrogates described their concerns about the lack of guarantees around prognosis and the often changing prediction of patient outcome. Surrogates' uncertainties were magnified when predicted patient outcomes changed or when the wording the health care professional used to phrase their update changed.

Surrogates also felt left out of the information loop and said: *"But I've been here for hours. I don't know. Yeah I've been here for hours. And you know I don't know anymore now then I knew hours ago"*. The lack of knowledge around the death process became increasingly stressful as the patient's condition deteriorated. For instance, another surrogate remarked: *"It's very stressful to think when is the moment going to be when it's time"*.

Discussion

This study supports previous research findings indicating that surrogate decision making is a demanding and difficult experience (10,13,26). The surrogates perceptions of stressors in this study adds new stressors to those identified in current research and expands on previously identified stressors.

Previous research confirms that participants recognize the enormity of the decision they are faced with (10, 26, 34). All surrogates in this study were concerned about the potential impact of their decision on the patient, other family members or themselves. Health care professionals' should anticipate the burden of this doubt on surrogates. Because surrogate decision making is usually an unfamiliar demand, it is of utmost importance that surrogates understand their role to communicate the patients wishes, values and beliefs to the health care team in order to protect the patient's autonomy, within a shared decision making model. This must be clearly outlined and re-iterated by the health care team throughout the process. Central to this is the health care professionals support and guidance, re-iterated clearly throughout the process.

Research studies have found communication which is fragmented, inconsistent and unclear at the end of life to be problematic for all involved (5-11,13). The surrogate's perceptions of stressors in this study also included difficulties in the relay of information. Information is perceived as both inadequate and problematic to relay between the health care team, the surrogate and other key participants. Communication guidelines should be in place to ensure team members share the same information and to provide surrogates with information as the situation unfolds. These guidelines have the potential to buffer some of the stress experienced by the surrogate.

The family related stressors surrogates' described often occurred because other persons close to the patient had different interpretations of the patient's wishes or different interpretations

of the message of health care professionals. The health care team can implement strategies for family communication, reassuring and supporting surrogates as they grapple with the demands of their role.

Surrogates also found relaying information to family and friends of the patient to be a key stressor, although many surrogates reported wanting to dialogue with other key participants while they made a decision. There is a need to balance the stress of providing information to a large communication network in with the need for exchange among the network. Health care professionals can use simple techniques to facilitate effective communication with all those involved. Strategies include planning meetings at a time where the majority of participants can be present and facilitating surrogate note taking as a basis for future reference, further questions and for relaying information to absent participants.

Health care professional awareness of the impingement of the surrogates' life outside of the intensive care should prompt inquiry. This would allow the health care team to direct surrogates towards other available support systems, if warranted, such as social work to problem solve and to offset some of the stress of outside commitments, allowing the surrogate to focus on their role.

Finally, this study illuminates that surrogate stressors include the unknowns inherently faced in making end of life care decisions. While health care professionals are unable to change the uncertainties of the prognosis, communication interventions could be developed, providing clear guidelines and timelines for communication during the end of life decision making process. Communication with surrogates must be a priority at the end of life with all health care team members working together to convey a consistent picture of direction of care, framing changes in patient condition within the larger context of expected patient prognosis and the context or environment within which the decision is going to be made. It is imperative that each member of

the health care team remain acutely aware that, although they guide surrogates in this process regularly, it is usually the surrogate's only experience in this role, often with a lasting impact.

Limitations

This study was limited by one researcher collecting all data from participants, however interview questions were validated by experienced Intensive Care Unit health care professionals. All interviews were conducted in one Intensive Care Unit, although different intensivists and a variety of nurses were caring for individual patients, providing a broad spectrum of experience within the unit. All participants were Caucasian and the majority were female. In planning interventions it is crucial to differentiate between surrogate decision making in acute and long term patient populations as stressors may be very different given varying lengths of time in the Intensive Care.

Conclusion

The surrogates' perception of stress clearly demonstrates that a gap continues to exist between patient care and surrogate support, demonstrating a need for focused supportive interventions targeting stressors identified by surrogates in the midst of the process. The health care professionals' assessment of surrogate need is central in anticipation of major sources of stress from surrogates to aid intervention as necessary to assist in modification of key stressors. These improvements have the potential to reduce the burden and long term effects of decision making by the surrogate. However, until the gap from theory to practice grows narrower and supportive intervention strategies are implemented by the Intensive Care team to facilitate practical, measurable improvements to surrogate stress are unlikely. Future research must include testing interventions designed to modify the surrogates' stress by facilitating the decision making process.

Figure 1.0: Surrogate Decision Making Stressors

Decision Making Stressors	
Doubt Self Efficacy	<ul style="list-style-type: none"> • Impact on Patient • Impact on Family • Impact on Self
Problematic Relay of Information	<ul style="list-style-type: none"> • Inadequate • Exclusion From • Key Participants
Impingement of Real Life	<ul style="list-style-type: none"> • Family and Friends • Career and Finances • Home and Pets
Facing Unknowns	<ul style="list-style-type: none"> • Unplanned • Changing Expectations • Uncertainty

Figure 1.1

Doubt of Self-Efficacy
<p>Impact on Patient</p> <p><i>“Our main stress is if we take out the breathing tube and she lives like this”.</i></p> <p><i>“She cannot talk at all she can hardly even open her eyes, she can open her eyes a little bit we don’t know what she seeswe hold her hand but there is no grip, no strength at all...She is just a vegetable right now...we don’t want to prolong that if it’s going to hurt her so there is not point”</i></p>
<p>Impact on Family</p> <p><i>“Yeah, yeah, because when we go back home we’ll have to go and see the kids and explain to them”</i></p>
<p>Impact on Self</p> <p><i>“His kids came forward and said how come it happened this way and he said it was my fault I made all the decisions”</i></p>

Figure 1.2

Problematic Relay of Information
<p>Inadequate</p> <p><i>“Like if you, I mean, J and I really hadn’t discussed it, like I mean we discussed it to the point that, yeah we want life support if it’s going to benefit, but, how do we know? Like sometimes they explain stuff to you, they don’t talk to you in laymen terms”.</i></p>
<p>Exclusion From</p> <p><i>“ Well we came in and the dialysis machine was off and I asked the nurse how come it’s off and she said well the filter went in the middle of the night and the attending said that is okay they are limiting treatment in the morning anyways. And I’m like WHAT? So you ask us to make a decision like that but then you take matters into your own hands?”</i></p>
<p>Key Participants</p> <p><i>“But after a while, you just get tired because you are repeating yourself. Repeating myself sounds like a record, I should have a little CD player and tape it and plug it in and I can just play it back”</i></p>

Figure 1.3

Impingement of Real Life
<p>Family & Friends</p> <p><i>“and this one sounds a bit selfish but I think for all of us our whole life is on hold while this process goes on and um you know it’s kind of like we’re not in a hurry to get rid of my dad but it’s like you know everybody is just living on the edge”</i></p>
<p>Career & Finances</p> <p><i>“I’m trying not to think about work. But we all know what that is like. You know especially in my, well I have 30 voice mails right now from clients”</i></p> <p><i>“the financial end of it has been very, very stressful”</i></p>
<p>Home & Pets</p> <p><i>“We’ve got two cats. I mean I know that you know that I can leave them food but they still have to eat. Still have to eat”</i></p>

Figure 1.4

Facing Unknowns
<p>Unplanned</p> <p><i>“But it’s just...he’s a very young man, he’s a very healthy 43 year old guy. Very healthy”</i></p>
<p>Changing Expectations</p> <p><i>“You know that he’s, that the situation is you know not as good as I would like it to be...even though it’s hard to hear you know”</i></p>
<p>Uncertainty</p> <p><i>“But I’ve been here for hours. I don’t know. Yeah I’ve been here for hours. And you know I don’t know anymore now then I knew hours ago”</i></p> <p><i>“Yea. It’s very stressful to think when is the moment going to be when it’s time”</i></p>

Table One: Patient Characteristics (n=19)

Patients' Illness or Injury

Diagnosis	No. of patients
Neurological Events	4
Cardiac Events	6
Respiratory Events	4
Hepatic Events	1
Sepsis	4

Patient Characteristics

Age (years)	
<ul style="list-style-type: none"> • Median Range 	69.94 (44-86)
Gender	
<ul style="list-style-type: none"> • Male • Female 	16 3
Marital Status	
<ul style="list-style-type: none"> • Married/Partnered • Divorced/Widowed • Single/Never Married 	16 2 1
Previous ICU Patient	
<ul style="list-style-type: none"> • Yes • No 	3 16
Advance Directive	
<ul style="list-style-type: none"> • None • Written 	17 2

Table Two: Surrogate Characteristics (n=19)

Surrogate relationship to patient	No. of surrogates
Spouse <ul style="list-style-type: none"> • Wife • Husband 	9 3
Adult Child <ul style="list-style-type: none"> • Son • Daughter 	2 1
Sibling <ul style="list-style-type: none"> • Sister 	2
Other <ul style="list-style-type: none"> • Grand-daughter • Niece 	1 1
Gender <ul style="list-style-type: none"> • Male • Female 	5 14
Highest Level of Education <ul style="list-style-type: none"> • Elementary • High School • College/University • Post-Graduate • Not Available 	1 5 10 1 2
Previous Experience with ICU Surrogate Role <ul style="list-style-type: none"> • Yes • No 	5 14
Time Spent with Family Weekly <ul style="list-style-type: none"> • Lives with • Daily • Weekly • Monthly 	11 1 2 6

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Chapter 4

Coping Strategies Employed by Surrogate Decision Makers for the Critically Ill Intensive Care Unit Patient at the End of Life

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Acknowledgements: The author is grateful for the support of the CARENET group throughout this project.

Submitted to Journal of Palliative Care
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Abstract

An increasing number of hospitalized patients dying in intensive care necessitate the involvement of a surrogate in end of life care decisions. End of life decisions in the intensive care are complex and demanding for surrogate decision makers with limited resources. Recent reports of post traumatic stress disorder symptoms following participation in this process indicate a need for increased awareness of coping strategies employed by surrogates during the decision making process to effectively plan interventions. The purpose of this study was to describe coping strategies used by surrogates while participating in end of life decisions for the critically ill, adult intensive care patient. A descriptive study design using qualitative interviews of nineteen surrogate decision makers was selected. Systematic thematic analysis was guided by Folkman and Lazarus' Stress and Coping Paradigm to extract the emotion and problem based coping strategies identified by surrogates. Emotion focused coping strategies included protecting and respecting themselves and seeking solace. Problem focused coping strategies included decreasing uncertainty, dealing with others and mobilizing time. Identification of key coping strategies assist health care professional in development of appropriate focused interventions to modify known stressors.

Recent studies have reported as many as one in five hospitalized patients die in the intensive care (Angus et al, 2004; Booth et al, 2004; Heyland et al, 2000). Most are unable to communicate their preferences for treatment because of the severity of their illness, leaving others the responsibility of making life and death decisions for them (Azoulay et al, 2005; Chambers-Evans & Carnevale, 2005; Tilden et al, 1999; Wiegand, 2006). In a health care system where patient autonomy is valued, health care professionals are required to approach a surrogate decision maker to obtain an accurate reflection of the values, beliefs and wishes of patients who are unable/incapacitated to make decision about treatment.

Unfortunately, surrogates placed in this role often experience stress related disorders following the process (Azoulay et al, 2001; Chambers-Evans & Carnevale, 2005; Murphy et al, 1992; Sjokvist et al, 1999; Swigart et al, 1996). Surrogate decision makers need to mobilize coping mechanisms in response to the distress engendered by this responsibility. How they manage the demands of their role as surrogates influences the decision making process itself and their future well-being.

The process of restoring balance between demands and resources (coping) provides a key area for intervention by health care professionals to support surrogates through this difficult process. Unfortunately, there is limited information about the coping strategies surrogates employ during the process of making end of life decisions. Hence, a more in depth understanding of the surrogate's experience prospectively is critical to effectively plan interventions and provide anticipatory guidance to support surrogate coping while making decisions regarding end of life care. Both the protection of patient autonomy and improved health outcomes for surrogates depends on a more sensitive engagement with decision makers during this process (Meeker, 2004).

Background

End of life decisions for the unresponsive intensive care unit patient are complex. Often the unexpected, unplanned admission to the intensive care unit allows no time for preparation for the role of surrogate decision maker for an incapacitated patient. Many patients have not specifically discussed their wishes about this, leaving the default appointed surrogate searching for direction and relying on previous related conversations. Furthermore, numerous health care professionals from a variety of disciplines are involved. Some may be uncomfortable with limiting therapy; others may communicate poorly, or provide information about prognosis with difficulty (Azoulay et al, 2004; Ho et al, 2005; Hunter Dean & Gowan, 2006, Cassell, 2003; Lang & Quill, 2004; Le Claire et al, 2005; Moreau et al, 2004; Simmonds, 1996). This can cause conflict among family members, putting surrogates already vulnerable in this new role, at greater risk for distress. In addition, disagreement between multiple family members may lead to family dysfunction, following the surrogates' decision (Prendergast & Puntillo, 2002). Although the health care professionals' primary role is to support the patient, the family must be included in a holistic care model.

Most previous research in this area has examined the family members' experience of making decisions for the critically ill patient either retrospectively or collectively with the family as a whole rather than the principle decision maker with whom the health care team identifies/communicates with regarding patient treatment decisions (Chambers-Evans & Carnevale, 2005; Swigart et al, 1996; Wiegand, 2003). Other critical care research has involved evaluation of satisfaction with care and assessment of communication strategies used by health care professionals at the end of life. Recent literature has also investigated the impact of surrogate decision making following the process. This reveals a large portion of surrogates participating in end of life decision making have high rates of anxiety following the process. One

study of 544 intensive care patient family members' found that over seventy five percent of participants had post traumatic stress disorder at six to nine months after involvement decision making in the intensive care for a critically ill patient (Azoulay et al, 2005). Thus, although the decision making process often reaches completion with the patient's suffering ending, the surrogate's suffering continues following the resolution of the situation. Health care professionals must assist surrogates to cope during the complex, emotionally charged and highly stressful process of making end of life decisions in the intensive care. There is little information however, for health care professionals regarding the ways the surrogate decision maker manage stressors related to their role, making supportive interventions during this difficult process (Azoulay et al, 2005; Heyland et al 2002; Curtis et al, 2001). The gaps in research about the surrogate decision makers' experience to date leave health care professionals with an incomplete guide to support these families during the process.

In summary, literature to date provides little information about the ways in which surrogates respond to the demands of making end of life decisions for the critically ill, adult intensive care patient during the process itself. A better understanding of the ways they cope with surrogate decision making is important for health care professionals to develop guidelines to assist surrogates and reduce their risk for serious long term stress following the event (Azoulay et al, 2005). A description of the surrogates' coping with making end of life decisions is vital for health care professionals to meet their obligation of supporting surrogates through this process.

Sensitizing Framework

The surrogate decision maker responds to the demands of this responsibility by choosing ways in which to deal with the perceived harm or loss involved in carrying out this role. Coping is the process of restoring balance (equilibrium) between excessive demands and inadequate resources (Lazarus & Folkman, 1984). Folkman and Lazarus' stress and coping paradigm (1984)

describes coping behavior as goal directed and responsive to stressors. It encompasses constantly changing cognitive and behavioral attempts to manage the external and internal demands of the situation (Lazarus & Folkman, 1984). Coping resources include use of individual and social network characteristics available to mediate or moderate the individuals' response to a stressor. Two broad categories of coping are identified: problem oriented coping and emotionally focused coping. Problem oriented coping describes adjustments that are deliberate actions directed at the cause of stress in an attempt to alter it. Emotion focused coping describes the adjustments that are focused on altering or managing the individuals emotions resulting from the stress-inducing situation. For example, people may cope by focusing on reducing the emotional distress induced by the stressful situation, and/or by focusing on changing the stressful source. Coping strategies are mobilized following the cognitive appraisal of a situation and may buffer the stress evoked. Together, problem and emotion focused coping determine the nature, intensity, and duration of the emotional reaction resulting from this experience. As well as providing a guide for analysis, this model provides a framework for health care professionals in planning interventions to assist surrogate decision makers to manage a difficult process.

The purpose of this study was to examine the emotion and problem focused oriented coping methods used by surrogate decision makers to manage or modify stress while making decisions for a critically ill, adult intensive care patient. It investigated the following research question: What coping methods are used by surrogate decision makers to manage or modify stress related to making decisions for a critically ill, intensive care adult patient?

Methods

A qualitative descriptive study design was employed. Thirty seven semi structured interviews were completed with nineteen surrogates participating in the process of making end of life care decisions for a critically ill, adult intensive care patient. Surrogate decision makers were

recruited for interviewing as part of larger project exploring appraisal, stress and coping during the end of life decision making process. Each participant was interviewed twice during the process of making end of life decisions for a critically ill intensive care patient. Open ended questions were included to capture the ways in which surrogates coped with the demands related to the decision making process such as “how have you managed the decision making role” and “what have you done to cope with making these decisions?” .

Over a period of seven months, surrogate decision makers were approached for all adult intensive care unit patients who were incompetent to participate in treatment decision making and met the following criteria: an estimated mortality of greater than fifty percent as assessed by the attending physician and admitted to intensive care for a minimum of 24 hours and maximum of 72 hours at the time of the first interview. This permitted recruitment of surrogates decision makers’ at greatest risk of making an end of life decision during a short stay. Following consultation with the attending physician of critically ill patients who met the criteria for suitability, a surrogate decision maker was approached by a member of the health care team to determine willingness to be approached to participate in the study.

Twenty surrogate decision makers were recruited to participate but one declined participation. Once participants consented to participation they were given an information sheet and a brief description of the process by the researcher. All participants provided written consent. Following consent, interviews were conducted by the researcher in a quiet, private room close to the intensive care. All interviews were tape recorded and transcribed verbatim by the researcher.

Surrogate characteristics were collected at the time of the first interview, patient characteristics were completed through chart review during the decision making process and when necessary following the patients’ death (See Table 1: Surrogate Characteristics & Table 2: Patient Characteristics).

Ethics approval was obtained through both the Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board and the Kingston General Hospital.

Data Analysis

Lazarus and Folkmans' (1984) stress and coping paradigm guided the thematic analysis of the interview transcripts (Folkman & Lazarus, 1984; Huberman & Miles, 2002). NVIVO 7 computer software aided extraction, coding and categorizing of surrogates' problem based and emotion focused coping strategies. Using Lazarus and Folkmans definitions, statements indicative of coping were first extracted and classified into emotionally focused or problem oriented coping and then coded. These codes were then reduced into broader categories of either emotionally focused coping or problem oriented coping.

To enhance the reliability of the coding decisions, a second independent analyst reviewed the categories of items and the reduction of items into themes of a random third of the data set. After comparison and discussion, revision and consensus was reached.

Findings

All surrogates participating in end of life decision making described both problem and emotion based coping strategies. Emotion focused strategies used by participants will be described first followed by problem oriented ways of coping.

Emotion Focused Coping Strategies

Emotion focused coping strategies are directed at managing the emotional response to the stressor. Two major categories were identified and extracted across all participants: protecting and respecting self and seeking comfort/solace.

Protecting and Respecting Self

Surrogates described managing the emotional response to the stress of end of life decision making by respecting and protecting themselves from negative self judgments during the

process. This involved confirming to themselves that they were acting in accordance with the patients' wishes through reflection on, and consideration of, what the patient wanted before they were incapacitated by illness. Surrogates drew on memories of prior discussion with the patient around end of life topics and their general knowledge of the patient. Although surrogates were often unable to recall specific discussion, they described themselves as knowing the patient and remembered having had conversations around preferred quality of life or discussions about death following media events, or illness of friends or family. As one surrogate said: *"I remember him being, you know, he was just so adamant about it you know. He didn't even want to be with a stroke"*.

Some surrogate decision makers had prior experience with an event where the patient was unable to participate in care decisions and thinking about what happened also provided them with a sense that the patients' desires were being met in the current decision making process. While difficult, this comforted the decision maker in the decision making process. For example: *"all I can think of is what he told me. "I don't wanna live that way". And I know darn well if he come too and he's got that brain damage which they said he has - they told me that he isn't going to be the same man so why would he want to live that way then? He has already told me that so many times"*.

Thus surrogate decision makers considered prior conversations or experiences with the patient and they found comfort in their role by reflecting on their perception/understanding of the patient wishes. As one surrogate explained: *"it helped that...things we talked about before"*.

Participants also described respecting and protecting themselves during the process of making end of life decisions by their approach to time. As the patients' prognosis unfolded they described receiving updates during the process as the patient improved or declined and they used time related strategies to manage their emotions as they made sense of the evolving prognosis.

One common time related strategy involved taking the process minute by minute or hour by hour. A surrogate explained: *“You just deal, you just, you take one, one breath at a time, one second at a time, and you just deal, you just, you learn to deal”*. Another noted *“we’ll just take it day by day, just day by day”*.

A second time related way of managing their emotions was to take time away from the patients’ bedside in intensive care. Participants reported leaving the hospital for exercise, meals and quiet time away from the busyness of the intensive care unit. Surrogates also described taking time away from the unit to get a break from the sadness of the intensive care unit as well as the waiting room, full of others waiting for a critically ill patient to die or recover. One participant shared, *“And so being on the water it’s nice, it’s beautiful so you can easily go away and you know you know you are going away and doing some other things you know you’re not, nothing is changing you know nothing is getting better because you are not here but it’s not getting worse either. So to get out and take your mind off it. Go for lunch have a beer, you know whatever might be sometimes a good thing.”* Another participant reflected, *“...the waiting room in that environment it’s not a positive environment right? It’s not. Everyone is in there solemn and it’s dark in there, it’s not the most uplifting place you know. And when I go downstairs and front and it’s sunny and there are students and you know there is things to do and you take a walk by the water whatever”*. Surrogates believed the time away assisted them to process the events. For instance, another surrogate said: *“It gives you time to sit, think things over, away”*.

Seeking Solace/Comfort

To manage the emotions resulting from participating in end of life decisions, surrogates also sought comfort from a variety of sources such as hospital staff, family, friends, pastors and the intensive care patient. They also sought solace by observing the patients and his or her care.

Surrogates found comfort in detecting a multi-disciplinary team consensus regarding the care of the critically ill patient. For instance, several sought out agreement between health care professionals such as physician, nurse and primary care provider. Participants described unanimous agreement between all in reducing the stress of making a decision about the end of life. They also found comfort in knowing what was happening to the patient as a result of constant, consistent communication of information from the health care team. Participants described this as a crucial component to manage the emotional response to the stressors. For instance, one surrogate said: “...*the most stress relieving thing is just to know that people are telling me what is happening whenever I want to hear it information is readily available*”. Another surrogate reflected: “*Oh yeah, yeah. Even if you don’t like to hear the information and it doesn’t draw on you, and it does it starts sinking in, like last night when I got home and it does, it starts sinking and it does make it a little easier. It’s better to know*”.

Surrogates identified family participation, presence, dialogue and support as imperative in helping them cope with the emotions generated by participation in the decision making process. They also described having good friends nearby to support them as an integral part of their ability to cope. This included old friends as well as new friends. Often those in the waiting room surrounding them assisted with coping. One surrogate noted: “*Just having my family with me while I’m sitting over here that’s the only help*”. Another commented: “*Yes. Yes. Yeah. I think it’s nice to have someone around right now. And it’s funny for me because I’m usually a person I, I like to have a time for myself. So it’s kinda been different for me you know but right now it’s just a blessing that they are there. And I, I enough their company right now. Just to know that someone is there*”. Another surrogate remarked on the physical presence of a close friend: “*Just, just being there, if I’m crying, or whatever, just being there*”.

Some surrogates sought this solace during the process of making decisions by using praying to a higher power. Faith in life after death was also described by surrogates as helpful in coping with making an end of life decision. For instance, one surrogate said: *“When Jesus decides that it’s his time, there’s not there’s nothing I can do about it and he’s going to help me get through this and I know that”*. Several surrogates also identified support from pastoral care as helpful in managing their emotions associated with the decision making role. For example one surrogate said: *“We had the minister up. He was just up here and that uh he said a prayer.....it feels good to have someone like that here”*.

Although they took time away from the bedside to help them cope, the majority of surrogates also felt that being physically present at the patient’s bedside was helpful in reducing their emotional response in this role. They sought solace by observing and noting that the patient appeared comfortable and was being provided good care by health care staff. This reduced the distress surrogates felt about making end of life treatment decisions. Observation that the patient was peaceful, being cared for competently by health care staff, or was not suffering, assisted them in managing their emotional response to the decision making process. One son reflected: *“I felt that, you know, that I was in good hands. My dad is in good hands”*. A busy intensive care with staff rushing around was often perceived as staff *“running around doing their best”* for the patient. As one surrogate considered his father’s care he reflected on the nurses care saying: *“Yeah. Well. You don’t have to. Well in my, you know in my dad’s situation at least you only have to spend about a ½ an hour to realize that they know what they are doing. Cause in a ½ an hour they do about 50 different things in a ½ an hour. You know they’re filling syringes changing readings on the ventilator they are doing a 1000 things at once multitasking and he was still there so it must be working..... it kind of relaxes you know”*.

Problem Focused Coping Strategies

Surrogates also employed active coping strategies to alter or reduce the stressors/demands of end of life decision making for the critically ill patient. Three main problem based approaches were identified: decreasing uncertainty, dealing with others, and mobilizing time (See figure 2.0). Each of these contained sub themes which will be further explored.

Decreasing Uncertainty

As noted earlier participants found comfort in knowing what was happening. In contrast, uncertainty was a stressor for them. The first problem focused coping strategy participants employed was to decrease some of the uncertainty in the decision making process. The most common methods employed to accomplish this were observation and consultation. All participants expressed a need for more information from numerous sources to decrease the stress of uncertainty. One surrogate said: *“I mean, the more information you get, I mean you got to learn to ask questions, and I guess since last year, I’ve learned to ask a few more questions”*. The key sources surrogates sought out to obtain more information were the members of the health care team, friends, family and pastor. One participant described his frustration with meeting with the doctors, *“Today I called in advance...we want to talk to the doctor about where it’s at and what is happening and what our options are right now”*.

Participants particularly valued opinions of health care professionals. A participant reflected her priorities in gathering opinions, *“Well first we had to talk to the doctors. That we’ve been doing”*. Surrogates also sought agreement from the health care team. One surrogate noted: *“Then the nurse came to me and she said you made a wise decision. So it helped a lot”*. Another surrogate described how she coped with making the decision to limit treatment on her brother: *“Well the doctor said no, he won’t be suffering because they will be keeping him on morphine”*.

Surrogates also actively consulted both the patients’ family and friends and their own, to reduce uncertainty about the critically ill patient’s values and wishes regarding life sustaining

treatment. One surrogate expressed the importance of this by saying “...by being able to talk to other family members if everyone is on the same page”. Another stated “there is not a discrepancy between us, it’s not like one of use is sitting thinking maybe we don’t want it, we know she didn’t want it you know”.

Some surrogate decision makers consulted their pastor for spiritual counsel, treatment advice, reassurance, and prayer. One surrogate commented on the visit of pastoral care to the patients’ bedside with the family: “Yeah. It was good...Just like reciting the prayers then he was going up there and God was going to receive him and everything was going to be okay with him”.

Dealing with Others

Although surrogate decision makers sought information from a variety of sources during the process of decision making, they also transmitted information to key participants and involved them in the process. Key participants varied in each situation, but they included blood relatives or close friends who had a relationship with the critically ill patient. All participants described reluctance to be solely responsible for the end of life decision and sought agreement of key participants during the process. For instance one surrogate commented: “Right, I told (his) sons that they need to be there. That they need to make decisions with me. I’m not, I don’t want to be the sole decision maker here. They need to help. Okay. I love them dearly, they’re part of my life and I do not want to overstep a boundary here they need to make the decisions with me”.

Surrogate decision makers discussed the decision with key participants and friends to obtain agreement.

Mobilizing Time

Surrogate decision makers described mobilizing time as a key part of coping with the decision making process. While they were seeking information around prognosis, patient wishes, and key participant opinion, all surrogates described the importance of finding time to be with the

patient so they could process information, and come to a conclusion. Although they took time away to reflect and cope emotionally, they also actively organized their time to be with the patient and identified this as a key coping strategy. For example, one surrogate reflected on mobilizing time to be with her critically ill husband: *"...Cause my priority is my husband, and I want to be with him as much as I can, because, I don't know whether he's going to be here tomorrow or not, so I want to be with him"*.

Often mobilizing time to be with the patient meant mobilizing a network to free them from other responsibilities. One surrogate decision maker described her coping strategy: *"And you know what? I have a nice network have friends taking care of my business side. I have her husband taking care of communication with the brothers and sisters. I have a friend that is taking care of my dog. I have a friend who is taking care of my home, my neighbor, my neighbor has a key and she is taking care.... I have a real nice network and the cottage someone is taking care of the cottage too"*.

Discussion

The surrogate decision makers for critically ill patients of this study moderate their response to the demands of this role by consciously utilizing coping resources available to them. All articulated coping strategies they believed were helping them in their role of end of life decision making. Although there was variation in surrogate age, cause of patient illness, and surrogate-patient relationships, their descriptors of common strategies provide health care professionals with a guide to assist surrogate decision makers manage this very difficult process. Supporting the types of coping surrogates identify as helpful has the potential of reducing the lingering distress highlighted in recent research (Azoulay et al, 2005). Therefore, these findings have important implications for future practice caring for surrogates at the end of life in intensive care.

Common emotion focused coping strategies described by surrogates to manage the decision making role were: respecting and protecting self and seeking solace. The main theme of respecting and protecting self which surrogates used to manage the emotional aspect of role, provides a key area for health care professionals to anticipate and guide surrogates. Critical care nurses at the bedside should include potential surrogate decision makers early in the process, exploring their perception of the critically ill patient's values and beliefs, regardless of whether a decision is imminent. The anticipation by health care professionals of surrogate attempts to manage their emotions by reflection enables health care professionals to guide surrogates in thinking about the goals of care. In addition, this intervention encourages surrogates to reflect on the patients' values, wishes and beliefs rather than their own, from the beginning.

This early intervention may lead to a more open, trusting relationship between the health care professional and the surrogate and has the potential to improve communication between health care professionals and surrogate decision makers, a common difficulty at the end of life in the intensive care (Curtis et al, 2002; Heyland et al, 2003). When decision making is anticipated an early exploration of patient wishes provides both an opportunity for discussion and familiarity in the clinician-patient relationship (Cook et al, 1999; Tracey and Ceronsky, 2001).

Surrogates managed the emotions of their role more easily if they had a discussion with the patient regarding end of life preferences prior to admission. Previous research acknowledges the difficult position the surrogate decision maker is placed in when there has been little, if any, prior discussion with the patient regarding treatment preferences in this situation (Abbott et al, 2001). Given that many patients' admissions are unexpected and few have advance directives clearly defined it, provides health care professionals with an avenue for intervention (Karlavish & Hall, 1997; Faber-Langendoen, 1996; Prendergast & Luce, 1997). Health care professionals should therefore anticipate that many surrogates will require assistance in determining patient

preference. This prompts the health care team to facilitate reflection of the patient's values and beliefs and provides an opportunity to clarify the surrogates' role as one of protecting the autonomy of the patient, not the surrogate. Confirmation of their perceptions of the patients' preference from other family members was important to participants. After considering the family dynamics the health care team may suggest involving the extended family in this discussion to provide surrogates seek this type of validation to ensure realistic reflection. This strategy has the potential to significantly reduce the impact of the emotional stress response.

In the midst of making end of life decisions, surrogates cope with their emotional response minute by minute. The overwhelming nature of the situation and intensive care environment prompted all surrogates to take time away from the unit to reflect and process the situation. Health care professionals can reassure surrogates that in the past other surrogates have found it helpful to cope by leaving the unit for a short walk, meal etc, as this time away often provides opportunity to assimilate events. As the majority of surrogates had not been in this role before (See Surrogate Characteristics: Table 3), they were unaware of the coping strategies other surrogates employ. A simple awareness of effective coping techniques of those who have gone before may also provide support for surrogates struggling to find ways to cope, conserve energy and decrease the burden of this role.

Members of the health care team may facilitate surrogate's search for solace and comfort. Surrogates sought comfort and solace from a variety of sources including health care staff. This confirms previous research identifying the family's ability to cope with the demands on them is linked to the nurses' capacity to support patients' families effectively (Williams et al, 2005). Staff need skills and knowledge to work with families to develop a therapeutic relationship to consciously support surrogates during the process and provides avenues for re-direction to other supports.

Another important part of support for some involved spiritual counsel. This prompts staff to have policies in place to offer consultation with spiritual care resources. The intensive care team can also encourage surrogates' to call on family and friends for support during the process of making decisions to assist surrogates in managing their emotional response.

Surrogates employed three common problem focused coping strategies. They actively sought to decrease their uncertainty, they mobilized time and they dealt with other key players in the decision making process. Previous research has indicated that surrogate decision makers need timely clinical and prognostic information, continuous psychosocial support from the health care team, guidelines for effective family conferences and a sharing of the burden of decision making (Curtis et al, 2001; Prendergast & Puntillo, 2002). While health care professionals may be unable to prognosticate with 100% certainty, frequent communication of information about the patient is critical in reducing uncertainty and the decision maker's ability to cope (McDonagh et al, 2004). Although surrogates may be unable to facilitate family/key participants around a difficult subject, the health team should incorporate strategies into their plan of care to facilitate dialogue.

Participant's observation of the patient, health care team and intensive care environment was also a way in which the surrogate decision maker decreased uncertainty and found solace. Encouragement by health care professionals of open or flexible visitation to the intensive care may facilitate this observation as well as provide time for the surrogate to understand that intensive caring may involve letting go of life sustaining treatments (Prendergast & Puntillo, 2002). Health care professionals' acknowledgement that in order to cope, surrogates find comfort in patient appearance (comfort, pain free, cared for) practice changes must include but not hasten death. Previous research has indicated that administration of sedatives and analgesics during withholding and withdrawal of life support from critically ill patients does not hasten death (Wilson et al, 1992). This study reflects previous research which has cited the second most

common reason to consider withdrawing was patient suffering, further highlighting the necessity of clear communication between health care professional and surrogate visiting the critically ill patient to prevent misinterpretation (Keenan et al, 1997).

In previous studies the stressful end of life decision for a patient has been found to be a source of disagreement between those close to the patient (Prendergast and Puntillo, 2002). Surrogates described dealing with others as a common coping strategy to reduce the demands of their role. The intensive care unit team must recognize that in the midst of a stressful and anxiety ridden situation facilitation of this may be required for any consensus between those close to the patient to occur. Strategies to facilitate dialogue may include physical space for families and friends of the patient to gather and may require a facilitator, such as a member of the social work or pastoral care team.

The surrogates' perception of their ability to cope with this stressful process provides important opportunities for health care practitioners to both facilitate and intervene, guiding surrogates through the process with less scaring/long term post traumatic stress disorder symptoms.

Limitations

The descriptive study was conducted in a single site university hospital. Data were collected through qualitative interviews and coded thematically. This design limits generalization of findings to other settings.

Conclusion

Implications for future practice include health care professionals incorporating current and past research to assist surrogate coping strategies in a role which they are most often unfamiliar with and unprepared for. Interventions to assist surrogate decision makers through the complex and stressful process of making decisions at the end of life for the critically ill intensive

care unit patient must include time sensitive interventions allowing surrogates to move the process making decisions at the end of life with as much support as possible to decrease the long term effects of participating in end of life care decisions in intensive care.

Table 1: Patient Illness or Injury

Patients' Illness or Injury (n=19)

Diagnosis	No. of patients
Neurological Events	4
Cardiac Events	6
Respiratory Events	4
Hepatic Events	1
Sepsis	4

Table 2: Patient Characteristics

Patient Characteristics (n=19)

Age (years)	
<ul style="list-style-type: none"> • Median Range 	69.94 (44-86)
Gender	
<ul style="list-style-type: none"> • Male • Female 	16 3
Marital Status	
<ul style="list-style-type: none"> • Married/Partnered • Divorced/Widowed • Single/Never Married 	16 2 1
Previous ICU Patient	
<ul style="list-style-type: none"> • Yes • No 	3 16
Advance Directive	
<ul style="list-style-type: none"> • None • Written 	17 2

Table 3: Surrogate Relationship

Surrogate relationship to patient	No. of surrogates (n=19)
Spouse <ul style="list-style-type: none"> • Wife • Husband 	9 3
Adult Child <ul style="list-style-type: none"> • Son • Daughter 	2 1
Sibling <ul style="list-style-type: none"> • Sister 	2
Other <ul style="list-style-type: none"> • Grand-daughter • Niece 	1 1

Table 4: Surrogate Characteristics

Gender <ul style="list-style-type: none"> • Male • Female 	5 14
Highest Level of Education <ul style="list-style-type: none"> • Elementary • High School • College/University • Post-Graduate • Not Available 	1 5 10 1 2
Previous Experience with ICU Surrogate Role <ul style="list-style-type: none"> • Yes • No 	5 14
Time Spent with Family Weekly <ul style="list-style-type: none"> • Lives with • Daily • Weekly • Monthly 	11 1 2 6

Figure 1: Emotion Focused Coping Strategies

Coping Strategies: Emotion Focused	
Protecting and Respecting Self	<ul style="list-style-type: none">• Considering Patient Wishes• Patient Observation• Using Time
Seeking Solace	<ul style="list-style-type: none">• Staff• Family & Friends• Spirituality• Patient

Figure 2: Problem Focused Coping Strategies

Coping Strategies: Problem Focused	
Decreasing Uncertainty	<ul style="list-style-type: none">• Consulting• Observing
Dealing with Others	<ul style="list-style-type: none">• Seeking Agreement• Communication with Others
Managing/Optimizing Time	<ul style="list-style-type: none">• Presence• Processing

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Chapter 5

Summary

Surrogates play a central and crucial role in protecting a vulnerable patient's autonomy while they are incapacitated. The process of making decisions for an incapacitated person at the end of life is demanding (Azoulay et al, 2005; Wiegand, 2006; Tilden et al, 2001; Jacob, 1998; Chamber-Evans & Carnevale, 2005). The long term distress which surrogate decision makers describe following involvement in end of life decision making indicated a need for prospective study during the experience. This research, conducted in one university affiliated hospital intensive care unit was undertaken to further understanding of the complex process of end of life decision making from the perspectives of the surrogate decision makers involved. It examined the surrogate decision makers' perception of stressors, coping strategies, and their appraisal of the demands of this role. The findings may assist in the design of interventions to modify the stressors related to the experience, support coping, and provide understanding of surrogate appraisals of the demands of this role.

A prospective, descriptive study design was selected and Lazarus and Folkmans' Stress and Coping Paradigm (1984) was used as a sensitizing framework to guide interviewing and analysis. This framework addresses the ongoing, reciprocal relationship between a surrogate decision maker and the intensive care environment. The paradigm identifies stress as a dynamic phenomenon (Lazarus, 1984) based on individuals constantly appraising and reappraising environmental demands in light of their perceived effects on them and on their perceived ability to respond to them.

The advantage of this framework was its ability to provide direction in capturing surrogate perceptions of the demands of their role and their ability to respond to these demands.

It facilitated the identification of the specific types of perceived stressors and coping strategies surrogates employed during the decision making process. From a research perspective, it provided an analytical framework for the interpretation of the findings as well as a guide to the coding and categorization of data.

The findings in this study have implications for all health care professionals who interact with surrogate decision makers in the intensive care unit. They may contribute to health care professionals' understanding of surrogate appraisal, stress and coping in end of life decision making for a critically ill intensive care unit patient. Furthermore, as noted the findings of this research may guide health care professionals in the future to assist surrogates through the process of making end of life decisions, a role most are unfamiliar with and unprepared for.

This chapter will describe the findings in relation to previously completed research, the limitations of the study and will discuss their implications for clinical practice.

Comparison of Findings to Previous Research

While this study supports findings of earlier research, it also offers new understandings of surrogate appraisals, perceived stressors and coping strategies used in the midst of the decision making process. The findings contribute to the literature to date in providing health care professionals in intensive care units with more avenues for intervention.

Appraisal

The surrogates' continuous appraisal of the decision maker role was identified in this study as both a complex and non linear process. Data reduction into primary and secondary appraisal revealed key themes in this difficult process. Primary appraisals were reduced into two main categories: default decision maker, and an awareness of the fork in the road. Previous research has indicated that surrogate's perceptions of patient suffering and predicted quality of life assist them in realizing the need for a surrogate decision maker (Jacob, 1998; Wiegand, 2006;

Chamber-Evans & Carnevale, 2005; Swigart et al, 1999). This study suggests that this realization occurs early on in the patient's stay as does their attempts to understand the demands of the surrogate role. Participants started thinking about end of life decision making before the subject was broached by the health care team and therefore with little guidance from health professionals. Participants stressed the importance of the health care team providing information about the surrogate role clearly and considered this to be central to their ability to function in this capacity.

The second primary appraisal category was surrogate awareness that the patient outcome would be either death or some lesser variation of the patients' previous quality of life. Previous research has described the magnitude of this for surrogates and this was supported by participants' appraisal of their role. Surrogate decision makers in this study found the decision in front of them very difficult and were acutely aware of its significance for the patient. As in previous research, some participants described their perception of a decision to end life sustaining treatments as murder (Swigart et al, 1994; Wiegand, 2003) and found this scheduling of death barbaric. However, similar to previous research, participants of this study also reported wanting to be involved in the decision making process despite the difficult nature of the role (Jacobs, 1998).

In their secondary appraisals participants identified what they required to function in the role of surrogate decision maker. These included partnerships with others, prior discussion and experience with the decision making role and time.

In previous research surrogate decision makers have commonly included multiple family members in end of life decisions (Jacob, 1998; Reckling, 1994; Swigart, 1994; Tilden et al, 1995; Tilden et al, 1999; Tilden et al, 2001; Wiegand, 2003). In this study surrogates identified partnerships as necessary for them to make end of life decisions. They described other family member involvement in the process as crucial to their ability to participate effectively, in part to

distribute some of the burden of the role, and also to prevent future blame for the decision made. In this study, however, a single surrogate decision maker was identified by the health care team to participate in end of life decisions. Swigart et al (1996) also found that each family had a primary decision maker. However, Wiegand (2003) found that families made surrogate decisions through a consensus process in order to maintain family harmony. While surrogate decision makers in the present study often consulted other family members and counted them as partners, they recognized their primary/ultimate responsibility in the role of surrogate although many found this position difficult.

Previous research has indicated that prior discussion with the patient concerning his or her wishes and advance directives are helpful for families making end of life decisions (Jacob, 1998; Swigart, 1994, Swigart et al, 1999; Tilden et al, 1999; Tilden et al, 2001). In this study all surrogate decision makers indicated that prior discussion of patient wishes would have significantly decreased their distress in this complex process.

Participants with previous experience in the surrogate decision making role also perceived this as enhancing their ability to function in the role.

All surrogates described needing time to be present with the patient in the intensive care unit to manage their role. Earlier research of family needs during a patient's hospitalization in an intensive care unit also indicated the surrogates' need to be present with the patient (Jacob, 1998; Chambers-Evans & Carnevale, 2005; Wiegand, 2003). This research highlights the importance of the health care team consideration of their need to process events first hand.

Finally, previous research has presented the decision making process as linear (Tilden et al, 1999; Swigart et al, 1996). Participants in this study appraised the role of decision maker throughout the process of making decisions, often moving back and forth between primary and secondary appraisal, identification of stressors, and application of coping strategies. Therefore,

this suggests that the health care team can reasonably expect surrogate education and role questioning will occur throughout the decision making process.

Stressors

This study identified four major categories of stressors for surrogates in the midst of decision making: doubt of self efficacy, impingement of real life, problematic relay of information, and facing the unknown. Although little previous research has explored the specific stressors of the decision making process, studies have revealed elements of the demands of this role.

All surrogates describe having doubt about their ability to make the right decision as they contemplated its impact on the patient, other family members and themselves. Surrogates' attributed a considerable amount of their stress to an unclear understanding of their role within a shared decision making model. A clear explanation of not only the surrogate's role but also the role of those close to the critically ill patient in the process in decision making has the potential to significantly decrease the stress involved. Education of health care professionals to provide clear expectations is crucial for future surrogates. Previous research has not explored the sources of surrogate self-doubt in this process.

Previous research has shown that family members' response to a critically ill patient's admission often results in their overlooking their own physical and psycho-social needs which exacerbates their stress (Engstrom and Soderberg, 2004; Halm et al, 1993). Surrogates consistently expressed distress because of the continued demands of their jobs, their pets, and their dependents, all of whom still counted on them to carry out various responsibilities while they were tending to the critically ill patient in the intensive care unit. Surrogates reflected on their exhaustion with countless demands on their time and energy, leaving very little reserve to deal with their own emotions in this process.

This study supports recent research indicating certain health care provider behavior decreases surrogate distress. These include clear, timely communication, clear indications of prognosis and consistent intelligible information from all health care professionals (Auerback et al, 2005; LeClaire et al, 2005; Tilden et al, 1995; Wiegand, 2003). Wiegand (2003) found that relationships with health care professionals were important to the patient's family at the end of life. They report that inconsistencies of communication among team members led families to believe that the care was also fragmented. This study re-affirms the importance of clear, consistent, timely information between surrogates and the health care team (Curtis et al, 2002; Curtis & Engelberg, 2006; McDonagh et al, 2004; Heyland et al, 2002). All participants in this study identified communication with health care professionals as a significant source of stress. Most often the communication difficulties they experienced were related to fragmented and inconsistent information provided to surrogates from different health care professionals.

All surrogate decision makers interviewed described the unknowns and the uncertainties they experienced as stressful. Previous research has found that the spouse of a critically ill patient experiences uncertainty and a roller coaster of emotions following admission to the intensive care unit (Engstrom & Soderberg, 2004). In addition, unknowns related to time to death following withdrawal of treatment has been briefly described previously and this was re-iterated by participants of this study (Wiegand, 2006).

Coping

Participants in this research project identified emotion focused and problem focused coping strategies. Although previous research describes surrogates maneuvering through the decision making process, the coping mechanisms used by surrogates have not been described (Chamber-Evans & Carnevale, 2005; Tilden et al, 2001; Swigart et al, 1996; Wiegand, 2005). Previous studies, however, have identified components of end of life care that contribute to

satisfaction allowing the health care team a glimpse of some components surrogates value when making end of life decisions.

Two major emotion focused coping strategies were identified and extracted across all participants: protecting and respecting self, and seeking comfort/solace. Participants considered patient wishes as they contemplated the decision making process. They drew on their memories of past experiences, conversations with the patient and also observed the patient closely as they considered the options presented and assured themselves that they would be doing what the patient wanted. As well, by considering the patients' very serious, often deteriorating condition, the surrogate processed their decision as based on evidence.

Participants also sought comfort to reduce their emotional response to the decision making process from other family, friends, staff and through spirituality. While the need for support is identified in earlier work it was not clearly identified by participants as a way they managed the emotions generated by the situation.

Surrogates also employed problem based coping strategies to alter the stressors/demands of end of life decision making for the critically ill patient. Three main problem based approaches were identified: decreasing uncertainty, dealing with others and mobilizing time. Participants sought to decrease the level of their uncertainty by consulting family, friends and staff about treatment options. In addition, participants continually observed the patient's condition in the intensive care unit, the care provided, and the health care team interactions with each other, and with the patient. Participants reflected on details to assist them in making a decision such as the wording each member of the health care team used to communicate prognosis. This highlights the importance for health care professionals to be aware of their interactions and also to informing surrogate decision makers, especially when communicating prognosis.

Surrogates also sought agreement between family members, health care professionals and others close to the patient to manage the responsibility of the decision making role. This knowledge suggests the use of an inter-professional team who consult each other when working with families. In addition, surrogates communicated with others close to the patient in order to reflect and consider the patients' wishes and values to ensure a good decision was made.

Limitations

Given the small, one site, homogenous population sample of this study the results are not intended to be generalizable to all populations, rather to further enlighten and inform existing research and provide the groundwork for future, intervention based research among this population. This addition to current knowledge will aid in the development and testing of focused interventions to reduce stressors and support surrogates during the process of making decisions at the end of life for a critically ill intensive care patient.

While this study highlights the stress, coping and perception of ability as described by the surrogate participating in end of life decisions it may not be reflective of the experience of surrogate decision makers for the longer stay intensive care patient.

Implications for Clinical Practice

There is an obligation for health care professionals to involve a surrogate in end of life decision making to protect the dying patients' right to autonomy via the surrogate. They also have an obligation, however, to protect the surrogate from potentially serious, long term effects while participating in these serious and difficult decisions (Prendergaast, 1997). This research highlights ways in which health care professionals can affect the experience of surrogate decision makers as they participate in making difficult choices, in the midst of significant stress. Findings demonstrate a need for more focused guidelines to support surrogates as well as an interprofessional collaborative approach. Surrogates should be assessed for their appraisal of

their role so the health care team can clarify misconceptions and provide guidance in order to protect patient autonomy. Giving the surrogates an explanation of a shared decision making process early on in the patient stay would permit a more informed anticipation of the role and should provide time for reflection around patient preference. Critical care nurses at the bedside, for instance should include surrogates early on in their nursing assessment, exploring with them their perception of the critically ill patient's life prior to admission, providing insight for both the staff and the surrogate regardless of whether a decision is imminent.

It is imperative for health care professionals to be consistent when describing the surrogate role and to be acutely aware of their behavior, as each action and word is often being carefully and continuously processed by the surrogate to prevent unnecessary burden on surrogates sharing decision making, not sole decision makers for the intensive care patient at the end of life. Assisting surrogates to understand the expectations of the role is essential in order for surrogates to be able to function well in this capacity and may decrease feelings of anxiety both during and after the decision making process.

Assessing the surrogate's on-going appraisal of their ability to function as decision maker is a challenge in a busy intensive care unit with rotating staff that often have different communication approaches. The use of surrogate-clinician meetings in a quiet place involving the multi-disciplinary team would allow for discussion and clarification. Equally important is the documentation of such meetings and discussions about end of life care on the patients' chart, to facilitate consistent communication among a rotating interdisciplinary health care team.

Another useful intervention would be the development an information booklet outlining the surrogate decision maker role. This would offer accessible information which may be shared among others close to the intensive care patient. Surrogates, as well as extended family members not present at each meeting with the health care team, could take home these booklets of

information and reflect on them further. Health care professionals should encourage questions from surrogates after reflection for further exploration and clarification in a face to face setting.

In the book, *Managing Death in the Intensive Care Unit*, Shannon (2001) outlines strategies to support families in surrogate decision making. The outlined strategies include advance care planning, assistance for families to interpret clinical signs accurately, cueing families to consider what the patient would have wanted, and creating private spaces to facilitate decision making. This study adds another strategy to this list. As surrogates appraised the condition of the patient at the bedside, they became aware of the patient suffering and the negative patient picture, making them feel more ready to face end of life decisions. This indicates the importance for surrogates to be physically present in the intensive care unit to process the patient illness. Health care professionals should facilitate and encourage open visitation of surrogates to the intensive care unit whenever appropriate to assist them in processing the patients' critical illness. In addition, participants in this study appeared to find it helpful to visualize patient care, to observe the health care team and the intensive care unit, and to process events as they occurred.

All families described the stress of the external world outside the intensive care which did not stop demanding their time and energy while the patient was in the intensive care unit. Often surrogates reported dealing with financial difficulties as well the demands of friends, family and work in the midst of the decision making process. These extra stressors required management to allow the surrogates to concentrate their energy to the task at hand. Participants reported the involvement of external supports such as social workers and spiritual care and assistance with concrete aspects of their lives such as parking passes, a place to stay and a phone to use near the intensive care decreased a portion of their stress. The health care team needs to direct surrogates

towards other available support systems such as a social worker or pastoral care to reduce the effects of external stressors.

This study illuminates surrogate stress surrounding the uncertainties involved in making end of life care decisions. While health care professionals are unable to change the inherent uncertainties in prognosis, communication with surrogates must be a priority and team members must work together to convey a consistent picture for the direction of care, framing changes in patient condition within the larger context of expected patient prognosis and the context or environment within which the decision is going to be made.

It is important for the health care team to realize that partnerships with family and friends may empower surrogates to mobilize their own support networks early on providing opportunity for dialogue, and consensus based decisions. Although this research study supports previous research indicating prior discussion of patients' preference assists surrogates in their role as decision maker, health care professionals must acknowledge that often this discussion has not occurred. This indicates the need to explore patient values and beliefs with the surrogate to inform the decisions at hand.

Implications for Future Research

This research has highlighted many areas for future research regarding the end of life decision making by surrogates. Ideally a population based intervention of community education on the importance of discussing one's wishes regarding end of life treatment would be implemented. Future research should be undertaken to evaluate the impact of an increase of advance directives on surrogate stress.

Future research is needed as well to evaluate trials of supportive interventions designed to modify surrogate stress while making end of life decisions with the goal of decreasing longer term distress after the event. The commonality of stressors perceived by surrogates, direct the

health care team towards interventions with the potential of investigating some of the stressors surrogates experience as they participate in making difficult choices for someone else. As noted earlier, interventions could include communication leaflets to provide information and decrease the potential for misunderstandings and/or a standard intervention of a designated staff member to work with families as they proceed through this process. Information leaflets should include clear explanation of the shared decision making model, intensive care routines, and how others have coped with this process previously.

This study suggests that future frameworks to support intensive care surrogates in end of life discussions must include intentional exploration with the surrogate decision maker of the following: expectations of the surrogate role, reassurance of partnership with the health care team, and mobilization of support systems identified by surrogates. Given the stretched nature of the intensive care environment, research to systematically develop and implement best practice guidelines incorporating a holistic approach would be very useful.

Finally, future research should include exploration of the bereavement process of surrogates leaving the intensive care after their relative has passed away. In this study participants found it helpful to share their experiences with the researcher during the decision making process, perhaps providing another key area for intervention.

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Appendix A

Research Ethics Approval Queen's University

QUEEN'S UNIVERSITY HEALTH SCIENCES & AFFILIATED TEACHING
HOSPITALS RESEARCH ETHICS BOARD



Queen's University, in accordance with the "Tri-Council Policy Statement, 1998" prepared by the Medical Research Council, Natural Sciences and Engineering Research Council of Canada and Social Sciences and Humanities Research Council of Canada requires that research projects involving human subjects be reviewed annually to determine their acceptability on ethical grounds.

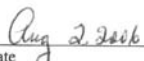
A Research Ethics Board composed of:

Dr. A.F. Clark	Emeritus Professor, Department of Biochemistry, Faculty of Health Sciences, Queen's University (Chair)
Dr. S. Burke	Emeritus Professor, School of Nursing, Queen's University
Rev. T. Deline	Community Member
Dr. M. Evans	Community Member
Mr. C. Kenny	Community Member
Dr. J. Low	Emeritus Professor, Department of Obstetrics and Gynaecology, Queen's University and Kingston General Hospital
Dr. H. Murray	Assistant Professor, Department of Emergency Medicine, Queen's University
Dr. W. Racz	Emeritus Professor, Department of Pharmacology & Toxicology, Queen's
Dr. H. Richardson	Assistant Professor, Department of Community Health & Epidemiology Project Coordinator, NCIC CTG, Queen's University
Dr. B. Simehison	Assistant Professor, Department of Anesthesiology, Queen's University
Dr. A.N. Singh	WHO Professor in Psychosomatic Medicine and Psychopharmacology Professor of Psychiatry and Pharmacology Chair and Head, Division of Psychopharmacology, Queen's University Director & Chief of Psychiatry, Academic Unit, Quinte Health Care, Belleville General Hospital
Dr. M. Sommerfeld	Physician and Assistant Professor, Department of Family Medicine, Queen's University
Ms. K. Weisbaum	LL.B. and Adjunct Instructor, Department of Family Medicine (Bioethics)

has examined the protocol and revised consent form for the project entitled "Surrogate Decision Makers for the Critically Ill Intensive Care Unit Patient" as proposed by Ms. Jeannette Suurd, School of Nursing and Dr. Cynthia Baker, School of Nursing at Queen's University and considers it to be ethically acceptable. This approval is valid for one year. If there are any amendments or changes to the protocol affecting the subjects in this study, it is the responsibility of the principal investigator to notify the Research Ethics Board. Any unexpected serious adverse event occurring locally must be reported within 2 working days or earlier if required by the study sponsor. All other serious adverse events must be reported within 15 days after becoming aware of the information."



Chair, Research Ethics Board



Date

NURS-188-06
2006-07-10

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**QUEEN'S UNIVERSITY HEALTH SCIENCES & AFFILIATED TEACHING
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Appendix B

Information and Consent Forms

Surrogate Decision Makers for the Critically Ill Intensive Care Unit Patient

Background Information:

You are being invited to participate in a research study directed by Jeanette Suurdt, graduate student at Queen's University School of Nursing, to better understand the stressors associated with being the surrogate decision maker for the critically ill adult intensive care patient. Jeanette will read through the consent form with you and describe procedures in detail and answer any questions you may have. This study has been reviewed for ethical consideration by the Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board. This study will be conducted over a four month period in this Intensive Care Unit.

Purpose:

The purpose of this study is to describe the perceptions of surrogate decision makers who are involved in making decisions for the critically ill. This research will provide health care professionals with a better understanding of your experience and may also help us to design better methods of supporting you during this process.

Procedure:

If you agree to participate you will meet with Jeanette in a room close to the intensive care unit waiting room for an interview. She will ask you questions about your perceptions with the intensive care unit experience thus far and explore with you ideas for improvement. At this time you will be asked to complete a brief demographic form and the researcher will also complete a patient chart review to obtain information including the patients' medical condition(s) and length of hospital stay. As often patients remain in the ICU over a period of time we would like to gain a better understanding of your perceptions over this period, at two points in time. The second interview will involve further exploration of your experience perceptions with the student researcher later in the patients' stay as your experience may change. These interviews will be audio-recorded for analysis.

Benefits and Risks:

While you may not benefit directly from this study, results from this study may improve understanding of the demand of surrogate decision-making in the intensive care unit and may benefit others in the future. There are no known risks to you because of your involvement in this study. Some surrogates find it helpful to talk about their experiences. Others may find it uncomfortable. Some may find it upsetting. If you become upset talking with the researcher you will be asked if you wish to be referred to pastoral care or social work. We will respect your wish to stop the interview at any time.

Rights of Participants:

You are under no obligation to participate in this study and your loved ones' care will not be affected in any way if you do not take part. If you do take part, you may withdraw at any time and this would have no effect on the care you receive.

Confidentiality

All information obtained during the course of this study is strictly confidential and your anonymity will be protected at all times. All information will be stored in a locked file and available only to the academic supervisor (Dr. Cynthia Baker), the student researcher (Jeanette Suurdt), and the Research Ethics Board if required.

A code number will be used to identify your information for analysis. Your name will not appear on any documents. The tape recordings and questionnaires will be destroyed within 5 years of the study. If the results of this study are published or presented no personal identifying information will appear. Although quotations from interviews may be used in future presentations or articles from this study, no personal information will appear with these quotations.

If you choose to participate, please complete and sign the below consent form and return it to the research assistant. If you do so, this indicates that you understand the procedures involved and gives us your informed consent to participate.

If you have any further questions, comments or concerns please do not hesitate to contact the student researcher (Jeanette Suurdt, 613 533-6000 ext. 74744), the Chair of Queen's University

Health Sciences and Affiliated Teaching Hospitals Research Ethics Board (Dr. Albert Clark at 613 533-6081), or academic supervisor (Dr. Cynthia Baker, 613 533-2669).

I have read and understand the consent form for this study. I have had the purposes, procedures and technical language of this study explained to me. I have been given sufficient time to consider the above information and the seek advice if I choose to do so. I have had the opportunity to ask questions which have been answered to my satisfaction. I am voluntarily signing this form. I will receive a copy of this consent form for my information.

By signing this form, I am indicating that I agree to participate in this study.

Signature of Participant

Date

Signature of Witness

Date

Statement of Investigator

I have carefully explained to the subject the nature of the above research study. I certify that to the best of my knowledge, the subject understands clearly the nature of the study and demands, benefits, and risks involved to participants in this study.

Signature of Student Investigator

Date

Appendix C

Patient Characteristics Forms

Patient Demographics

Patient Initials:

Date of Consent:

DOB:

Gender:

Ethnicity:

Primary Admitting Diagnosis:

APACHE II score within 24 hours of admission:

Co-Morbidities listed on chart by MD:

- 1.
- 2.
- 3.
- 4.
- 5.
- 6.

LOS ICU:

At first interview:

At second interview:

Total:

LOS in Hospital prior to ICU:

Previous ICU patient:

YES: NO:

Presence of advance directives on chart:

YES:

NO:

Appendix E

Interview Guide

1. Can you describe what has happened?

Probes: admission cause, diagnosis, treatment options, illness, prognosis, expectations of recovery.

2. Can you describe what has been the most difficult/challenging for you being here?

Probes: sources of stress

(i) aspects – alarms, bells, whistles, nurses, volunteers, age of doctors

(ii) waiting room, proximity to patient

(i) uncertainty

(ii) waiting

3. What has been helpful for you?

4. Have you been asked to make any decisions?

What types of decisions have you had to make?

How did you make the decision?

(i) Do you feel you understand the decisions/options you are asked to make/consider?

Enough information? Conflicting information?

(ii) Do you feel supported?

(iii) Had you ever discussed any of these issues prior to this admission?

(iv) How do you feel about your decision?

(v) Do you think you made a good decision?

(vi) Has anyone questioned your decision? (family, friends)

4. How about other people? How do you deal with the numerous people you need to deal with regarding patient x's illness?

(i) Attending, residents, RN's, SW, Pastoral care, housekeeping

(ii) other family members (influence, presence, disagreements)

(iii) phone calls, inquiries

(iv) Do you discuss decisions with anyone else?

5. What do you do and what have you done to manage being a surrogate decision maker for patient X?

(i) asked for help? Clarification?

(ii) pray, seek counsel?

6. How well are you coping? Have any of these ways to manage your role been helpful?

(i) what helps you cope with this? What actions have you taken? (information seeking, good cry etc.)

8. What factors weighed in the decision you are considering? (have made?)

9. Who initiated the discussion?

10. At what point did you begin to consider the possibility of making this decision?

11. Does your family member have an advance directive?

12. Have religious or spiritual beliefs influenced your family's experience?

13. Have you had any experiences in the past that may have influenced this experience?

14. How do you think you will feel after this experience? (ie. 6 months)

15. Is there anything else you would like to tell me about this experience?

Appendix F

Meeting Summary Log

Source: Researcher

Meeting Date:

Location of Meeting:

People Present & Title:

Start Time:

Finish Time:

Description of Environment:

Purpose of the meeting (information update, decision making, suggested or requested by family or health care team?)

Key content covered (ie. key words, topics, areas of focus, themes)

Observed non-verbal behaviors and cues:

Researcher Impressions (discomfort of participants regarding certain topics, emotional responses)

Researchers' Self Reflections (regarding interactions observed)

Interruptions during interview/or technological problems