

Whose Life is it Anyhow?

An Exploration of End of Life Decision Making in the ICU

by

Dawn Pethybridge

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Abstract

This thesis examines how end of life decisions to withhold and withdraw treatment are made in the intensive care of a regional hospital in the interior of British Columbia. The study asked, “How are end of life decisions made in the ICU? How are they shaped? How is it that nurses’ involvement is less than satisfying to them?” The study uses data gathered in the research ICU as staff were involved in several patient cases in which the decision to withhold or withdraw treatment occurred. The experiences of the physicians and nurses of RICU have been examined using the qualitative methodology, institutional ethnography. Using this analytic method, the daily, lived experience of those involved in patient’s end of life decision making becomes the entry point for explicating the more far reaching set of social relations that shape these experiences. The study argues that physicians’ treatment decisions are organized by absolute adherence to empirical data collection and a logical and systematic approach to documenting care. This approach is organized by medicine’s need for legal and professional accountability. Nurses, rather, are organized by the professional need to employ esthetic, ethical, empirical and personal knowledge of the patient in their practice. Nurses, the study argues, feel the knowledge they gather in caring for the patients is essential to good treatment decisions and the nurse’s role as patient advocate. The study concluded that the current institutional means of documentation and communication between and across disciplines

undermines the knowledge of nurses, thus rendering them mere supporting players in the decision making process at their patient's end of life.

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DEDICATION

To my mother, Arlene Hanna, who taught me that all things are possible if you want them enough and work to achieve them.

INTRODUCTION

The work of intensive care nurses is unique and challenging. It is a specialty that has developed in response to the need to treat critically ill patients and has opened a vast field of technology, pharmacology, and clinical interventions. While this advancement in medical and nursing practice has resulted in the prolongation of patients' lives, it has also opened the door to a myriad of ethical questions that challenge both medicine and nursing. Which patients should have access to ICU resources? How much treatment is enough? When is treatment too much? Who makes that decision? What about patient autonomy? What is the role of families and advocates? Such questions preoccupy the medical and nursing professions and strain the relationships of these same professionals within the ICU setting. The following is a story from the research ICU as it was shared by Nurse D working in the department. It identifies some of these issues as seen from a nurse's perspective.

Lilly was a patient we had in the ICU last winter. She came to us with an initial diagnosis of progressive weakness. She had been at home and had become weaker and weaker until she was having trouble breathing on her own. When her husband brought her in, we asked him why he had waited so long to seek treatment for her. He told us that Lilly was terrified of hospitals and made him promise not to bring her. Finally, guilt ridden and exhausted and no longer knowing what was right,

Lilly's husband Fred brought her to hospital. He told us he hoped we would be able to give Lilly medication and treatment that would allow her to die in a dignified way. After the initial consult by the internist, it was felt she probably had ALS, you know, Lou Gerhig's disease. The doctor explained to Fred and Lilly that it was essential that we have a diagnosis and know "what we are dealing with". So although they were scared and reluctant, they agreed to admit Lilly and wait to go for an MRI. All of us RNs felt strongly that we were heading in the wrong direction and we should be preparing a palliative plan for Lilly based on the feedback she and Fred had already given us. But no...God knows we have to have a diagnosis. After all, what if it isn't ALS and we can fix it!?! So the months and weeks pass and she gets gradually weaker and thinner. And the Docs talk them in to more and more! They talk them into all the tests and then a feeding tube and finally, yes, a ventilator. They know exactly what buttons to push. " You don't want her to starve to death do you?" that's what the doctor says to Fred when they talk about the feeding tube. Well of course what else is the man going to say? And pretty soon Lilly is agreeing to everything too because she doesn't want to upset Fred. We keep asking for a family conference but the doctor is against it because he's afraid of

the son, who asks a lot of questions. Finally, we get a conference to talk about whether or not we ventilate the patient. The doctor makes sure it's on a day the son can't come. Then he gets Fred in the conference and tells him that we "can't let Lilly die gasping for breath". So of course, Fred agrees to a breathing machine for his wife! The nursing staff was so mad! I mean like we can't make people comfortable and let them die peacefully. I've never had a patient in my career that died "gasping for breath". We take her to the OR and she gets a tracheotomy, which is very painful. By now she is very thin and her skin is starting to break down a little. She seems quite painful and she has long periods where she is confused and doesn't know Fred or the son. Fred is just exhausted and looks terrible. But we push on. We put Lilly on the machine for longer and longer periods, as she gets weaker. Again, we approach the doctor about stopping this and just providing comfort care. He says no, the family isn't ready and he doesn't want to look as if he is giving up on the patient. We disagree and tell the doctor he should talk to Fred. The doctor tells us "we had our conference, now I'm making the decisions". Finally, Lilly goes into cardiac arrest. The doctor on call is the emergency physician and he makes the decision not to intervene any further and Lilly passes away.

It was a very long ordeal and I'm not saying we shouldn't have done anything to try to prolong her life. I do think the patient was not heard by medicine. When she first came in, she was clear she did not want all this stuff and all the doctor talk just frightened Fred into thinking he was doing the wrong thing by leaving her to die. It just amazes me that the job of both nursing and medicine is to do what is best for the patients and yet in so many cases we see "best" as very different things. Since the doctors have the final say on everything, we just follow orders and that's it. Its really hard and every case like this takes something out you that you never really get back (Nurse D, interview, February 18, 2004)

In this researcher's fifteen-year practice as an intensive care nurse, scenarios such as Lilly and Fred's case are not uncommon and do indeed take an emotional toll on the nursing staff. This study was driven by the need to explore exactly the dilemma identified by Nurse D. Why is it that physicians and nurses, who both want only what is best for their patients, seem to, at the end of the patient's life, constantly disagree on what "best" is? Moreover, in that disagreement, nurses are intimately involved with patients who are dying and yet they are excluded from crucial decision-making. In previous work in my masters program, I explored nurse's knowledge of the Canadian Nurses Association Code of Ethics (CNA, 2002) and the ways in which nurses use it in their clinical

practice. The Code of Ethics was most recently revised in 2002 and upholds the professional values of safe and competent care, health and well being, choice, dignity, confidentiality, justice, accountability and quality practice environments (pg.6). What I discovered in this previous work was that while nurses could not always name these values exactly as the code does, they shared stories of their practice that clearly demonstrated the importance of those values in their everyday work. Nurses spoke passionately about their need to hear the patients and to promote the patient's right to choice in decisions related to their care. They talked at length about the great fear that they were prolonging life at the expense of an end of life experience that diminished suffering and promoted dignity.

The responses I received were no surprise to me as I had experienced the same kinds of concerns in my own practice. I often wondered, as did my peers, how cases such as Lilly's had such frustrating and unsatisfactory outcomes for nurses. I pondered how it could be that two professions, nursing and medicine, could seem to want the same things for the patient and yet approach the case so differently, leaving nurses, including myself, feeling powerless and inadequate. With these questions in mind, I began my exploration with the everyday work of the ICU in hopes of a better understanding of how such events happen as they do. I express the problematic for my study in the following way:

How is it that the RNs and doctors in ICU find end of life treatment of patients so disturbing, both for themselves, and the patients and families involved? What happens in the ways decisions are made that creates trouble for everyone?

The Setting

To help introduce readers to the study, a short description of the setting is offered here. Further details appear in Chapter Two. The research hospital (RGH) is located in the interior of British Columbia in the center of a large retirement community. The intensive care unit (RICU), the setting for the institutional ethnography I conducted, is an eleven- bed unit that accepts referrals of critically ill patients from five surrounding communities. It does not provide service for patients requiring neurological interventions but otherwise cares for a full range of patients including cardiac, shock, sepsis, renal and respiratory failure.

The normal staffing complement is five specially trained registered nurses per shift with flexibility to higher staffing levels if the acuity warrants it. It should be noted that responding to higher acuity with increased staffing levels has been a significant challenge in the last three to four years because of the nursing shortage. Nurses in this unit are often required to work “short staffed” because extra staff cannot be found. Five years ago, sedated patients on a ventilator required a one to one staffing ratio. Now, nurses are often asked to take two patients on ventilators as an assignment. Medically, the unit has a trained internist on call at all times. Unlike some peer units that have a permanent intensivist or an internist that is on duty a week at a time, RICU has a different physician covering the unit everyday for 24 hours at a time which can sometimes present a challenge to continuity of care.

One aspect of policy that makes this unit unique is the admission policy or rather the lack of one. Many peer hospitals use a set of admission criteria to screen patients for acceptance to the ICU. For example, some ICUs will not admit

patients of advanced age or with documented underlying chronic health conditions such as advanced chronic respiratory or cardiac disease. RGH does not employ any such policies and operates under an informal “open unit” policy. Minutes of several ICU Committee meetings in the study hospital document discussion suggesting change in this area of policy but show that any attempt to initiate a screening policy was defeated in committee. Since RGH admits many aging patients the practice of operating an “open unit” is one that could test the resources of the RICU.

The Study

In Chapter One of this thesis, I conceptualize the inquiry, exploring literature underlying the dilemma of end of life decisions in a critical care setting. This includes review of ethical principles recurring in the literature and inherent in ethical decision making models in healthcare. I then explore the concept of moral responsibility as it pertains to end of life and its relationship to the notion of legal and professional responsibility. I discuss the concept of locus of control and explored the literature for studies which address current attitudes and expectations of both the lay public and healthcare professionals in relation to end of life decision-making. In conceptualizing the problematic, I introduce some of the concepts that are central to institutional ethnography, including the notion of “everyday work” and make explicit what is meant by social organization and ruling relations as they pertain to treatment decisions in the ICU.

In Chapter Two, I outline the methodology I chose for this research, institutional ethnography. Developed by Dorothy Smith (1987), it is an approach

which seeks to explicate “how things work” through analysis which begins in the everyday work and then explores the social relations that shape what happens but are not readily visible. I was, as a researcher, able to examine the social relations from the standpoint of the nurses as they became involved in troublesome end of life cases in the ICU.

In Chapter Three, I begin my analysis with a discussion of the work of physicians in the research ICU. I report my observations of how patient data is collected, assessed and processed, how diagnoses are made and explore the importance to physicians of naming the patient’s disease. I then make visible how treatment decisions are made and finally how a prognosis is determined and communicated to the patient. I explore the implications of determining the reversibility or irreversibility of the patient’s illness on end of life decisions. From the data I collected on the documentation of a patient’s treatment and response to it, I show how accountability is constructed authoritatively. The documents provide both legal and professional accountability when they contain a proper expression of the course of action taken by the physician.

In Chapter Four, I draw from professionally situated accounts of nurses’ ways of knowing including esthetics, ethics and personal knowing and show how nurses unique relationships with patients in the research ICU relates to these concepts. I am then able to demonstrate how this unique knowledge disappears from all levels of written and formal oral clinical communication including the patient’s chart, shift report and the ICU rounds.

Finally, in Chapter Five, I explore the multidisciplinary conference, a routine feature of work in the RICU. I argue that the conference, which is held to

be a venue for all disciplines to contribute to treatment decisions, becomes just another place for physicians to exercise their power over end of life decision-making.

In Chapter Six, I conclude my data analysis by examining the impacts on nurses of the way end of life treatment decisions are made and consider the tensions created in the professional relationships of physicians and nurses.

CHAPTER ONE

A CONCEPTUAL FRAMEWORK

Reviewing the Literature

My inquiry into nurses' concerns about end of life decisions made in the RICU is framed by the relevant literature – both about other studies of end of life issues and about my own approach to my particular study. On review of the literature from the nursing, medical, legal ethics and administrative journals, I note that scholars and professionals have spent considerable time and resources exploring many aspects of the phenomenon of “end of life”. In my review, I begin with literature which examines frameworks for ethical decision making; exploration of morality, virtue, legalities, and economics surrounding the issue; patient rights; family rights; professional discipline issues and locus of control in decision-making. I then include a review of the work of experts in institutional ethnography in order to present for the reader a clear understanding of what is meant by experience, social organization and social and ruling relations within the context of the methodology I have chosen for this research. Finally, I present the research question, in the form of a problematic, a puzzle to be solved, as it arises from the preliminary exploration of the relevant literature.

In the Intensive Care Unit, the impact of technology has significantly changed the way work is carried out and the manner in which decisions are made. One dimension of this process is decision making as it pertains to end of life and the withdrawal or withholding of treatment. As medical treatment becomes more complex and medical technology more

advanced, patients and families are given an increasingly diverse range of treatment options when they, or a loved one, fall ill. The information is presented to them, mediated by the healthcare professional who delivers it, and in the best of all scenarios, the patient and healthcare team collaboratively decide on a course of action. Patients are admitted to the highly technical environment of the ICU, critically ill, with the hope that modern healthcare's invasive procedures, constant monitoring, one to one nursing and intensive drug therapy will cure them. When these measures fail, sometimes insidiously, decisions must be made regarding the prolongation or withdrawal of treatment.

When the topic of ethical issues arises, the literature makes repeated reference to a 'four point' framework that encompasses the principles of autonomy (freedom of self determination), beneficence (promoting good), non-maleficence (do no harm), and justice (fairness) (Slomka 1992, Storch 1994, and Lee & Swinburne 1994, Noseworthy and Jacobs 1990). Some sources suggest we can build a model from these principles, which is useful in case review, helping professionals examine how decisions were made and if they were 'correct' (Shaefer & Tittle 1992). Others (Noseworthy and Jacobs 1990) acknowledge that tension exists when the value of respecting a person's autonomy conflicts with the value of 'doing good' for the patients. Slomka (1992) argues that professionals need to develop intrinsic ways of dealing with the unease they may feel in these situations and points out that end of life issues, because of their finality, are often the most difficult decisions to deal with. Rodney and Storch (2002) agree that end of life decisions raise troubling moral issues for nurses and so they must look to improve their own knowledge of end

of life care in order to provide it with confidence and comfort. Michael Yeo (1996), in his discussions of ethics, notes that morality and moral choices are encountered in all areas of life and practice. These choices become complex for three reasons. Firstly, people often disagree about moral ideals. Secondly, even those who agree on the ideal may disagree about how that ideal should be applied in any given situation. Lastly, moral ideals will often conflict with one another. Ethics then, provides us with an analytical process for understanding moral dilemmas better, identifying existing conflicts and arriving at resolutions for challenging situations. It is interesting to note that many authors of these frameworks and guidelines attach different value to them for physicians versus nurses. Physicians are encouraged to use the ethical principles to *make* the decisions while nurses are encouraged to use them to *live with* the decisions (Phelan 1995, Cook 1997).

Another key concept, often discussed in the literature, is that of moral responsibility (Slomka 1992, Storch 1994, Schneiderman, 1996). One serious issue explored is who accepts ultimate responsibility for the outcome of the decision. Slomka (1992) illustrates the difference between withholding treatment and withdrawing treatment. She argues that one approach to handling the contentious issue of moral responsibility is for the doctor to shift the onus to the patient. Doctors who withdraw supports to the patient in the form of discontinuing drugs, tube feeding, or a ventilator must take direct responsibility for the decision. However, if the supports are merely withheld, the onus moves to the patient and their physiological capacity to heal. In fact, two of the authors refer to a new ICU catch phrase which states that the patient will 'declare

himself' when treatment is withdrawn. This refers to the patient's ability to live or die under those circumstances but clearly, by its terminology, shifts responsibility for recovery from the doctor to the patient (Slomka 1992, Noseworthy & Jacobs 1990).

The discourse around this issue changes dramatically when the phrase *moral responsibility* is altered to read *legal responsibility* or *professional responsibility*. The focus of the decision-making shifts from the rights of the patient, and their best interests, to the interests of the medical profession and the organization in which the ICU is housed. Phrases like professional judgment, legal implications, utilitarianism, quality of life and resource allocation are constantly being defined, dissected and discussed (Slomka, 1992). Noseworthy & Jacobs (1990) argue that who physicians have discussions with, and how they present end of life actions are mediated by the need to 'cover' themselves legally. Physicians are aware of the need to be united and provide congruent information when multiple doctors are involved in a case. This affects how doctors communicate with patients and families. The amount of information given must be adequate to give patients and families the impression of being informed and no more, according to Lee & Swinburne (1994). One author states that doctors often prefer to deal with families rather than the patient because 'the families outlast the patient' and the chance of litigation is diminished if the families are satisfied with the physician's performance (Slomka 1992, pg. 253). For nurses, while honest patient centered communication is encouraged, information given to the patient is mediated by the nurse's responsibility to treat physicians as the authoritative knower. Nurses must not create within patients

and their families a sense of distrust by offering different views from the physician (Cook, 1997, Viney 1996). Varcoe (2004), in her study of ethical practice in nursing, also identifies this conflict in nurse's ethical practice and describes it as "in-between ness" (pg. 319). She argues that ethical decisions are often played out in a way that positions nurses in between their own values and those of the institution or physician.

From an organizational standpoint, "ICUs function under financial constraints which ought to provide a check on the mindless subjugation of the hopelessly ill to care" (Noseworthy & Jacobs 1990, pg. 5). Many hospitals are using the APACHE SCALE (Cook, 1997) that measures a patient's chance of survival and are insisting physicians use it in determining the level of treatment a patient should receive and whether or not it should be continued. Administrators use resource allocation and the principles of utilitarianism, the greater good, to justify their insistence on this type of decision-making tool (Noseworthy & Jacobs, 1990).

The discussion of responsibility, moral, legal, and professional, moves us logically into the issues involving locus of control in the decision making process and an examination of end of life decision making. In 1994, Storch and Dossetor conducted a large-scale study in Edmonton, Alberta focusing on public attitudes toward healthcare treatment decision-making, living wills and treatment decisions, and prolongation and quality of life issues. Forty seven percent of respondents wanted to make their own treatment decisions with some variation for age, culture, educational status and socioeconomic standing. Younger, richer, more educated respondents wanted more control. Ninety percent of those studied

agreed with living wills and would want control over end of life decisions. When given the scenario of being a 75- year-old patient with a life threatening illness, seventy-five percent of respondents stated that they would not want their life prolonged regardless of its quality (Storch 1994, pg. 76 & 77). In relation to Storch's results, other studies have noted that only nineteen to twenty-one percent of patients discuss these issues with their doctors prior to an event, and only thirty percent discuss these decisions with family prior to a serious illness (Noseworthy & Jacobs 1990, Lee & Swinburne 1994). This means that while patients may have preferences, something else has to happen before those preferences will make a difference to what happens in actual settings such as ICU.

Despite evidence that patients want control over end of life decisions, the literature is clear that physicians make them (Storch 1994, Noseworthy & Jacobs 1990, Slomka 1992, Lee & Swinburne 1994, Schafer & Tittle 1992, Cook 1997, Phelan 1995). Slomka (1992) notes that physicians have difficulty observing and facilitating patient autonomy, even though they value it, because they consider themselves to be medical experts and thus, responsible. In the ICU, it is rare that the patient is well enough to contribute actively to decisions regarding end of life, so physicians are most often dealing with the family as proxy. Slomka (1992) and Cook (1997) note that doctors do include family in decision making but when there is conflict, the physicians most often have the final say. In contrast, Phelan (1995) and Viney (1996) found that some doctors feel that they are abdicating their professional responsibility by expecting loved ones to make decisions about withdrawing treatment. Doctors are at a distinct

advantage in influencing patients and families' choices because of their medical expertise and the fact that they mediate what information is given to the family and how it is delivered (Storch, 2004; Varcoe, 2002). Families feel uncomfortable with the highly technical environment of the ICU and so their confidence and assertiveness may be greatly undermined (Slomka 1992, Noseworthy & Jacobs 1990).

Storch notes that although doctors make most of the decisions regarding end of life, it is the nurses who have the most interaction with the patient and families. Research indicates that nurses feel a great need to be part of these decisions and to facilitate a process which allows them to be advocates for their patients (Erlen and Frost 1991; Storch 1994; Shannon 1997; Rodney 1997). Shannon (1997) tells us that nurses see their participation as imperative because of the quantity of time they spend at the bedside with the patient and the family. Erlen and Frost (1991) identified that while many saw their role as important in ethical decisions, they complained of a lack of knowledge of alternatives to dilemmas they encountered in practice, a lack of respect for their role as experts and a perceived lack of power to influence the decision making process. Notably absent from the literature on end of life decisions is a mention of nursing, or other healthcare team members, in the decision making process. In the previously mentioned study by Storch, the recommendations noted that the responsibility of the nurse continues to be gathering information about the dynamics of family interaction, cultural issues, and patient wishes and passing that information to the physician for use in his decision- making. Almost ten years later, Storch and Rodney (2002) in their study of the meaning of ethics for

nurses in direct patient care, still found nurses' contributions to ethical decision-making constrained by hierarchical organizational and physician driven practices (pg.10). Viney noted, in her 1996 study of senior ICU doctors and nurses, that even though multidisciplinary collaboration has been shown to improve decision making in ethical dilemmas (Bragg 1993 in Cook 1997), nurses are seen primarily as 'information brokers' (Viney 1996, pg.185). There is little in the literature to suggest that nurses bring another dimension or viewpoint to the process or that they should be allowed to. Varcoe (2004) demonstrated not only that nurses were not invited to participate in decisions, but that they were often ridiculed, or they feared professional repercussions for doing so.

While there have been significant research and soul searching done surrounding the issues which influence end of life decisions in the ICU setting, none of the work reviewed seems to address the tension and discomfort I have experienced in my nursing work when a patient's treatment seems futile and recovery unlikely and decisions must be made about withdrawing treatment. Storch (1994) recognizes there is more to nurses' involvement than the research shows. She argues that research must be done in a practical setting at the bedside because often what professionals say they will do in a research scenario is not what they actually do in a clinical setting (pg. 86). Deborah Cook (1997), in her review of current decision making processes in the ICU setting, notes the absence of qualitative research in this area of study and calls for qualitative investigations that will help us understand "determinants of the human experience" (pg.18).

Identifying and Conceptualizing the Problematic for Inquiry

Heeding the conclusions of Storch and Cook, I started at the bedside with the lived experiences of patients, families, nurses and doctors in order to understand how end of life decision making really works. Campbell and Manicom (1995) in their book *Knowledge, Experience and Ruling Relations*, discusses institutional ethnography which “beginning in experience helps the researcher identify ‘whose side she is on’ while constructing an account that can be trusted” (pg. 7). They note that the conceptual importance of experience lies in providing a real-life context against which to reflect on everyday organizational and professional practices and their powerful effects on people’s lives. Phelan (1995), in his discussions of withdrawal of treatment in the ICU, argues that concepts such as autonomy, justice and futility look very different for professionals when they are attached to real people under their care, rather than the abstract scenarios presented for research. Cook (1997) states that we can only understand decision making in the ICU when we “shift from the explicatory, mechanistic orientation of critical care medicine to a paradigm in which we observe behavior. Then, we can expect to generate a insightful understanding” (pg. 18).

Cook (1997) argues that previous studies of end of life decision making in the ICU have been focused on content and that true understanding of this phenomena will only come with attention to the context of the process. Dorothy Smith (1997), in her work in feminist sociology, conceptualizes “context” as social organization defined, and she discusses it in terms of social relations, social organization and ruling relations. Smith (1987) defines social relations as

“concerted sequences or courses of social action implicating more than one individual whose participants are sometimes, but not always, present or known to one another” (pg.155). Jackson (1984) shows how events within organizations are almost always determined by circumstances outside the immediate experience of the individual or groups of individuals. Social relations refers to those translocal coordinating processes. In this view, the interactions within an organization cannot be understood without reference to the social context (political, administrative, economic, historical), within which they are situated (Campbell 1988, 1992). In the ICU, some of these contextualizing and coordinating elements included such things as the historical development of nurse-doctor relationships, the educational and professional socialization of nursing and medicine, the role of the institutional ethics committee, and the culture of multidisciplinary in the healthcare institution. Jackson (1995) illustrates how social relations “appear” in local settings in people’s talk, but implicitly. It is my intention to explicate these relations identified in the talk and activities of the RICU staff and to examine their role in end of life decision-making.

Smith (1987) draws attention to another facet of social organization. She insists that people’s experience in organizations derives in no small part from the “artful construction of text-based methodologies and the practices of formal organizations” (1987, pg. 153). Smith postulates that local practices experienced everyday are organized translocally by such organizational processes as its routine recording and reporting forms, policies, assessment tools and other documentation. While this seems unremarkably true, Smith proposes an approach

to studying everyday life that draws on its, often invisible, textual organization. Exploration of this organizational apparatus can provide a greater understanding of 'how things work'. In the RICU, practitioners use nurses' notes, doctors' progress notes, and Level of Intervention forms, among others, to write up accounts of their work. All these are elements of how the organization "works".

Smith (1987) notes that organizational relations owing their existence to international, national, social, economic and political processes can be understood as ruling relations. Ruling relations connect powerful interests to local settings in ways that are often not easily recognized and therefore not well understood. Regarding end of life decisions, I am interested in knowing more about how power is exercised in the RICU, in routine and taken for granted ways. Smith (1990) states that power, when seen as a concept, is mystifying, capturing a sense of 'something', yet incapable of explicating this 'something'. She challenges the notion that power somehow 'happens' in the absence of human endeavors. Rather, Smith argues that power arises in, and through peoples' activities and the way those activities are "coordinated to give the multiplied effects of cooperation" (1990 pg. 70). The literature, previously reviewed, made frequent references to the power of physicians. This was attributed to their ability to mediate information and direct treatment. Other sources (Viney 1996, Cook 1997, Slomka 1992) discuss the historical development of doctors' ruling relationship with patients and nurses. In contrast, Noseworthy and Jacobs (1990) and Lee and Swinburne (1994) argue that physicians are organized by the ruling practices of law, hospital administration, and an obligation to show responsibility for resource allocation to promote the

greater good. It may be that doctors are part of the ruling apparatus or are themselves ruled, or perhaps both. My study of one ICU, attempts to discover the existence and scope of the ruling relations that are operative there and I explore to what degree they affect end of life decisions. Following Smith's views on how power works, I address my analytic attention to who does what in the setting, to begin to explore how it is ruled.

THE RESEARCH QUESTIONS

How are end of life decisions made in the ICU? How are they shaped? How is it that nurse' involvement is less than satisfying to them?

CHAPTER TWO

RESEARCH METHODOLOGY

Inquiry of this kind builds in an open-ended character. It is like the making of the piece of a quilt that remains to be attached to other pieces in the creation of a whole pattern. We begin from where we are. The ethnographic process of inquiry is one of exploring further into those social, political, and economic processes that organize and determine the actual bases of experience of those whose side we have taken (Smith 1987, pg. 177).

Institutional ethnography is a post-positivist methodology based within the constructivist paradigm, and relying on the social organization of knowledge (Smith 1987, 1990). Analyses within this analytic framework goes beyond assertions that everything is socially constructed to a research interest in how experienced realities are put together by people. Institutional ethnography seeks to explicate 'how things work' and explore "those social, political, and economic processes that organize and determine the actual bases of experience of those whose side we have taken" (Smith 1987, pg. 177). This research approach begins in everyday experience, gathering, through participant observation and interview, data that originate in the 'talk' and activities surrounding and constituting the phenomena being investigated. From such data Smith (1987) explains, it is possible to explicate the social relations of a setting. Jackson (1984) explains that in the social organization of knowledge social relations consist of not only the ongoing activities of individuals but also the circumstances in which these acting individuals find themselves. People enact social relations, and when they speak, their talk contains and expresses them. Social relations are not necessarily bounded by the setting in which people's everyday lives are lived, but are

translocal, carrying power and authority across diverse settings. As previously noted in this paper, Smith describes those complex social relations that are part of social, economic, and political processes of government, the professions, and management as *ruling relations*. Smith (1987) tells us that local experiences of the research subjects are often influenced by extra local organizing processes of an institution or social/political structure. Institutional ethnographers look for evidence of that sort of social organization in institutional texts because an organization's ruling relations are frequently text mediated (Smith 1990). This is true in hospitals where the work is coordinated through people's use of texts. Thus, when institutional ethnographers do participant observation or interviews, they collect evidence of how the work is textually mediated and coordinated. Practitioners are understood to be experts in working with texts and it is their everyday knowledge that institutional ethnographers rely upon.

In institutional ethnography, analysis begins in everyday experience to explicate 'how things work.' Campbell (1998) tell us that this approach is grounded in the assumption that there are multiple perspectives and versions of reality produced by people who are located differently from each other. Institutional ethnographers claim that everyday life as certain people, specified in the research, experience it, can be understood truthfully (Smith, 1999). In contrast to many postmodernist claims that there is no reality beyond the discursive, institutional ethnography explores and explicates what actually happens in people's everyday lives. In other words, knowledge about social life can be generated in a trustworthy manner.

Smith (1987) explains that researcher objectivity, in the positivist paradigm, is built upon the idea that it is not only possible but also preferable to stand outside the phenomena being studied in order to gain neutrality. A social constructivist begins with the view that reality is co-created in the activities of people, including researchers, and that it is impossible for the researcher to stand outside of the reality she is studying and ongoingly creating (Smith 1987). So the goal for the research must be different than producing an objective and neutral account. In institutional ethnography, the researcher's interest is in exploring how the identified subject participates in constituting life as she lives it. The inquiry "begins in experience and returns to it, having explicated how it happened the way it did" (Campbell 1998, pg. 55).

Researchers in a positivist mode use a representative sample in order to generalize their findings to the general population. Methodological conventions are rigidly adhered to by positivist researchers to overcome potential problems of moving between the observed world, data and valid scientific conclusions drawn from them. Instead of validity, Smith (1987) speaks of 'faithfulness' to the presence of subjects and to the explication of actual everyday practices both local and extra local. In institutional ethnography, the researcher must explicate the 'generalizing' social relations. The researcher's task is to identify the otherwise 'invisible' social relations, that within any setting are general and that generalize what happens across people, time and geographic space (Smith 1987).

My research explored work in the RICU to attempt to find out how staff acted as they did with regard to end of life decisions. I will be using the

notion of 'social relations' to understand what they did and their talk about it, including their explanations that I captured during participant observations. My research did not stop at participant observations but traced its translocal organization back to the professional rules, ethical guidelines, or organizational procedures to which RICU staff attended, as they took the actions I was interested in. In doing so, my inquiry relies on Smith's theoretical writings (1987,1990) that make the argument that social action is coordinated purposefully and in big organizations, through text mediated processes. To the extent that I can show that the coordinative and ruling practices are general and apply across actors and sites, my findings will also be generalizable beyond the setting I studied.

Ethical Reviews

I applied for ethical approval from both the research site and the University of Victoria. At the research site, the ethics committee reviewed my proposal and then brought it to a full committee meeting. Several questions were asked regarding confidentiality and what would be done with the results of the research. The committee showed considerable interest in the study as a recent accreditation of the research site had identified end of life decision making as an area in need of review. The discussion was pushed forward to the next meeting. At the second meeting, I answered all of the committee's outstanding concerns and the study was passed. I then presented the study to staff members in the RICU who responded with great enthusiasm as they identified the area of my study. I also presented to the internist group who work in RICU and answered their questions related to the study. Finally, I submitted the research proposal to

University of Victoria Ethics committee who were very rigorous. In my submission, I identified potential problems with the anonymity of physicians due to the small group (only 8) of internists working in RICU and potential problems with confidentiality due to the size of the community in which RGH is situated. As a result, I am identifying physicians only by coded initials and the actual clinical details of the cases used in this research have been modified to provide anonymity for the patients in RICU. As well, my dual role as researcher and clinician in the ICU was identified as a potential conflict of interest. I therefore conducted my observations only while working as an auxiliary staff member during my off hours and clearly defined my role of researcher during these times. After several modifications of procedure, the research was approved and proceeded. (Appendix A)

Data collection

My data collection took place over a two-month period in the winter of 2003/2004 after receiving approval for my work from the university and facility ethics committees. Although I have worked in the research setting for many years, I negotiated a manner of being in the setting during this period of time as an “extra pair of hands”. For the first month, I worked full time hours split between days, evenings and night shift and in the second month, I worked two day shifts and two to three evenings a week. I helped out with daily care in an extranumerary capacity while collecting data for this work. The staff and families were aware I was present as a researcher. I began by focusing on the every day work of nurses and physicians as they provided care for critically ill patients in

the RICU and observed the routine interaction of physicians and nurses in relation to decision-making. During my observation of everyday work in the RICU, I focused my analytic attention on cases in which specific instances of decision-making were beginning to evolve. Referring back to my problematic of the trouble over decision making, I looked for cases in which I saw issues occurring I refer to treatment decisions that were beginning to include discussions regarding withholding and withdrawing treatment. In the end, I chose two cases for which end of life treatment decisions had to be made. Further data was collected from the following sources:

1. Attendance at multidisciplinary family conferences organized for the purpose of making end of life decisions
2. Interviews with nurses and physicians involved in end of life decision-making events as identified in my observations.
3. Examination of texts including chart sources such as physicians' progress notes and nurses' notes; mission statements of the institution; institutional policies and procedures including those specific to the ICU; Codes of Ethics of the Canadian Medical Association (1996) and the Canadian Nurses Association (CAN,2002); policy statements and joint decision making policies of the Canadian Medical Association and CNA (1998).

Data Analysis

I began with identifying “talk” or interactions in which physicians and nurses make interpretations about how to practice. From these, I attempted to discover the social relations of which they are a part. The social relations I was

interested in are those in which professional practice is embedded and that guide a practitioner's beliefs and actions. In relation to my data, I wanted to discover how a physician or a nurse actually enact their practice in the manner they did, producing individual professional acts as legitimate, authorized, appropriate or in other words, competent. Using institutional ethnography as an approach, I treated what I saw, heard and read in the everyday work and communication in the ICU as potentially offering traces of socially organized relations. Participant observation, then, is the entry point for my analysis. Once I saw traces of the social relations I was interested in, I began to make a study of the way in which the ICU nurses' and physicians' individual actions were organized textually or professionally and institutionally conditioned. This required that I study hospital policies and procedures, professional codes of ethics, professional codes of conduct and standards, patient charts and professional educational curriculum. It also required interviews with doctors and nurses to discover how professionals account for their own practice. But regardless of how people theorize or explain their behavior, institutional ethnographers look for evidence of how participants in research setting make the settings work as they do. I brought together "decisions" as talked about, enacted and recorded with my observations of what actually happened to draw some conclusions about the tensions around end of life decisions I was interested in understanding from the standpoint of nurses.

That is, having established as problematic the troubles of nurses, I focused on how everybody's work contributed to these particular tensions.

CHAPTER THREE

The Social Organization of Physicians Decisions to Withhold or Withdraw care in the ICU

“ I will prescribe regimen for the good of my patients according to my ability and my judgment and never do harm to anyone. To please no one will I prescribe a deadly drug or give advise or care which may cause his death”
From the Hippocratic oath, AD

I begin my inquiry into the troubles that nurses experience around end of life decisions in the RICU by discussing how RICU physicians think about it, largely because they carry the ultimate responsibility for these decisions. Drawing on my interviews and observations, I argue that physicians' professionalism and legal and moral accountability constrain both the process they use for making decisions and the knowledge they may legitimately draw on to make them.

In this chapter I describe and analyze how physicians' treatment decisions are organized by their adherence to a logical, step by step, decision-making process that is initially aimed at curing the patient. It begins with collection of assessment data, progresses to a definition of a differential diagnosis and determination of prognosis, prescription of treatment for the disease diagnosed, and ends with an evaluation of that treatment. It appears that assessment data used to make treatment decisions are entirely empirical data and that ICU physicians make deliberate decisions to try to exclude other types of data even when they are aware they exist. My analysis suggests that this logical progression of care and exclusive use of empirical data leads, in end of life cases, to the physician's ability to identify the prognosis for the patient's illness as

reversible or irreversible. It is the identification of irreversibility that opens the door to the possibility that the patient's disease is not ultimately curable and that further treatment is futile and should be withheld or withdrawn. It is my contention that the textual accounts of patients' progress in the RICU are created to reflect the use of logic and empirics in decision making. This form of accountability satisfies institutional and professional expectations of moral, legal and diligent behavior by the physician however, it is my contention that this textual process misses important elements of what actually guides physicians in making end of life decisions.

The logical progression of care in ICU physicians practice: the process as a whole

In this section, I examine the four-step process physicians use to facilitate clinical decision-making. Later sections in this chapter will deal in more depth with the data collected in assessment and the implications of determining a prognosis.

Much has been written about the physician's ethic to cure. Professional bodies such as the Canadian Medical Association (1999) designate the practice of curing to be a three- step process: that of diagnosis, treatment and determination of prognosis. Shannon (1997) tells us that doctors are drilled on case presentation constantly in their medical training. They learn to present the critical features of a patient's case in an organized and concise manner, beginning with the patient's presenting symptoms, significant history, findings from the physical examination, results of various tests and concluding with a diagnosis (and competing

explanations), reasonable prognosis or prediction of outcome, and a treatment plan. High value is placed on a succinct, thorough, process grounded in a solid understanding of pathophysiology, presentation and treatment of disease (pg.17). The preferred outcome of the process is resolution of the illness because, as Marshall (1995) notes..."the biomedical tradition is fundamentally orientated to the preservation of life and driven by the overwhelming desire to take action, to cure the problem and do something to overcome the debilitating force of disease and the sense of helplessness it can evoke" (pg. S10). This becomes particularly true in the ICU where, Cook (1997) states,"our purpose is to improve the survival of patients with life threatening illness" (pg.15).

In the research hospital, interviews with and observation of RICU physicians demonstrated a high value for this logical, decision-making process. During my observations in the RICU, I saw physicians follow this process everyday as they made rounds on their patients. Each day the pattern of this process was unaltered. They would ask nurses for information from the nursing flow sheets, examine the patient, review diagnostic information, document changes in the diagnosis and then direct a treatment plan by ordering more tests, adding or discontinuing medication and treatment and directing the scope and frequency of observations to be completed by the nursing staff. One RICU physician, Dr A, very succinctly described the process that he describes as his job in the RICU:

Our job is to be able to analyze, break down and use our logical progression, analytical skills to identify all the pathological processes in that patient and to anticipate

what the complications might be or where we could be; to have markers so that we can readily identify and can intervene early before we find ourselves going to another pathological process we can't reverse (Dr A, interview, January 12, 2004)

Step One: Data collection and assessment

Within the practice of medicine, the process of clinical decision-making and indeed the development of clinical judgment is governed by what the profession calls rules of clinical prudence (Shannon, 1997; Cook 1995). One critical rule is that the focus of data collection for the purposes of diagnosis is physical signs and symptoms, results of diagnostic tests and knowledge of disease patterns. "This data collection must absolutely focus on objective information or facts, not on hunches or intuition. The evidence of the effectiveness of this strategy is the unprecedented success of modern medicine in success fully diagnosing pathophysiologic problems" (Shannon 1997, pg.17). Two physicians I interviewed in RICU were also clear that emotion and intuition has no place in their decision making process as these two excerpts from interviews demonstrate. Asked about family's feelings about an impending death, they replied as follows:

Dr A: that's emotional, I need logic. If we get caught up in the emotion, if you let it influence you, you will make poor decisions. (Dr A, interview, January 12, 2004)

Dr L: I can't think about that. If I let myself get close to all those feelings (of the family), it will influence how I do things. I need to focus on the chart and what it tells me...what the tests tell me...what the patient's clinical presentation tells me. (Dr. L, interview, February 18, 2004).

These two interviews show not just the fact that the doctors intentionally discount non empiric data but that they fear that inclusion of emotional intuitive data will cloud logical decision making and result in poorer outcomes for the patient. The following is an observation of interaction between the RICU nurse caring for Sam, one of the patients whose case I followed in my research, and Dr A, who was the RICU physician in charge of his care. It clearly demonstrates the method of scientific data collection used by physicians on a day-to-day basis and how it requires nurses' work and the data they gather to support it:

Dr A: is he awake?

Nurse: He rouses at times when we turn him.

Dr A: to voice?

Nurse: Sometimes, not consistently

Dr A: How much sedation is he getting?

Nurse: Three doses of ativan and morphine since
midnight

Dr A: No more, I want him lightened up so I can see where we are at.

Nurse: what if he gets agitated?

Dr A: No sedation, I need to be able to assess him and I can't if the nurses keep snowing him. There is no reason for him to need sedation, he should be used to the ventilator now and he isn't in pain. Any grimacing you see is just reflex. The literature tells us that's the case. What are his O2 Sats (oxygen levels)?

Nurse: 90-94%

Dr A: Volumes?

Nurse: About 400-500 cc

Dr A: OK, leave the ventilator settings alone

Nurse: Do you want a chest x-ray today?

Dr A: Nothing here to indicate we need one.

How's his heart rate been?

Nurse: 70-90 most of the time, goes up when we move him. We might run into problems if we discontinue all the sedation.

Dr A: No sedation. What about his gut? How much are we feeding him?

Nurse: 50 cc an hour, he has good bowel sounds but he gets all diaphoretic and restless when we try to put the amount of feed up.

Dr A: I want the feed at 80cc. If he has bowel sounds you can put it up.

Nurse: OK

Dr A: what about urine output?

Nurse: dropping even though you are giving him more fluid. About 20cc per hour now.

Dr A: has the ultrasound of his kidneys been done? If not, tell them I need it done today. I can't make any decisions without it. Is his lab work here?

Nurse: Not up yet.

Dr A: great...phone them and get it up here. I need to make a decision about dialysis and I can't do it without the ultrasound and the lab work.

Nurse: have you discussed dialysis with the family?

Dr A: No point. I don't have enough for me to decide what to do and then I need to talk to nephrology. Once I know what I'm doing, we'll tell them what the plan is. OK, that's it...get the blood work up, get on x-ray for that ultrasound, leave the ventilator alone, no x-ray of the chest and NO SEDATION. (Dr A and Nurse L, observational data, January 26, 2004)

This observational data is one example of how physicians collect data exactly according to the previously identified parameters of physical exam, significant history, symptom presentation and results of diagnostic tests. At no time in the conversation was there an opportunity for the nurses to expand or be descriptive about the patient's condition. It leaves no room for nurse's own ideas about the patient that might "cloud" the scientific process. The physicians would never say, "describe his neurological status" or "how is he doing?" When Dr A was asked why he didn't allow nurses to give a free narrative report, he responded:

When I come in the room, I am working with my differential (diagnosis) in my head from the last time I saw the patient. I have specific things I'm looking for. I don't want to deal with a lot of information I don't need. Its nothing against the nurses, it's just I need to work through a logical process in my head. I know what (information) I need...I just need to get to there (Dr A, interview, January 26, 2004).

This data once again shows that this physician is focused on scientific or empirical data and that for them the presentation of other data introduces the possibility that the process of decision-making can be thrown off track.

Step Two: Diagnosis

The second step in the physician's process of clinical decision-making is the formulation of the diagnosis for the very ill patient. It is a critical step in defining why the patient is ill and what treatments can be offer or expected. This is the process of studying the accumulated data and, using knowledge of pathophysiology, to name the illness and differentiate it for other illnesses. Taber (1988) defines a differential diagnosis as "a scientific comparison of the symptoms of two or more similar diseases to determine what the patient is suffering from" (pg. 8).

Nurses may not always understand or approve of the physician's singular focus on defining a diagnosis. Several nurses told me that the decision to admit the patients to the RICU at all was a major source of tension between doctors and nurses. In the case of two of the patients I followed in my research, Sam and Jewel, both had significant underlying chronic disease before becoming acutely ill which is what brought them to the RICU. In light of that, nurses in the RICU told me that they felt the patients should have been treated on the regular units when they became acutely ill, to allow "nature to take its course". Nurses claimed that physicians were not considering the patients' overall condition or quality of life issues before making the decision to admit to the ICU. My interview data appears to support the nurse' view. Physicians, in their decision making process, need to identify and attempt to treat the disease process that has advanced a chronic illness to an acute one. Often, as in both Sam's and Jewel's cases, the cause cannot immediately be diagnosed. That becomes the occasion for greater diagnostic activity.

One of the physicians I interviewed spoke of the need to admit to ICU “until they could clearly define what the problem was”. Physicians told me that the decision to admit into the RICU was most often made because they felt they had insufficient information to make an accurate diagnosis and then the decision whether to withhold treatment or push forward. Dr A explains the focus on diagnosis in the following interview data.

I need time, and part of admitting the patient to ICU is buying yourself time to assess them. You have to stabilize them because they are dying, you put them on the ventilator ... giving yourself some time to ask- what have we got here? (Dr A, interview, January 26, 2004).

When Jewel was readmitted to the emergency department for the third time in a year and after a lengthy stay in the ICU on her last admission, nurses questioned the decision to treat her aggressively. Dr L told the nurses:

No consideration for withholding of treatment could be considered because we cannot let the patient die without a diagnosis. I have to know why she is sick this time. What has tipped her over the edge? (Dr L, interview, February 18, 2004).

Dr A went even further to explain the onus on the physicians to provide a diagnosis by suggesting that without doing all the appropriate tests and information gathering, we were, in fact, lying to the patient and family. In my interview with him, he stated:

We may not be purposely lying, but by remaining ignorant of the actual disease process, we are acting without information and if you don't have it, you can't give it, and you cannot make appropriate decisions (Dr A, interview, January 26, 2004).

Step Three: Treatment

Once a diagnosis has been established, the physician prescribes treatment. In other clinical areas this may be a relatively simple procedure. For example, on a general medical unit, if a patient is admitted and diagnosed with pneumonia he/she would be treated with an antibiotic and the disease would resolve. My observations in RICU demonstrate a much more complex process. As the cases I researched progressed, the physician's clinical decision-making process is replayed daily. Each day new data is collected, a new diagnosis identified, others considered resolved. Treatment was initiated each day as new systems failed. Sam was initially admitted with acute infection in the abdomen and associated low blood pressure that was treated with antibiotics and drugs to elevate his blood pressure. Eventually, the infection became overwhelming affecting his lungs and kidneys. After several weeks in the ICU, Sam was on a

ventilator, receiving three different drugs to maintain his blood pressure and heart rate and had begun to lose his ability to produce urine. Dialysis was being considered.

In Jewel's case, she presented initially with shortness of breath and a lung infection, and she was put on the ventilator. Eventually her heart began to fail and as a result of the fluid building up in her lungs, any attempt to let her breath on her own failed. Each day the physicians would review the cases, re-diagnose the patient and treat whatever system was failing. This is the nature of the physician's work of curing. As with data collection and diagnosis, medical treatment is a process that physicians regard as parallel to rather than integrated with nursing treatment. Consider for a moment the previously documented interaction between Dr A and Sam's nurse that took place during daily morning rounds. Dr A made the assessment that Sam was not as awake as he would like in order to assess Sam's true level of consciousness. Based on that assessment and the diagnosis that Sam's neurological status may be deteriorating, Dr A. orders sedation of the patient discontinued. This change in treatment greatly affects the nurse's ability to do her work. The work of nursing, turning, bathing, positioning, maintaining the artificial airway and providing comfort and safety would be hugely impacted if Sam becomes agitated or combative as a result of the lack of sedation. Nursing care also becomes difficult to administer if the patient is in pain. This physician does not acknowledge the interdependency of nursing treatment and medical treatment but is concerned only that the medical mandate is met.

Step Four: Prognosis: Reversibility and Irreversibility

Assessments were carried out as previously described, and, as the clinical course of the patient progresses, physicians eventually use this information to make a prediction as to the likelihood of survival for the patient. “The ability to forecast is an important part of clinical medicine. Whether physicians are communicating a prognosis to a patient or implicitly considering a patient’s prognosis in order to construct a treatment or management plan, forecasts should be specific and accurate. Prognostic accuracy is particularly important in the realm of critical care” (Christensen, et al. 1993, pg 302). Prognostic accuracy allows physicians the ability to determine the likelihood that the treatments they are directing will result in recovery or whether the treatment cannot in fact reverse the progression of the disease and is then deemed futile (Shannon, 1997). The daily care in the research ICU reflects this cognitive process by the physician. Based on their scientific knowledge and past clinical experience, individual physicians build parameters for predicting survival of the patient and the chances that the disease process will reverse itself. In all my interviews, ICU physicians cite reversibility or irreversibility of the patient’s condition to be the single greatest factor that influences the decision to withdraw treatment or to carry on. Even if the patient presented with an underlying chronic condition, even if the admitting diagnosis did not seem to be resolving or if new disease processes were developing, the physician made the decision to continue treatment as long as they can identify something ‘curable’ or ‘reversible’. The following passages from my interviews demonstrate this:

Is it reversible? Can we fix it? Sure we know he has other problems but what brought him here today, right now, might be fixable, reversible (Dr A, interview, January 26, 2004).

The biggest factor here is: is there something reversible here? For the physician and the staff looking after the patient, is there a reversible component to this disease or not? (Dr L, interview, February 18, 2004).

Finally, when this cycle of logical process of clinical decision making has run its course and all that is reversible has been reversed the physician must come to terms with the difficult concept of futility.

Futility: the end of life in the ICU

This section deals with the difficult concept of futility and its relationship to both physicians' clinical decision-making process and the decision to withhold or withdraw treatment at end of life. The literature offers dozens of definitions of futility. The Canadian Medical Association defines treatment as medically futile or non-beneficial if it offers no reasonable hope of recovery or improvement or because the person is permanently unable to experience any benefit (CNA/CMA/CHA 1996, pg.3). Both medicine and nursing literature have started to make a distinction between quantitative or objective futility as determined by a

physician and subjective or qualitative futility as determined by the family or the patient (Bowman 2000; CNA, 2002)

During my observations in the research ICU, both of the patient cases my research explored reached a point in their treatment where doctors felt that further treatment would not change the outcome. In Sam's case, Dr A told the nurses that as a result of his kidneys now ceasing to function, the patient had "three body systems down" and there was little hope for recovery. In Jewel's case, Dr L told staff that because Jewel could not be weaned off the ventilator and allowed to breath on her own, and was requiring higher and higher levels of oxygen, that it was time to "call in the family and talk about how this will end". As well as their own objective clinical judgment, ICU physicians can rely on a special set of clinical scenarios found in the critical care literature referred to as "critical indicators" which suggest that the patient has irreversible disease. For example, if the patient's blood becomes very acidic with a PH falling below 7.0, or if the patient requires oxygen levels of 100% for a period exceeding twenty-four hours or if the patient has acute kidney failure requiring dialysis with a very high blood creatinine, the patient's condition is deemed irreversible and further treatment futile (CCM, 2000). According to several authors within the critical care literature, futility is the cleanest, most clearly defined and legally supported reason to withhold or withdraw care (Cook, 1997; Cook et al, 1995; Daly et al 1994; Christensen et al 1993; CHA/CMA/CNA, 2000). The daily "talk" in the RICU, especially physician to physician, demonstrated not only the use of these critical indicators in the decision making process, but conviction that they were accurate. As a result, it was the occurrence of these "critical indicators"

indicating “futility” in both cases I studied that initiated a family conference or multidisciplinary meeting to discuss whether further treatment should be withheld or withdrawn.

The Text: Documentation of the Case

In this section I will demonstrate how physicians use routine recording in the RICU in order to create a document that shows their provision of care to the patient in RICU to have been logical in its approach and scientific or empiric in its consideration of diagnosis and treatment. In doing so, physicians who face end of life dilemmas and the task of deciding to withhold or withdraw treatment do so having created a record which clearly shows evidence of progression toward futility. Documentation of process, scientific data and rigorous treatment decisions protects the physicians and the institution legally, professionally and morally.

The patient’s chart is both the main communication tool between healthcare providers and a legal representation of the care the patient received while in hospital. There exist many legal and institutional rules concerning how the patient’s case is to be documented. These rules protect the physician, other healthcare providers, and the healthcare institution from legal action. It satisfies processes of review by professional regulatory bodies such as the Canadian Medical Association, BC College of Physicians and Surgeons¹ and the RNABC. CMA policy states, “ The medical record must contain information on past and present conditions and treatment, family history, diagnosis, progress notes,

¹ In instance of practice complaints against B.C. physicians, the College adjudicates through the College Committee process, for instance, the Ethics and Conduct Committee.

consultation reports, and laboratory tests. The record is to provide continuity of care and maintenance of an optimal standard of care” (CMA policy, May 2000, pg.1). The CMA, and the RNABC caution that the chart should record care decisions that reflect accuracy and timeliness and demonstrate what a “reasonable and prudent physician/ nurse would do in a similar situation” (RNABC 2000, pg. 2). As well, physicians recognize that the chart is the main means of communication between themselves and other members of the medical team caring for the patient, be that the RICU specialist on call or another physician specialist being consulted to the case. Dr A, in my interview with him, confirms that the chart is not just a tool of communication but also a means of demonstrating a rigorous process to colleagues.

It is important to me that my colleagues can follow the logic of my care through the notes...that he can see I followed a process and didn't fail to cover the bases (Dr A, interview, January 26, 2004).

For physicians, making the logic of care visible means recording daily care that reflects a basis in science and a rational, structured decision-making process. The physician's charting consists of two parts: a consultation page in which the first examination and history is dictated and the progress notes in which the daily progress of the patient is recorded. Both of these records consist of only a blank piece of paper with hospital letterhead. Although there is no textual structure to the document, all the physicians in the ICU use exactly the same

format to chart the daily changes in the patient and it closely reflects the scientific process identified by the CMA. Physicians record the results of the daily physical exam, any diagnostic results, an ongoing differential diagnosis and, under the heading “plan”, how they intend to manage daily care. The management decisions are written as doctor’s orders, which the nurses then implement. This method of recording the patient’s progress in the RICU produces a document that reflects accountability and the legal expectations of the professional bodies and the institution. All treatment decisions can be traced back to hard data found in the diagnostic results and the nurses’ flow record. The nurses’ flow sheets are, in fact, formatted for the use of the physicians as I discuss in Chapter Four.

Of the cases I retrieved, without exception, the decision to withhold further care or to withdraw care is never mentioned in the physician’s notes until the patient was in the end stages of disease and treatment has failed. When, according to clinical data, the patient is approaching death, the first notes are written that indicate the physician is considering withholding or withdrawing care. The documentation of this decision is unaltered from all other daily documentation. The physical exam is charted and the diagnostic reports evaluated and then under the heading of “plan”, the physician writes, “ condition futile” or “discontinue treatment”. The decision to cease treatment is thus rendered textually as an outcome of entirely scientific data.

So, is the chart then an adequate representation of all the knowledge that is attended to in making end of life decisions? Is it just science that a physician uses with no attention to the subjective data surrounding the patient’s case as the record in the chart suggests? I argue that the answer to those questions

is no. Rather, other considerations seep in although their traces disappear in official documentation.

As I will now show, in formal interviews and in daily “talk” in the RICU, physicians often disclosed how much they knew about the patient’s life and relationships. They talked about the patient’s family and the kinds of social roles they fulfilled. Dr A talked about Sam’s relationship with his wife and how it had grown in the time Sam was ill.

He said he was really quite appreciative of her.

Sam had changed since they got back together and he was mellowing...went to counseling, the whole bit (Dr. A, Interview, January 26, 2004).

Dr L often discussed the family’s feelings and emotions at rounds. She talked about Jewel’s role as the head of the family and how the husband would manage if she didn’t make it through the illness.

Physicians frequently had long discussions amongst themselves, and very occasionally with the nursing staff, about the patient’s quality of life before the illness. They talked about discussions they had with the family regarding the level of disability the patient might experience following the ICU illness and how that would affect the patient’s activities of daily living. Dr A noted that:

He (Sam) has been at home and obviously life is good for him...Sam may not be really active, he’s the kind

of guy who likes to sit on the stump and tell stories...that's enough for him (Dr A, interview, January 18, 2004).

Dr L noted that her patient (Jewel):

believes in her quality of life and who am I to disagree? (Dr L, interview, February 18, 2004)

So, while the “talk” demonstrates that in all cases the physicians knew their patients in ways that went beyond clinical assessment data and also had, at length, considered and deliberated on what else they knew, it was not in any way reflected in the daily progress notes.

I conclude that the written account, as it is currently created, is less than helpful in representing how end of life decisions are made. While the chart is meant to be a true accounting of the patient's care, it also functions as a communication tool, both physician to physician, and among other healthcare team members. I argue that despite physicians' mandate and absolute dedication to the logical science based process of clinical judgment, physicians seem to become aware of other subjective data even without the benefit of asking nurses or those around them for it. This subjective data does not appear in the chart and therefore cannot be communicated to physicians assuming care for the primary physician or other members of the multidisciplinary team. The impact it has on end of life decisions is uncertain. The chart does accurately reflect scientific data that guides physician decision-making building a clear case of reversibility and

irreversibility of the patient's disease process. At end of life, this allows the physician and the institution to demonstrate a course of clinical treatment showing that every physiological base has been covered and every reasonable treatment offered and yet the patient's illness is now irreversible and further treatment or continuation of treatment is *futile*. However, this approach to documentation and communication greatly subordinates less empiric knowledge that is important to the decision making process. This significantly impacts other members of the multidisciplinary team such as nurses, who see themselves as advocates and information brokers dealing with the psychosocial aspects of the patient's care. Even more troubling is the apparent strict adherence to the science in decision making that may lead to decisions that do not represent the patients best interests.

CHAPTER FOUR

Nurses Knowing and the Organizational Context of Patient Information

“As subjects, as knowers, women are located in their actual everyday worlds rather than in an imaginary space constituted by the objectified forms of sociological knowledge built upon the relations of the ruling apparatus and into its practices” (Smith 1998, pg.108)

The comment Smith (1998) makes about women’s location and their knowing has a particular relevance for nurses and nursing. Even though nursing is a conceptually organized activity, many nurses are also located in the everyday worlds of patients, sharing with them experiential aspects of lives organized within the healthcare system. While nursing theory attempts to capture and conceptualize this experiential knowing, nurse also know their patients interpersonally.

Nurses are educated and socialized to know the patient as part of a family and social system not independent of those around him. (Carper 1978; Benner 1995; CNA 2002) Thus, for nurses, the patient is a being composed of psychosocial and spiritual as well as physiological needs. Even physiologically, the proximity and intimacy of the physical care nurses provide creates a special embodied knowledge of the patient’s physical needs that nurses learn, rely on and are trusted by patients to value. This knowledge includes information about the patient’s management of pain, comfort, anxiety, coping mechanisms, family and personal relationships and the effect the environment has on the patient. In the ICU where patients cannot speak for themselves, the unique way that nurses come to know their patients allows the nurse to advocate for the patient’s autonomy and

the principle of non-maleficence, or “do no harm”, as treatment decisions are being made at end of life.

As my data will show, although both the nursing profession and hospitals expect nurses to assess patients and act on the basis of their professional knowledge and judgment, what nurses know about their patients in ICU is charted and communicated in a way that minimizes all but the scientific or empirical knowledge. I argue that the practice of recording on graphic forms and other flow sheets means that nurses’ unique knowledge of patients nearing the end of their lives is lost to multidisciplinary decision making and undermines the ability of nurses to fulfill their role as advocates for the patients.

In this chapter, I will first discuss the work of nursing scholars whose research illustrates various kinds of knowing and nursing knowledge. This allows me to demonstrate how nurses in ICU learn about their patients in different ways that the profession values and that are useful for their care. I will demonstrate how the documentation requirements of the institution and the scientific practices of physicians marginalize all but the empirical knowledge of nurses in a quest for a record that focuses on physiological endpoints and legal accountability. Lastly, I argue that the subordination of nurses’ knowing in the charting undermines the effective communication of nurses with physicians in other arenas such as daily verbal communication and participation in weekly rounds.

Nurses’ Knowing and Knowledge

Embedded in the framework of nursing education and nurses’ practice is the belief that nurses incorporate into their care a special kind of knowledge of

their patients as well as the scientifically based knowledge that is used by physicians and valued by institutions.

Theorists call on nurses to use all types of knowing to make good clinical decisions. This is well reflected in the current curriculum of nursing programs and in the standards of nursing practice (RNABC, 2003) and yet not supported in the hospital documentation used in everyday practice. In the Collaborative Curriculum used at ten campuses across BC, “ways of knowing”, based on the work of Carper (1978), White (1993), Habermas (1972) and others are a foundational concept of the program. The RNABC Standards reflect an onus on nurses to provide a level of care that could not be achieved without employing the different ways of knowing in their care:

“Nurses must base their practice on relevant research findings” (RNABC, 2003, pg 19).

“ Nurses should be sufficiently clear and reflective about their personal values to recognize potential value conflicts” (RNABC, 2003, pg 19).

“ Nurses should provide care addressing the well being of the patient within the context of that person’s relationships with their family and community” (RNABC, 2003, pg. 19).

“ When prior wishes for treatment and care of an incompetent person are not clear, nurses’ decisions must be made based on what the person would have wanted as far as is known” (RNABC, 2003, pg. 21).

“Nurses must seek out and honor persons’ wishes regarding how they want to live the remainder of their life” (RNABC, 2003, pg. 21).

These various demands, made for nurses to know and respond to patients, suggests the diverse skills and forms of knowledge nurses must use and master in their practice.

Barbara Carper (1978) in her article “Fundamental Patterns of Knowing in Nursing” described patterns of knowing in nursing which she defined as empirics, ethics, personal knowing and esthetics. Empirics is the science of nursing and includes nursing theory and the research and advancements nursing has made in the scientific realm. Perhaps nowhere in nursing is empirical knowing more noticeable and defined than in the ICU. In my observations of Sam’s and Jewel’s cases I found the clinical environment driven by tasks and technology. The nursing record matches this prominence given to “empirics”. Nursing routines in the ICU reflect empirics in the following ways. The nurse’s day begins with the “room check”. The head of the bed is checked to ensure that all emergency equipment is present and functioning. The cardiac monitors are checked for settings that indicate the alarms will sound if the something is “wrong” with the patient. The ventilator settings are checked to ensure the patient is receiving enough oxygen and the correct number of breaths per minute. The fluids being infused into the patient are checked to verify that the patient is hydrated and is getting the correct dose of medications. All of these parameters are checked and recorded in the chart without the necessity for the nurse to ever touch or speak to the patient in her care. As the day progresses, blood pressure, pulse, respirations, ventilator settings, drip rates of the fluids, and urinary output are observed hourly and recorded in the patients ICU “flow record”. Pain is assessed according to a set of criteria established in policy and assigned a number

on the pain scale. Hospital recording forms make the interpretation objective (See Appendix B). Pain is assessed as being between 1 and 10, 1 being no pain and 10 being the worst pain ever experienced. A number is assigned to the patient's pain and recorded each time pain medication is given. Level of alertness is also assigned a number on a sedation scale from 1, which is "unarousable" to "dangerous agitation", which is 7. In Sam's chart, physicians ordered the nurses to "maintain a sedation level of 4" which is defined as "calm and cooperative" and nurses would then record the sedation level every hour on a flow record. The number recorded should reflect the sedation ordered. Thus, for empirical purposes, both pain and level of consciousness are recorded as a measurement rather than an experience.

Carper (1978) describes ethics as the moral knowing of nursing and is focused on obligation and the clarifying of values and ethical codes. Storch (2003) defines nursing ethics as something more than obligation and codes but rather, "a part of every nursing role and function because ethics is about relationships and the moral commitment of nurses to those they serve" (pg. 3). Nursing practice is based on a set of values and ethical principles clearly defined in the Canadian Nurses Association Code of Ethics (2002). These include choice, dignity, confidentiality, justice and accountability and safe, competent ethical care. Janet Storch (1994), in her model for ethical decision-making in practice, demonstrates a clear connection between foundational ethical principles and the values identified in the CNA Code of Ethics. In my interviews, nurses were not able to name the values identified in the code of ethics but they talked about ethical knowing and how important it is for them to advocate for "the right"

ethical choices for the patient. They stated this meant more than just respecting autonomy or dignity. In ICU, where the patient is often unable to speak for him or herself, nurses feel an obligation to know their patient, to gather information through stories from the family and friends or through non-verbal communication, in a way that allows them to advocate for the ethical outcome the patient would want for him or herself. They describe the process they go through to try to understand the patient's preadmission quality of life, the relationships the patient values, religious affiliations and all the other factors that would influence the kind of moral decisions the patient would make if they were able to make them for themselves. It seems clear from the following data excerpts that my nurse informants were attempting to be ethical actors.

Nurse D: I basically know what's right and wrong and if we are going against the patient's wishes. That's what I go by and what I think. Not for myself personally, but what the patient thinks is right or wrong. We are there for them, not for anything else. It is their rights. That's what I work by.

Dawn: What about the family?

Nurse D: Well...most times the patient can't talk to you. You spend a lot of time with the family and you try to get a feel for what the patient would want. They tell you stories about the patient's life and say things like "he was always a fighter" or "he

was always afraid he would end up a vegetable” and you start to try to understand what the patient might want if he could wake up and tell you.

Dawn: What about Sam? (referring to the patient the ICU nurses had been concerned about).

Nurse D: His wife is here all the time. Sam couldn't do a lot of stuff even before he came in this time. Do you remember he was here a couple of times before?

Dawn: Yes

Nurse D: Even though he couldn't work anymore, he seemed like he had some happiness in his life...with his grandkids and stuff. He has fought so hard the last times he was here; you figure he might want to fight through this too. I don't know, you wonder if he's tired of this by now (Nurse D, interview, February 25, 2004).

According to Carper, personal knowing is the use of self to “actualize an authentic personal relationship between the nurse and the patient” and calls upon the nurse to know the patient not as an object or a category of illness but as an individual in whose shoes the nurse must stand (1995, pg 80). Carper tells us that the process of establishing this relationship consists of two levels. The first is the ability of the nurse to know herself and understand her personal standpoint when

interacting with the patient as a unique being. This involves a process of reflection and values clarification. For example, when a nurse is involved in a case where end of life decisions must be made, the nurse must reflect thoughtfully on her own feelings and experiences about death, dying and quality of life in order to understand how those values might influence a truly caring and empathetic relationship with her patient. In my observations I noted that nurses often talk about these feelings and experiences with each other. The following is a conversation observed between the emergency and ICU nurses upon Jewel's admission to ICU for acute respiratory distress.

ER Nurse: That's Jewel...you remember her, you guys had her in the unit for months.

ICU Nurse: I was on holidays but I heard about her...couldn't get her off the vent forever...kept crashing when they tried to wean her.

ER Nurse: Well good luck...the husband is in the waiting room...wants everything done like before.

ICU Nurse: Did Jewel say anything about what *she* wants

ER Nurse: She also said she wanted everything done...Dr did ask her... but you know, she's so sick, who knows if she really knows...I saw her out in her garden a couple of weeks ago...dragging her oxygen tank around with her..

ICU Nurse: OK Do me a favor...when its me, just load a big syringe with insulin and...

ER Nurse: Yeah I know...me too...but not our call this time....

(ER Nurse and ICU Nurse, observational data, January 26, 2004).

Other nurses described the kind of personal reflection they do especially when they identify that their own feelings about the patient's choices may be in conflict with their own. Nurse L describes a situation with a patient she recently cared for who chose to be discontinued from life support when he had a good chance of recovery. Nurse L cared for the patient and tried to support him and his family through the death even though she did not agree with the decision because of her Christian upbringing.

Nurse L: ...it was a spiritual conflict for me because of my own Christian values...you get home and go for a brisk walk just to clear your mind and divert your energy and get the frustration out. You scrub the floor, weed all the garden...I guess you have to accept the limits of your control...you can support here and not there... I guess quite a bit is understanding the limits of your involvement. (Nurse L, interview, February 26,2004)

The second level of personal knowing is said to be information gathering and understanding all the facets of the patient's life, physically, psychosocially, and spiritually that influence clinical judgments and treatment decisions for that patient and thereby helping the patient to make meaning of the illness (Carper, 1980; White, 1995). Carper describes this kind of knowing as the ability to "understand the patient and his world as if I were inside it" (Carper, 1980, pg.42) This kind of knowing is also an integral part of the kind of meaningful information gathering that Benner and Tanner (1995) describe in their work and will be covered later in this section.

Also interesting to me is the esthetic knowing that Carper terms the "art of nursing" (1995, pg 86) that some other authors term as "intuitive practice" (White, 1995; Benner 1987). It is not the "doing " of tasks or delivery of the science of care; rather it is making "visible through action" the nurses' perception of what the patient needs (White, 1995). During my research time in the ICU, I observed countless incidences of esthetic knowing demonstrated in even most basic care the nurses gave Sam and Jewel. One example occurred in the practice of turning the patient every two hours. Nurses demonstrate both empiric and esthetic knowing when they turn the patient at regular intervals. They draw on the empirical when they use research showing that turning prevents skin breakdown, facilitates the movement of secretions in the lungs that can cause pneumonia and allows the joints to move to prevent stiffening. Esthetic knowledge, however, is demonstrated in the careful positioning of the patient with pillows behind him and between his knees for comfort, a cool face cloth place on his forehead to cool it and the administration of pain medication

prior to turning to decrease pain and anxiety. As nurses are doing the turn, they tell me:

Nurse S: We always position Sam longer on his right side than his left...he sleeps on his right side at home and we use cream to rub his back, not powder...his wife says he has always hated the smell of baby powder, even when his kids were little (Nurse S, personal communication, January 8, 2004).

Carper is careful to emphasize that no type of knowing should exist alone but rather that all knowledge is used interdependently in good clinical judgment. To me, the simple act of turning a patient and providing comfort illustrates her claim.

Benner and Tanner (1987) in their work on the role of intuition in practice, noted a recurring discourse among nurses that spoke of “ the kind of knowing that is very different from the formalized, explicit, decontextualized, data-based knowledge that constitutes formal assessments and scientific technologies and yet is central to skilled clinical judgments”(1987, pg. 273) In their later work, “ The Phenomenology of Knowing the Patient” (1993), Tanner and Benner explored nurses’ knowing in order to answer the questions: 1) What do nurses mean by knowing the patient? And 2) what difference does knowing the patient make in nursing care?

What do nurses mean by knowing the patient?

Interestingly, when asked the question by Benner and Tanner (1993) who focused in their research on what knowing the patient means, nurse's responses to interview questions reflected the kind of knowing previously described by Carper. Several nurses stated that knowing a patient means understanding the patient as a person. Without that knowledge, nurses state that care becomes detached and uncaring. Nurses' way of knowing embodies the essential humanness of the patient and transcends the experience of being "the patient". It may include such things as the patient's personality, normal mode of expression, everyday habits and practices, their work, commitments, fears, hopes and dreams, religious beliefs and cultural customs. This knowledge is gained through intimate contact with patient and /or the patient's family (Tanner & Benner 1993).

As nurse scholars indicate, nurses, through the intimacy and proximity of their care develop specific knowledge about the particular patient's responses and begin to see patterns in them. In how a patient moves or positions themselves, in the way a certain patient responds to a medication, in how they eat or react to pain. Nurses then deliver care based on the patterns they see in how patients respond to therapeutic measures, what kind of routines the patient responds to, what kind of coping mechanisms the patient demonstrates, and what kind of physical capabilities and endurance the patient reveals. Recognition of these patterns allows nurses the ability to make predictions about how successful a patient's new therapies might be or how a patient will respond in a related situation. While this kind of knowledge is often called "intuition", it is actually

the ability to make “qualitative distinctions which require local, specific and ineffable knowledge of how a patient responds” (Tanner& Benner, 1993, pg. 276)

In my interviews with nurses in the ICU, nurses often spoke of experiences with pattern recognition although no nurses would name it in that way. Nurses spoke of the importance of being attuned to the changes in non-verbal behaviors of their patients because they were so often dealing with unconscious patients who could not communicate needs to the nurse. As well, the patients whose cases were used in this study were very ill, requiring “one to one” care. Therefore nurses spent a great deal of time with them and gathered an immense amount of knowledge about patient reactions to care, changes in response to treatment and patterns in body language. In the case of these patients for whom end of life treatment decisions were looming, nurses shared stories of patterns of response that suggested that the care the nurses were giving was becoming less effective and may actually be causing harm or distress. An example is found in my interview with Nurse L.

Nurse L: It becomes very frustrating. You see the patient is not getting better.....And even if they do...how much better? You give them medication and treatment and it doesn't seem to do anything. You might gain a little on the pressure (blood pressure) but the skin is a little cooler and they are not quite so bright as the day before.... small changes..... You are in that room turning, pushing, pulling.... they groan that silent groan they do on the

ventilator and their face closes up and you know they don't want you to touch them.

D: If they are aware enough, do you ask them if they want it ... the care I mean?

Nurse L: Sure, we try to but that is the ideal situation...most often you are getting closer to the end and they can't respond to you. The hardest thing to cope with is "the look".

D: the look?

Nurse L: The look they give you at the end. The look they give you that says ...fuck you, get your hands off me...

D: Really?

Nurse L: Yeah... it happens and that is the hardest thing of all...you can just feel the hostility...they are ready to die...you can see it in the eyes.... but we won't let them.

D: Do you document this?

ICU nurse: Where? Its just a feeling you get, there is no place appropriate to write it down. The docs don't want to hear it...some in particular...give me the facts, just the facts...BP, pulse, coma scale...they are in and out of that room in five minutes, not there for hours on end like us...they

don't see what we see (Nurse L, interview, January 21, 2004)

Nurse L seems to have gained some special understanding of her patient through her close bodily association. Even though ICU nurses were expected to emphasize “empirics” in order to support physician logic of care, their level of intimacy with the patient and their attention to the patient as a person meant they generated other forms of knowledge.

What difference does knowing the patient make in patient care?

According to many nursing experts, knowing the patient is central to skilled clinical judgment and is broader than what is captured in formal assessments of clinical systems. First, because the nurse knows the typical response to treatment, certain aspects of care will stand out as salient and others will recede in importance. Secondly, knowing the patient as I have indicated ICU nurses do allows them to particularize care. Nurses believe that the mere application of scientifically based knowledge is not enough. Rather, that clinical judgment requires nurses to particularize formal prescriptions and abstractions through understanding how *this* patient responds in *these* circumstances (Tanner & Benner, 1993, pg. 278).

One of my informants offered this account of her judgment, based apparently on ‘knowing the patient’ in ways other than empirics.

Nurse S: I know when Jewel has had enough. Some patients will strike out at you or push at you. Jewel just ignores us as if we don't exist. You will lose eye contact and not get it back until you leave her alone. When that happens I just back off until she is ready (Nurse S, interview, February 1, 2004).

Nursing researchers argue that nurses' non-empirical way of knowing is essential to advocacy. According to Carper, 1980; White, 1995; Benner and Tanner, 1993 nurses believe it is impossible to stand behind patients and families, empower them, and allow them voice without an understanding of the particular patient's responses and an understanding of that patient as a person outside of the clinical experience. It is this understanding of the patient that allows the nurse to support the principles of autonomy and non-maleficence in end of life treatment decisions. Nurses state that the connection they make with their patients and the unique way they have come to know him/her allows them to try to speak for the patient's wishes as if the patient were speaking for himself thus supporting the autonomy of a patient who cannot speak for himself. Nurses also tell me that the proximity and continuity of their care and the resulting knowledge of subtle responses to care permits them an insight into the possibility that the treatments being administered to prolong life may, in fact be causing pain and distress. It is with this unique knowledge and the power to share it that nurses support the principles of autonomy and non-maleficence.

Institutional Organization of Nurses' Knowledge

The Chart

What nurses know presumably should be communicated to other members of the staff caring for the patient. The patient's record is the formal communication tool, however as I will show next, the nurses' recording is organized in a document that subverts the use of the chart to capture anything other than empirics. I argue that what works for support of physicians' diagnosis, undermines the capacity of nurses to communicate their knowledge.

In the ICU, the primary means of capturing patient information is the use of the "24 Hour ICU Nurses Notes." This is a document that is implemented immediately upon admission to the RICU (Appendix B). A new record is initiated everyday at midnight and carried through the following 24 hours. The 24-hour record is made up of two sections: a flow record and the narrative nurse notes. The format of the charting is very structured and follows a 'problem orientated' format. The front page of the flow sheet is a numerical record of the patient's status including hourly monitoring of blood pressure, pulse, respirations, oxygen levels, fluids in and fluids out. The second page of the flow sheet is a series of small boxes organized according to each of the bodies' systems. This section of the flow record is used "to indicate that each system has been assessed and problems identified by nursing" (policy 8.34, 1999). Each box has an accompanying legend of codes that are to be used to describe the status of each system. For example, respiratory status can be described as regular, shallow or labored. The patient's pulse is designated as A (absent), S (strong), M (moderate), or W (weak). If the nurse identifies a problem, a P/NN is written in the box and

this indicates that nurses notes have been written in the narrative section that describe the problem. The charting policy states, “ if no problems have been identified, further documentation is not required in the nurses notes” (policy 8.34, 1999). According to policy, the flow sheet is completed four times a day or as ordered by the physician.

This organization of charting too, allows for clear presentation and easy accessibility of the scientific clinical information needed by physicians but allows the nurses no mechanism to chart the subtle observations and unique knowledge gathered by nurses in the course of their care. Nurse L, in her interview, describes the difference between the empiric impressions generated by the flow record and the kind of knowledge important to nursing:

Nurse L: you know on the flow sheet we assess for level of consciousness using the Glasgow Coma Scale and there is a place where I assign Sam a 3 and say that he “responds to voice”? Well that’s the number and I guess that tells the doctor what he wants to know, but for us it’s different. How do we tell them that when we say Sam’s name, and tell him to open his eyes, he does it, but in this slow kind of listless way...but when his wife comes in and says his name softly in his ear, Sam opens his eyes and gazes at his wife in that special way that you just know he’s *there*...he’s present and with us

in a way he isn't when she's not there...and that tells you so much about how much he wants to go on fighting the fight...you can't say all that by writing the number 3.

Dawn: So do you write all that in the chart?

Nurse L: No, I mean the guys (physicians) hate wading through all that stuff to get to what they need. Sometimes I try and tell them, if they let me, but they don't always have the time to listen...I don't think it means to them what it means to me...us. If the patient's awake, he's awake... right? (Nurse L, interview, January 30, 2004)

If, as was previously discussed in this thesis, the purpose of the chart is both an accurate record of the patient's course of care and a communication tool between health care providers, then I argue that the ICU record in the research hospital does neither. It well supports the empirical knowledge of nurses but makes invisible other important aspects of what they know. In doing so, the chart undermines treatment decisions essential to the well being of the patient, including those at end of life, by excluding information about patient preferences, relationships and quality of life issues. This and other contextual information would support a decision made uniquely for the patient as they experience life at that time rather than a decision that reflects only the treatment of a set of symptoms belonging to a defined disease process. As a communication tool, I argue that the

chart does not promote dialogue among disciplines. This occurs partly because information not charted or captured cannot be shared but also, a system of written communication that so clearly undermines the knowledge of certain team members can only lead to interdisciplinary communication that is uncollaborative and even tainted with disrespect.

Shift report and report sheets

During the weeks of data collection in the unit, I often observed nurses talking about patients and sharing information about patients that was never recorded in the chart. At shift change, nurses would give each other a verbal report and include descriptions of subtle changes in patient status and information about Sam and Jewel's family:

Nurse S: She (Jewel) seems a bit brighter today...mostly when her son is here...

Nurse C: I wish her husband were here to see that...he told me that he is almost ready to give up... to him she seems so sad and angry...he's scared he's doing the wrong thing letting this go on and on

Nurse S: OK, I'll pass it on tomorrow and see if someone can talk to him

Nurse D: I don't know what we are going to do about pain control for him (Sam)

Nurse S: yeah...did he (Dr) discontinue all the morphine?

Nurse D: just great...did you chart it ...or call him?

Nurse S: what am I going to call him about? He (Sam) only looks like that when we turn him, he doesn't moan or scream but the look on his face...we've seen it a million times...he's in agony but unless he (Dr) sees it for himself we are not going to get anywhere. How do I put it on a sedation scale for him (Nurse S and Nurse D, observational data, January 30, 2004)

As the researcher, I would go to the chart and attempt to find some documentation that supported the discourse I would hear at shift change, only to find that none existed. Several times, I found a similar discourse to the ones I would hear in report recorded on the shift nurses' report sheets. These are patient information sheets used to transfer information among nurses from shift to shift and do not become part of the permanent record. When I asked nurses why they would not record information in the chart that they felt was important enough to pass from shift to shift, Nurse L replied:

They (Drs) will not think its that important. There is no point in passing it on to them. We talk to each other and deal with it as a group. Each shift will cope and deal with it

their own way. Half the time, the Doc won't care and the other half he wouldn't know what to do about it if they did!

(Nurse L, interview, January 30, 2004)

The experience of having their non-empirical knowledge discounted makes nurses weary of attempting to express them. Nurses' then find a way to communicate what they consider important amongst themselves. Although this allows nurses to "carry forward" knowledge between nurses and from shift to shift, it is further evidence of the way in which nursing and medical knowledge becomes isolated from each other.

Friday Rounds

Another institutional process for communication of patient information is "Friday rounds". These rounds began approximately four years ago in order to facilitate the transfer of information from attending internists to the internist on call who was taking over patient care for the weekend and were originally called transfer rounds. Gradually, these rounds, facilitated by the nurse clinical resource coordinator in the RICU, started to take on a planning function between physicians and notes were made in the chart to direct changes made in care as a result of this mass consultative type of approach. Increasingly, other disciplines began to attend, as physicians required them. Nursing was first to be included because physicians identified the need to have them present to prompt them from the chart if they needed to know a blood pressure or a lab result. It soon became routine that nursing would organize their patient care and coffee breaks so that

they were present at rounds. Eventually, respiratory therapists, dietitians, social workers and pharmacists began to attend as physicians required information on ventilator settings, tube feeding, social services and drugs. But while rounds have come to look like a multidisciplinary group endeavor, it does not function like one. Physicians sit in a tightly knit circle in the nurses' station while all other staff members lean like birds on a wire on a high counter surrounding the station looking in on the process. As the rounds progress, each physician presents their patient, the diagnosis, results of recent tests and the plan of care for the weekend. If the doctors require information from a team member, they ask, but no disciplines are invited to freely impart information to the team. Occasionally, a brave nurse jumps in and asks a question pertaining to family, comfort or end of life issues. If the physician were comfortable with the topic, he would open it up for discussion but if the topic was one in which nursing and the physician had a difference of opinion, the nurse might be told, "this is not a question for the group, and we will discuss it later." During one set of rounds I attended, the nurse looking after Sam tried to raise the issue of Sam's pain control, describing the challenges of managing him on minimal or no sedation. She was told that "the information is not relevant and we will discuss this later". Nurse S later told me that she was "not trying to make trouble" but was hoping for a chance to present her problem and have a brain storming session with the group that would result in a solution. As a result of the dynamics in rounds, nurses in RICU voted at the staff meeting on February 7th, 2004, to no longer participate in Friday rounds but to initiate nurses' rounds on Friday afternoons. The purpose of nurses' round would be to discuss ongoing care concerns in light of decisions made at the physicians

morning rounds and make a nurses' care plan to deal with nursing concerns. This decision by the nurses was to be presented by the clinician to the Director of ICU at the next ICU committee meeting.

In this chapter, I have explored the work of nursing theorists who attempt to define the scope and breadth of nurses' knowing and I demonstrated how nurses in ICU learn about their patients in exactly the ways described in the literature. I show how this unique way of knowing the patient permits the nurses in the ICU to advocate for treatment decisions for patient "as if they were there in the patient's place" (Carper 1980, pg.14). I demonstrate that the empiric charting practices of the institution, that support scientific and legal requirements, subordinate nurses' knowing and render it lost to decision-making processes in the hospital. I demonstrate that nurses clearly recognize the marginalization in charting practices of the patient information they gather and see as important to patient care, and as a result, have begun to self regulate their participation in other arenas of decision making such as daily and weekly rounds. The knowledge that physicians are interested in is not inclusive of what nurses think is important. Neither the organization of the record nor the Friday rounds enable a 'break through' to better communication. There remains one explicitly organized avenue for doctors and nurses to share decision- making and I discuss that in the next chapter.

CHAPTER FIVE

Multidisciplinary Collaboration in End of Life Decision Making

In questioning the “troubles” nurses and physicians experience in end of life decision-making, what I saw and heard in everyday relations in the RICU led me to examine how decision making itself is socially organized. In previous chapters, I have discussed how nurses and physicians come to know their patients and responsibilities to them differently according to professionally embedded principles and practices. I have shown the way in which nurses’ knowing is subordinated in the recording and communication of the patients’ care, and I have argued that this marginalizes nurses’ impact in treatment decisions in the ICU, including those surrounding end of life. In this chapter, I demonstrate that there exists a societal and professional trend toward multidisciplinary decision-making processes in healthcare. Both nurse and physicians express commitment to collaborative decision- making. Yet, in the research hospital, even though a process has been especially created to offer opportunity for interprofessional collaboration, I draw on observational data to demonstrate that the social relations of medical practice remain such that physicians maintain dominance over the process. When expectations for collaborative decision making collapse it leaves nurses pushed into a mere supporting position with physicians and families. This is a position that is troublesome for nurses, as it does not allow them to fulfill the role they value as advocate for the patient.

Expectations vs. Multidisciplinary Practice

In the recent literature on decision-making in medicine, social work, nursing and other helping disciplines, there is an increasing emphasis on creating a culture of multidisciplinary decision making in healthcare (Shannon 1997, Genesen 1997, CHA 1999, Marshall 1995, Brody 1995). The profession of nursing is being organized to consult with other disciplines in decision-making and respect the specialized knowledge other healthcare team members may bring to their practice. The Registered Nurses Association of BC (RNABC), in the Standards for Nursing Practice (2003), directs nurses to “collaborate with other members of the healthcare team regarding activities of care planning, implementation and evaluation” (RNABC 2003, pg.18). The Canadian Nurses Association (CNA), directs nurses to “respect and value the knowledge and perspectives of other health providers and actively collaborate and where possible seek appropriate consultations and referrals from other health team members in order to maximize health benefit to patients” (CNA 2002, pg.10). As well, research suggests that while nurses understand that family’s wishes for end of life cannot be considered to the exclusion of all other data, they see the inclusion of family as a critical part of the advocacy process (Viney 1996, Shannon 1998, Dodeck 2000). Nurses also want to believe that multidisciplinary decision-making is a means to convey the unique information they believe they bring to the situation. Viney (1996) and Shannon (1997) concluded that nurses highly value the role of information broker and feel that the best outcome for the patient occurred when physicians incorporate the nurses’ perspective into the decision making process. Nurses in the ICU of the research hospital told me that they believed in the process of multidisciplinary family

conferencing as a way to have all voices heard, with the hope that all perspectives would result in a better outcome for the patient. They also told me that they see the family conference as a formal means of being “invited into” the decision making by medicine and a key chance to present information they feel is important to the process. Nurse L stated that:

As frustrating and time consuming as the meetings can be, it is a way for us to tell the doctor what we know from being with the patient all day and from talking to the family all day and all night for days on end. We see what no one else sees at two o'clock in the morning. They see vital signs and blood tests. We see the other stuff. It's all-important and one can't work without the other. Hopefully, someone there will back us up, whether it is social work, clergy or a family member (Nurse L, interview, December 27, 2003).

Nurse D agreed, saying: those conferences can most often make you crazy but you always go into them hoping for the best. Hoping for a decision everyone can live with. Sometimes, when the doctor won't let you get a word in, you feel like you want to scream...Or quit.... But at least you are there for the family and in the end, if you have helped them in some way, you feel like you've done

something (Nurse D, personal communication, December 27, 2003).

Physicians too, are under considerable pressure to consult with other healthcare professions and to include the family in the decisions that are made. The medical profession's own governing bodies now direct physicians to participate in multidisciplinary forums with nurses, social work and other disciplines. The Canadian Medical Association (CMA) recently participated with the Canadian Nurses Association and the Canadian Healthcare Association in developing the *Joint Statement on Preventing and Resolving Ethical Conflicts Involving Healthcare Providers and Persons Receiving Care (2000)*. This document outlines the principles of a therapeutic relationship and clearly defines the responsibility of the physician to:

- 1) Provide a patient or the proxy with all "information and support necessary to access options for care".
- 2) Recognize that when a patient is incompetent, every effort must be made to ensure that healthcare decisions are consistent with the patient's known preferences.
- 3) Determine the best course for incompetent patients whose wishes are not known by taking into account diagnosis and treatment options as well as information from those significant in the patient's life and aspects of the person's culture or religion.
- 4) Clarify with all healthcare providers' goals of care so as not to compromise their relationship with the person receiving care.

5) Respect healthcare providers' responsibility to advocate for the patient so that all persons will have access to appropriate treatment. (CMA, CNA, CHA 2000, pg. 2)

Addressing issues of end of life by providing a forum for information gathering and exchange between disciplines, and with family present, is still fairly new to the critical care setting. In the past, planning for a "good death" was the responsibility of hospice, oncology or extended care where death is supposed to happen (Cooke, 1995). In 2000, the Canadian Critical Care Society issued a consensus document, based on research done in six tertiary care ICUs, that directs physicians to seek information they need for the process of reaching end of life decisions from all disciplines including nurses and social work as well as the family (CCCS, 2000).

As well as being mandated by the professional bodies, there are social pressures on physicians to include all interested bodies in decision making at end of life. Patients' rights societies and several web sites (Smith, 2002) are devoted to making the public aware of their rights regarding end of life decisions. Recent legislation by the government legalizes both Advanced Directives and the right of the patient to assign a healthcare proxy who will make health care decisions for them in the event they are unable (Gov of BC, 2000). Although this legislation is relatively new, information is making its way into the public realm and patient's families are beginning to question their rights to participate in end of life decisions within the context of the new laws. Research done by the Canadian Critical Care Society showed that families were most satisfied with outcomes of

end of life if the decisions were made jointly with physicians and nursing in an informal conferencing setting (Heyland, Rocker and Dodek, 2002).

My interviews with RICU physicians revealed that they are getting the message about collaboration but remain conflicted about how much to trust it. Physicians in the ICU told me they see family conferences as necessary but not always valuable. They verbalized the need to communicate with family and the value of being seen as a “team player” but stated that they often didn’t feel the multidisciplinary conference accomplished that. Dr S stated:

Including the family can absolutely be important if they can give you clear direction but often the family is unprepared or ignorant of the medical situation. If there is any uncertainty, you intervene until you can make a proper withdrawal (Dr S, interview, January 18, 2004).

Physicians in the RICU also indicated that while they were willing to listen to the nurses’ input, it did not significantly impact decisions. Their primary concern was for enacting their science-based leadership role. Dr A stated:

It’s our job to pass on the science, to give the facts. It takes away the personal anguish that people might experience. Nurses are handling, touching, feeling, and dealing with the family. Of course they feel threatened by

our approach, they are all wrapped up in the emotion. (Dr A, interview, January 26, 2004)

Physicians see end of life decisions as fraught with the possibility for professional sanction. They were much more concerned with the input of their physician colleagues regardless whether those peers were actively involved in the case and seem very aware of the scrutiny of those peers. Comments from Dr S and Dr A illustrate this:

I hope it will never influence me what the staff thinks, though I'm definitely into a team approach, but it doesn't go to the nth degree with being a team. It ultimately is my decision or a decision with my colleagues (Dr S, interview, January 18, 2004).

When another Doc looks at my cases. I want him to be able to see what I see... that I did what needed to be done and now we stop...and he can help me out with that decision...support it (Dr A, interview, January 26, 2004)

These views make nurses' expectations for collaboration seem less than viable.

Organizing the Conference

Family conferences are the strategy that arose purportedly to advance family and multidisciplinary decision-making in the ICU of the research hospital. Despite professional trends that would appear to encourage and support multidisciplinary, family centered decision- making, it is my contention that the way these conferences are organized functions to maintain the decision making role that physicians hold and prevent outcomes that meet the expectations of the nurses.

Initial troubles begin with the timing of the conference. In the case of both conferences I attended, the nursing staff had been asking the internist for a conference for weeks prior to one being called. ICU nurses were worried about how information was being related to the families about the patient's prognosis and courses of treatment. Nurses expressed the feeling that they were not "on the same page" as the physicians and a conference would help to open communication and clarify a plan of care. In one case the nurses had requested a family conference two Fridays in a row at RICU rounds and been told by the physician that " we are not there yet". Nurses were frustrated with the response. One nurse reported to me her own sense of urgency:

Nurse D: it (a conference) lets us all know where we are. I know its his decision (the doctor) but he won't be here...he's off for the weekend. Something will happen...Sam may go down hill.... No one will know what to do...we just want a 'talk' with the family.... something,

anything to give us direction (Nurse D, interview, December 27, 2003)

In Jewel's case, Dr L told nurses they had to wait a bit for the conference and give the patient time to 'declare herself' so more concrete decisions could be made.

Despite concerns voiced by the nurses about delaying them, both conferences I attended were organized in the last forty-eight hours prior to the patient's death. Timing of the conferences coincided with the patient reaching a critical point in their recovery at which reversibility of the patient's illness was questioned, thus satisfying the physician's need for a scientific end point to the patients' care. In Sam's case, the conference was triggered by the need to start dialysis. Dialysis had become necessary due to acute kidney failure but as everybody recognized, it significantly decreases the chance for survival (Apache II, 2002). The conference was being delayed until signs of "futility" of treatment appeared. This satisfied the physician but not the nurses.

Dr A stated: I wasn't going there with the wife until I was sure I had nothing left to offer her. I didn't even want to talk about quitting until I was sure we have hit the wall. They lose faith in you. They need to know you've done all you can do (Dr A, interview, January 30, 2004)

The same thinking was evident in how the conference was arranged regarding Jewel. In Jewel's case, three attempts that had been made to disconnect the patient from the ventilator failed as a result of heart failure. The choice had finally had to be made about whether to keep the patient on the ventilator indefinitely, remove it and let her die or send her to Vancouver for intervention. Dr L stated that he would agree to a conference but that:

The family will not have a lot of impact as far as decision making goes. We have to talk to them but the decision to send her to the coast was a reasonable decision amongst my colleagues, my medical colleagues (Dr S, interview, January 20, 2004).

All these interactions pointed to the physicians maintaining their control over the decision making, as a taken for granted feature of medical responsibility.

The issue of inclusivity was also a problem for authentic collaboration. As well as controlling timing of the multidisciplinary conference, physicians also determined who would attend. Once the decision was made to arrange the conference, the physician would give the charge nurse a list of his own available times their availability and ask the nurse to arrange the conference. The families were then notified and asked to arrange their schedules around when the physician was available. This sets the stage for the family's impression that, rather than a

multidisciplinary conference, this is a meeting with the doctor and other members of the team may be present for support. In both cases the physicians also made clear to the nurses what other team members they considered appropriate to attend the conference, and who were not to be invited. During my weeks of data collection, I noted that physicians would exclude either clergy or certain members of the family. Clergy were deemed of no value by medicine. In Sam's case, the family had asked for a priest several times in the past when Sam's condition worsened. When Dr A was asked if the priest should be included in Sam's conference, he replied:

What for? They have nothing to contribute!

Some family members would be excluded if the physician saw them as either having a distant or volatile relationship with the patient. In Jewel's case, Dr L stated:

There seems to be a lot of friction between Jewel and her son. None of us need to deal with a lot of pointless hostility. It would be better if he just didn't show up. (Dr S, interview, January 24, 2004).

Nurses noted that physicians would sometimes exclude family members if the physician themselves didn't have a good relationship with them. Once, the charge nurse was directed to set up the conference at a time when the undesired family member was unavailable so they could be excluded from the decision making process. In Sam's case, Dr A told Nurse L:

Try to set that conference up when Sam's son isn't around, I'm tired of fighting with him (Dr S, interview, January 24, 2004).

Staff participating in the conference were briefed prior to the arrival of the family and told by the physician what input was appropriate and what was not to be discussed. The staff was never told at these briefings that their input was of no value. Rather, the physician would tell staff what information would confuse the issues, upset the family or that the family would be incapable of understanding the information therefore it should not be included. Prior to Sam's conference, Dr A asked the charge nurse and the nurse assigned to the patient as well as the clinician into the family room and told the nursing staff:

There is no point in speculating with family what Sam's life will be like on dialysis. It is complicated and will only confuse them. We are making decisions for now, not trying to predict the future (Dr A, interview, January 30, 2004)

These data excerpts highlight the degree to which physicians in the research hospital see the careful management of end of life decision making as their prerogative.

The organization of a conference expresses to the physicians' management of the case. It appears that in the cases observed, the conference was an opportunity for the physician to relay to family members that everything possible had been done. Choices about who should attend also related to physician management of the situation. It appeared that physicians were attempting to avoid what they considered unnecessary involvement of those who might interfere with their own interpretation of the best management of death. In some cases, it seemed that the physicians, expecting a difficult or emotionally trying meeting, were attempting to set up a situation that would be as easy to manage as possible.

The Conferences

Besides controlling the planning for the multidisciplinary conferences, in both conferences I attended for data collection, the physician controlled the conduct of the conference. Physician dominance was aided by the physical arrangement of people in the space. However, as I show below the structure of interaction clearly placed leadership on the physician and constructed other disciplines and the family members as subordinates. In the ICU, all family conferences are held in a small conference room that is used for both family conferencing and as a sleep room for family members when their loved one is critically sick. Thus, it resembles a small living room with a couch along one wall, two recliner chairs opposite the couch and a small coffee table in the center. In both conferences, the physician took the recliner at the head of the room and the family members took the other recliner and the couch. Nurses sat on either arm of the couch and other providers such as social workers lined the walls. This set up a dynamic where only the physician is interacting face to face and on eye

level with the family. Observations made at two conferences, presumably organized to consult with family and make collaborative decisions, illustrate the restricted understanding of ‘multidisciplinary’ operating in the RICU.

Sam’s “Family” Conference

Dr A started Sam’s conference by telling the family:

We are here to discuss Sam’s disease and his chances for survival. There is no point in predicting what Sam’s life might be like if he gets out of here. We’ll deal with that later (Dr. A, observation note, February 1, 2004)

Dr A gave his information first which was completely clinical data. He would occasionally ask other staff members for clarification of lab or other diagnostic reports. If the nurses gave an answer, such as summarizing the results of a CAT scan, Dr A would ask the nurse to confirm her answer by referring to the chart. Dr A did not ask for any input from staff members. Despite instructions to the contrary from Dr A prior to the conference, the nurses and social workers tried to open some discussion of what Sam’s life would look like on dialysis, were he to survive ICU treatment and return home. Immediately, Dr A stated:

It is hardly worth discussing this when we don’t know if Sam will make it home. (Dr. A, observation note, February 1, 2004)

With this single comment, the doctor cut off all discussion about Sam's quality of life that might have come from pursuit of the conversation. Immediately after making this comment, Dr A got up and moved to a position beside the exit door and then asked the family " Any questions?" The family responded by saying "no" and thanking the physician for "making time for them".

Much of what nurses considered to be important information in the decision making process was excluded either before the conference took place or during the conference itself. There was no discussion of pain control or quality of life issues and no exploration of the family's or patient's feelings about death and dying. Nurses provided physical comfort; often reaching over to rub the wife's back or hold the daughter's hand but were not asked to contribute to the data given to the family. Although recent literature tells us that families want to be involved in decision-making, Sam's family asked few questions and did not fully explore options. They did not challenge any of the information given by the doctor. The family waited for Dr A to leave before they asked for clarification from the nursing staff.

Following the conference, nurses began acting as interpreters and mediators. A group of three nurses answered many questions by rewording physician data into language that could be understood by the family and giving additional information generated by the doctor's presentation. This included attempting to explain the differences in CAT scan results when the family asked, "what did the doctor mean when he called Dad's illness end stage lung disease?"

and clarifying the significance of several lab values, which were the indicators for kidney dialysis.

Some information given by the physician conflicted with impressions gained by the family while at the patient's bedside. During the course of Sam's care, the nurses often had discussions with family regarding control of Sam's pain. The family raised concerns when they would notice that Sam winced or grimaced during turning, suctioning or dressing changes. They voiced to the nurses that one of the reasons they sometimes considered discontinuing treatment for Sam was their perception that Sam was in pain. Nurses responded by informing the family of the measures being taken to control his pain and validating the family's feeling that pain was a consideration when examining the course of Sam's recovery. During the conference, Dr A stated, " Sam has no pain. It has been proven that the grimacing is just reflex". The family did not challenge this information or ask any question until Dr A. left the conference. The family then asked many questions about the validity of the doctor's information and the information they had been receiving from the nurses. They voiced relief that the grimacing and moaning they had witnessed during care were not signs of pain and stated, "that they could see how the nurses could make that mistake". The conversation ended with the family expressing relief that the nurses were wrong and the patient was comfortable.

Following the conference, the nurses voiced frustration that they felt the family was given only information the physician wished them to have and this resulted in the family and staff being unequal partners in the process and undermining of the nurse's relationship with the family.

Nurse L stated:

I am so angry about how this has turned out. Not only are we not allowed to give any input but also he makes this blanket statement about Sam's pain that makes us all look stupid! What's the point? (Nurse L, observational data, February 8)

This conference is an example of how an opportunity for collaboration was lost and, in so doing, nurses were left feeling that they were unable to participate in a way that allowed them to be heard.

Jewel's "Family" Conference

Jewel's family conference began with the same physical dynamics as those encountered with Sam. Dr L sat in the recliner at the head of the room and the family occupied the other seats in the room. The charge nurse took a seat on the arm of the husband's chair and the other nurses present squatted on the floor by the feet of one of the sons. Dr L took the husband's hands in hers and leaned into him as she spoke. Dr L then presented all the clinical data to the family and laid out the options, which were to transfer Jewel to Vancouver, continue to attempt to treat as they had been or to withdraw treatment. The discussion ended with the comment that "I discussed Jewel's course at rounds and all five specialists agreed that sending her to Vancouver is the "best course of action" and then invited the family's comments and questions. It appeared that Dr L's comments were intended to reassure the family that "the best" decision had been

made, one on which “all five specialists agreed”. However, her declaration entirely undermined open discussions in which the family might have shared their views. Now, if they chose not to send their mother to Vancouver, they would be acting against the advice of a whole panel of experts. The family immediately agreed that Jewel should be transferred.

As with Sam’s case, nurses’ had been asked to not contribute to the conversation with the family in any way. Nurses told me going in to the conference that from what they had seen in giving care they felt strongly that Jewel should be given some opportunity to make her wishes known. Nurse L said:

Jewel is a very strong willed person. The family told us that time and time again.

When we interact with her, it is very easy to tell when she wants something and when she doesn’t even though she can’t speak. It’s obvious to us that she is not a lady who likes to have things *done* to her. We really wanted to advocate for an attempt to let Jewel speak for herself but I guess the decision has been made. I don’t know what I was even there for. They didn’t need me! (Nurse L, interview, February 8, 2004)

Again, nurses professional concerns could not be heard in a forum apparently organized to hear from everyone. As a multidisciplinary and family centered conference, it is a failure.

So Much for Expectations

In this chapter, I have outlined the mandate and expectations within the institution, the professions and society for multidisciplinary decision-making. The multidisciplinary family conference is meant to be a forum where all types of knowing come together to give a complete picture of the patient's condition and the options for treatment. If it worked the way it is supposed to, it would be a venue for physicians to present empiric information about the patient and present a picture for the family of the potential reversibility or irreversibility of the patient's disease and render an opinion as to whether the care is futile. In a true multidisciplinary environment however, the nurses would also have an opportunity to present their unique perspective of the patient and raise issues such as pain control, suffering, dignity, and quality of life. Discussion of these issues is important to everybody. Nurses in particular see themselves as advocates for the patient when they cannot be speaking for themselves

I have marshaled evidence showing what actually happened in two multidisciplinary family conferences that, according to the nurses I interviewed, were typical. Timing, organization and dynamics of the conference are set to facilitate the physicians' agenda. Physicians, as I have already argued, are following a practice model that commits them to taking charge and using a science based process of decision-making. I have shown how this marginalizes nurses and

their unique knowledge. As a result, families end up with only part of the information they require to try to make an informed decision that represents the patient. Physicians construct the situation so they retain total dominance over the decision making process. Thus, this venue of last resort for the nurses becomes a source of their greatest frustration and discontent.

CHAPTER SIX

CONCLUSION

This research is about the way in which treatment decisions are reached at end of life in the research hospital's intensive care unit. I initiated this research in order to gain a greater understanding of how and by whom these decisions are made and why the decisions are so often troublesome for both nursing and medicine. I was seeking to understand why, when both professions profess to want what is best for the patient, decisions are made at the patient's end of life that leave the nurses feeling demeaned, powerless and unable to meet their own ethical standards.

In the conceptual framework of the study I examined the literature for many of the recurrent issues pertaining to end of life decision-making in clinical practice. I began by introducing the key principles inherent in biomedical ethics, autonomy, beneficence, non-maleficence, and justice, and demonstrate how competing principles set the stage for ethical dilemmas. I then explored the notion of frameworks for ethical decision-making and the potential they have for allowing helping professionals a tool to deconstruct ethical dilemmas. I examined the concepts of moral responsibility and professional responsibility and their implications for nurse/ physician relationships. I introduced the issues of patient and family rights and current trends in inclusion in decision-making. I included a discussion of locus of control in decision-making and the differences in how professional disciplines determine what becomes important in the process. Finally, I set the stage for my inquiry by arguing that little of the current literature explores what really happens in everyday practice at the bedside.

In Chapter Two, I established institutional ethnography as my methodology and explained that it allowed me to examine how these decisions were made about end of life that left nurses feeling so negatively about them. I explained how this research begins in the observation of everyday work at the bedsides in the RICU. I then introduced the notion of social relations, both local and translocal, and made clear how they can be seen in the everyday talk and charting practices of the nurses and physicians of the RICU. What happens has an organizational character and it is that element of end of life decisions I want to explore.

In Chapter Three I begin my discussion of the social organization of physician's decisions to withhold or withdraw care in the RICU. I clearly demonstrated how physician's treatment of the very ill is organized by absolute adherence to empirical data collection and a logical and systematic approach to documenting care. It is essential to physicians that the chart reflect that proper diagnostics and examinations are complete, that a diagnosis and prognosis is established and finally, that ongoing empirical reassessment is carried out until the patient's case can be considered irreversible and further treatment futile. I argue that this approach is organized by medicine's expectation of professional accountability that begins in a physician's training and is carried on by the expectations of both the medical associations and peer relationships within the medical staff.

In Chapter Four, I explored nurses' ways of knowing and the organizational context of patient information. I have already demonstrated physician reliance on empirical information when making treatment decisions.

Nurses, through proximity and prolonged contact with their patients, come to know them in a very different way. I argued that the curriculum of nursing programs and the standards of nursing's professional bodies demands that nurses employ esthetic, ethical, and personal knowing in order to establish a unique understanding of the patient. The RICU nurses I interviewed spoke about the knowledge they gained of the patient's family relationships, coming to understand the person the patient was before their critical illness, and subtle physical cues they assessed while caring for the patient. Nurses trust and value this special embodied knowledge and they believe it is what leads to a caring relationship with their patients. The establishment of a caring relationship allows nurses to be effective advocates and information brokers for their patients' in end of life decision-making. Nurses insist that if the organizational setting were supportive of their knowledge and involvement, better decisions about end of life decisions would be made. While nurses feel the information they gather about the patient is essential to treatment decisions, the way in which formal documentation of the patient's course is organized subverts nurses knowing and captures only the empirical knowledge valued by physicians and the institution. I argue that this process of documentation undermines communication among disciplines and leaves nurses with no way to contribute to the patient's record in a way that legitimizes their view of the patient. Nurses, as a result, find different ways to pass amongst themselves the information they feel is important. They use the shift report sheet, which is not a part of the legal account of the patient's course, to communicate information from shift to shift or they pass the salient patient data verbally from one nurse to another. While these processes ensure that knowledge

is passed to those nurses delivering care and was valued by nursing peers, nurses I interviewed expressed the view that their information was not valued in multidisciplinary decision making.

In my final chapter, I presented literature that supports the trend toward multidisciplinary decision making in patient care and examined the multidisciplinary family conference as a means of end of life decision making in the research ICU. I argued that while the conferences do happen, the way that they are timed, arranged and played out clearly puts physicians in a dominant role that leaves nurses, and indeed other disciplines and family, in mere supporting roles in what is meant to be a collaborative process. Nurses told me of the frustrating experience of participating in a conference they attended because rather than representing an opportunity to share information, they left the conference feeling more devalued than ever. I argue that physicians do not participate in order to facilitate a truly collaborative process, but rather to give the impression that they have. I further argued that physicians in RICU do not believe that collaboration improves the decisions that are made and that the driving force behind physician participation in the conference is, in fact, merely professional and legal accountability.

My research was initiated to address the question of how end of life decision in the RICU were made and why nurses' involvement in the decisions are less than satisfactory to them. Clearly, nurse and physicians working in everyday practice gather and prioritize information about the patients in different ways. Physicians' training in medical science, reinforced by professional codes and peer pressure instills loyalty to an empirically based practice. They depend on

making decisions can be measured and documented, creating a record of the patient's course that demonstrates exactly this form of professional accountability for treatment decisions. It is this requirement of proper practice that made the physicians that I interviewed need to disregard information that fell out of the realm of empirics. They consciously avoided being influenced by knowledge that they considered non-scientific or subjective. Nurses, on the other hand, learn various things about their patients and feel it is their responsibility to share with the physician any information about the patient that they think might affect end of life decisions. Much of this information is empirical in nature, but also includes ethical, esthetic and personal ways of knowing. Nurses value all these types of knowing and believe they cannot fulfill a true advocacy role until they communicate their findings in this regard.

While it might appear that RICU nurses are entirely too passive in their interactions around end of life decisions, my research provides experiential evidence showing how nurses' observations, ideas and even their suggestions are disattended. Their reporting, structured to support physicians' practice, suppresses any nursing knowledge except the clinical data that physicians rely on nurses to record (for them). Nurses' voices are actively silenced by the structuring of meetings that would offer them a place to discuss their own views of patient care. The nurses I interviewed and observed often played along with physician's ideas and wishes related to end of life decisions even when they disagreed strongly with them. When questioned, they cited lack of organizational support as a problem in challenging the processes for decision-making. Often they explained their passivity by saying that disagreements between nurses and physicians were likely

to confuse the patient or family and undermine the trust in the physician and the team.

One question that arises from my findings is how well does this organization of doctor-nurse interaction serve either professional interests or the well being of the patients being cared for? How can decisions be made that support the most basic principles of ethical practice if all aspects of the patient's humanity are not considered? In order to make those decisions, professionals must be able, at the very least, to evaluate harm and benefit to the patient *as it would be seen by the patient* and develop some sense of the patient's own wishes in regards to treatment and degree of intervention. How can that be accomplished without knowledge of who that patient is outside their diagnosis? It is probably unease about these kinds of concerns that accounts for the call, from all sides, for greater collaboration, supported by evidence, to improve treatment decisions. Professionals are being encouraged to work in a cross-disciplinary manner and guidelines for health care organizations increasingly sanction multidisciplinary practice. Now organizations, and nurses themselves, must find ways to make it a reality in everyday work at the bedside.

Within the kind of setting and under the organizational conditions that I have observed, how can nurses make their professional presence felt in more substantial ways? It is a difficult question and my research does not directly supply an answer. My data does clearly display the way in which decisions are made and may well provide a starting point for change by opening dialogue across disciplines. Change will be difficult. For one thing, everyone contributes to sustaining the current processes. It appears to satisfy certain goals of

administrators, organizations, and physicians – by building a solid documentary trail for accountability purposes. Nurses, by not questioning it, themselves contribute to maintenance of the status quo. This having been said, nurses will certainly need to “push the envelope” if any meaningful change is to occur. It may take nurses asking awkward questions, raising these issues at rounds and request multidisciplinary review of treatment decisions to draw everyone’s attention to weaknesses in the current processes. After all, the groundwork has been laid, at least in principle. The CMA/CNA joint document previously referred to in this paper provides an excellent beginning point for the implementation of policies and procedures to solve interdisciplinary conflicts over end of life decisions.

Nurses will also have to draw hospital administrations into the debate about how well ethical standards are being met. Professional responsibility forms are a tool (initiated within the BCNU bargaining process) used to identify practice issues that occur when nurses find themselves unable to meet their standards. In the research hospital, hospital administration has accepted the contractual obligation to address issues raised in these forms within seven days and make recommendations to deal with them. Nurses in the research hospital feel justified and supported in using these forms when faced with equipment and manpower issues that jeopardize their standards. One wonders what the outcome might be if nurse were encouraged to use these forms when they felt unable to practice according to the responsibilities identified in the CNA Code of Ethics.

The research hospital has recently formed a clinical ethics committee. The mandate of the committee is to support clinical ethical decision

making at the bedside. The group has begun its work using a four-point decision making framework to explore dilemmas submitted by the staff. Inherent in the framework is inclusion of nurses' knowing and consideration of all types of information known about the patient. The ultimate mandate of the committee will be to develop the expertise to provide facilitation of multidisciplinary problem solving groups on the wards. Nurses need to lobby for the opportunity to develop this expertise, which would then put them in a leadership role when staff identify the need for multidisciplinary conferences. Imagine how different the dynamics of the conference might look from those described in my research if nurses called the conference, circulated the agenda and then invited the physicians to participate!

Less dramatic, perhaps, is my view that all possible opportunities should be used to engage the people involved in discussion of how end of life decision-making occurs. Currently, the ICU committee at the research hospital has agreed to review the work being done by other institutions in regards to documentation and communication processes around end of life decision making in critical care. This comparative review may help open up our own practices for discussion across disciplines. My own research also offers an opportunity for members of the different professions to see their current practice described. I have displayed my findings about how the professions interact, attempting to replace in my account the social organization of our own practices. This sort of "visibility", set out in words and actions, displaying background routines and requirements, and so on, that people can recognize as their own, may also go some way to help create a climate of inquiry replacing the rancor that now surrounds different approaches.

Perhaps one of these small steps toward increasing dialogue and understanding between disciplines can, over time, empower nurses and increase their inclusion in and/or comfort with end of life decision-making.

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APPENDIX A