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Brief Encounters: End of Life Decision-Making in Critical Care

A thesis submitted by

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ABSTRACT

The health care system has, in many respects, been developed to oppose suffering. Yet health care's almost compulsive urge to treat death as the enemy and to battle disease and injury with all available technology unavoidably results in suffering for someone. This paradox and its impact upon the decision-makers in critical care, has attracted some interest overseas, but none to date in Australia. This study sought to understand the interactions between the key stakeholders in end-of-life decision-making in critical care in the interests of developing strategies to ameliorate the avoidable suffering arising from these processes.

A modification of Denzin's Interpretive Interactionism (Denzin, 1989), was developed to apply the epistemological and ontological principles of the critical paradigm while preserving the advantages of Denzin's design in the investigation of interactions. Semi-structured interviews with relatives, nurses and doctors from a variety of critical care units in South-East Queensland and New South Wales, provided the data that enriches this study. Using the critical lens, analysis focussed on the interactions (and gaps and silences) between the decision-makers at the key moments of decision-making: initiation, maintenance or withdrawal of life-sustaining treatments. A model of 'best practice' with respect to end-of-life decision-making was produced and concrete recommendations made. This project has found that the amelioration of avoidable suffering in the critical care environment related to end-of-life decision-making requires policy and procedural changes at the organisational level.

Certification of Thesis

I certify that the ideas, work, results, analyses, interpretations and conclusions reported in this thesis are entirely my own effort except where otherwise acknowledged. I also certify that the work is original and has not been previously submitted for any other award, except where otherwise acknowledged.

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Signature of candidate Date

Endorsement

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--Signature of Supervisor Date

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His sufferings, growing more and more severe, did their work and prepared him for death ... Hitherto each individual desire aroused by suffering or privation, such as hunger, fatigue, thirst had brought enjoyment when gratified. But now privation and suffering were not followed by relief, and the effort to obtain relief only occasioned fresh suffering. And so all desires were merged into one - the desire to be rid of all this pain and from its source - the body. But he had no words to express this desire for deliverance, and so he did not speak of it, but from force of habit asked for the things that once had given him comfort. 'Turn me over on the other side,' he would say, and immediately after ask to be put back again. 'Give me some beef tea. Take away the beef tea. Talk of something: why are you so silent?' and directly they began to talk he would close his eyes, and would show weariness, indifference and loathing ...
While the priest was reading the prayers, the dying man showed no sign of life. His eyes were closed...When he had come to the end of the prayer, the priest put the cross to the cold forehead, then slowly wrapped it in his stole and, standing in silence for a minute or two, touched the huge bloodless hand that was turning cold.
'He is gone,' said the priest. And made to move away; but suddenly there was a faint stir in the clammy moustaches of the dying man, and from the depths of his chest came the words, sharp and distinct in the stillness:
'Not quite ... soon.'
A moment later the face brightened, a smile appeared under the moustaches, and the women who had gathered round began carefully laying out the corpse.

= The death of Nikolai Levin - from Anna Karenina by Leo Tolstoy (1828-1910) =

1.1 INTRODUCTION

This example, drawn from the turn-of-last-century's literature illustrates a simpler time when death, though still an unwelcome visitor, was accepted when he came. In scenes like the one painted above, the pain of parting was shared by patient, loved ones and priest in a supportive, community atmosphere. No doctor was involved – not even mentioned here. The social world and medicine's involvement in life and death have changed radically since then. The developments in public health and to a lesser extent, science and technology in the latter half of this century have seen decreased mortality and morbidity rates for virtually all the potentially lethal illnesses and injuries likely to afflict mankind (Little, 1995; Callahan, 2000). We act as if we have the ability to thwart death at virtually any juncture with mechanical, chemical or transplant options. The difficulty is that "somebody" (at present read the doctor) has to decide whether and when such options should be used or withheld.

This study is critical research using qualitative methods - it concerns the current practices related to end-of-life decision-making in critical care environments and their effects on all those concerned with the impact of such decisions - i.e. the families, nurses and doctors of, and to a much lesser extent, the critically ill, unconscious patients themselves. The thesis that this dissertation argues is that unnecessary suffering related to end-of-life decision-making in the critical care environment can be minimised through the application of a combination of structural, procedural and educational interventions.

1.2 THE PROBLEM

This study concerns two different yet intimately related phenomena - the genesis and the aftermath of the end-of-life decision. My own struggles to come to a clear definition of the problem under investigation reflect the complexity and inexactitude of the ethical and clinical challenges of end-of-life decision-making and the way in which these are intertwined so that it is difficult to say with certainty that a particular decision is ‘only’ clinical or ‘only ‘ethical’.

It seems to me, as a critical care nurse with over fifteen years’ experience that the shiny coin of the wondrous knowledge and technical capabilities of modern day critical care medicine presents us with a darker obverse. The capabilities of modern medicine allow us to rescue individuals from the brink of death and yet we sometimes bring them back to an existence whose quality is often much less than ideal. Our ability to technically intervene in what would otherwise be fatal situations has far outstripped our moral preparedness to deal with the consequences of these interventions (Cassell, 1982; Holly, 1993; Wright, 2004). Therein lies the problem that this project is concerned with - the uncertainty of end-of-life decision making for all the individuals at the centre of the ethical and emotional maelstrom.

The critical care environment does not normally include the luxury of time to consider the possible ramifications of “urgently needed” treatment when a client’s health crisis presents. What should health professionals do when the choice is between an almost immediate death and initiation of a high technology intervention in the face of uncertainty? My experience as a critical care nurse has led to the belief that most end-of-life decisions (ELDs) are not conceptualised as ethical decisions at the time they are made; they occur under pressure and are regarded as if they were purely clinical decisions by the health professionals involved. The very existence of the ability to intervene in a life-threatening situation seems to impel us as clinicians to use that intervention. These are often highly conflicted choices because at the same time, those of us with experience are aware of the poor prognosis of many such extraordinary treatments. The outcomes for the particular individuals cannot be predicted in the heat of an emergency- thus the life-sustaining treatments are started and it is only later that the wisdom of the intervention can be questioned. Then there is a new dilemma and that is the challenge of deciding clinically and ethically whether and how to stop what has already been started?

How does one measure therapeutic success when the best prognosis for a person following an horrific motor vehicle accident may be a persistent vegetative state? Is an intervention to the patient’s “good” if it prolongs their life yet condemns them to a future characterised by pain or dependence? Usually this cannot be known with certainty. These are the questions health care professionals and relatives of such patients may face in the aftermath of “successful” resuscitation or extraordinary treatment.

The story of J and her family is an example from my own clinical experience, which can serve to introduce some of the complexity that this dissertation seeks to unravel. J, 26 years old, and a relatively new mother of her first child was admitted to the general ICU of the large teaching hospital. She had been knocked off the back of a friend’s motorbike by a car that had not stopped at the lights. She sustained severe head injuries, fractures to her right arm, leg and pelvis. Following successful resuscitation in Emergency, a C/T Scan showed diffuse cerebral oedema, but luckily, no sign of a cerebral bleed. J was sedated, drug paralysed and ventilated for 48 hours to “rest” her head in the hopes that the oedema would settle and J would be OK - that was how it was explained by medical staff to the her husband - B. The time came to wean her sedation and drug-induced "paralysis" in order to assess her cerebral status – level of damage.

J didn't wake up. She did recover brain stem functions, i.e. she could maintain her airway/ breathe/ cough/ gag; but she couldn't respond to B or her new child. This accident and the possible side-effects of the technological treatment had left B with a wife in a persistent vegetative state. It seemed to me that B was left with two children to care for as a result of our "successful resuscitation". Obviously it is unwise to generalise from one example, but this is but one from the countless patients my colleagues and I have cared for and discussed together. Indeed we have all also had pleasant experiences of caring for the patient who, despite all our expectations to the contrary, has progressed to discharge from critical care with excellent quality of life. One such story related to me by a physician, Gordon, illustrates the uncertainty surrounding the issues related to this dissertation.

> *[She was an] elderly woman with a gangrenous leg with history of COAD who was pushed to the side of the unit at a very busy at the time; this was a Friday evening. The decision had been made to let this lady die. The surgical registrar came and appealed to me and based on her faith in the lady - an amputation was performed under an epidural. I elected to care for her up to the point of ventilation. Surprisingly, she did very well and was eventually discharged home - well enough to request to go to her own home, not her daughter's because her daughter was too bossy.*

1.3 THE QUESTION

These patients are usually in a critical care environment with family in constant attendance or close by. At some stage decisions have to be made about the initiation and/ or continuance of care for such patients. It is this situation, its context, and impacts on the individuals involved - the family members, nurses, and doctors - with which this study has been concerned. The investigation has been directed by the question:

> *"How might avoidable suffering related to the process of decision-making that accompanies the implementation, maintenance or withdrawal of life-sustaining treatment in the critical care environment be ameliorated?"*

1.4 BACKGROUND TO THIS STUDY

1.4.1 Historical/ Political Context

Critical care as a speciality area marks its origin in the 1940's with the development of recovery rooms in the United States of America. The coronary care unit, which is more characteristic of the prototypical critical care setting did not evolve, however, until the early 1950's in the USA and the late 1960's in Australia (Thelan, Davie & Urden, 1990; Romanini & Daly, 1994). Importantly, these units and the associated specialities of critical care medicine and nursing developed primarily in response to advances in biotechnology developed by American multi-nationals like Hewlett-Packard (Thelan et al., 1990; Romanini & Daly, 1994). Their difficulties are compounded by the fact that the effectiveness of critical care is largely unproven - the advanced medical technologies upon which critical care is based were not properly evaluated either prior to or following their initial introduction and enthusiastic application (Romanini & Daly, 1994). This is reflected in the media where new technology and its potential benefits are quickly lauded while some time later its side effects and ethical implications are debated. Indeed we still remain unconvinced as many innovations are introduced without evaluation and remain without evidence of their effectiveness in terms of long-term patient outcomes - witness large organ transplantation (Lumby, 1997).

At the same time, the current political climate sees our health professionals struggling more and more under the yoke of calls for "fiscal prudence". Economic concerns guide the decisions made about the care given to patients- for example funding levels limit staffing levels and therefore quality of care; the funds available to a unit limit the number of beds and therefore patients it can take. These and a myriad other considerations challenge the contemporary critical care unit's ability to deliver "... humane, empathic and ethical medicine…" as the health care dollar gradually shrinks (Nadelson, 1993). Once a patient is admitted to a unit, however, there would seem to be no constraints, either ethical, or financial imposed upon those managing the individual patient's care. This dissertation problematises this situation.

1.4.2 Ethical Context

As within other areas of health care, the ethical framework, which guides decision-making in the critical care environment, is the biomedical ethical model. Like their health care colleagues, critical care professionals' preparation for practice has included discussion of the major ethical theories; together with discussion and debate of the issues that arise when one tries to apply and balance the principles of Beneficence and Nonmalificence, Justice and Autonomy (Mappes & DeGrazia, 1996; Braunack-Mayer and colleagues, 2001).

Often, decisions that have a large ethical dimension are not recognised as such as the clinical imperative is focussed upon in critical care. In practice, while ethical dilemmas are being encountered with 'daily' regularity, response to the challenges and issues of critical care to date has generally been piecemeal and ad hoc. In general, ethical dilemmas are dealt with as they arise or more precisely, as they are recognised (Gaul, 1995; Kendrick & Cubbin, 1996). This is both a response to the nature of the work carried out in the critical care environment and a product of the specialist area's historical development. This approach to the ethical implications of critical care continues today where often it appears that the implementation of interventions is based more in our ability to intervene than our moral authority to do so (Pace & McClean, 1996; Moynihan, 1998). Are we expecting too much from the health professionals involved in asking them to recognise both the ethical and clinical dimensions of a patient's problem on presentation? In many critical care scenarios, especially in emergency departments, health care professionals will not have seen the individual ever before. Conversely, in those situations where the health professionals do know the history of the person for who the clinical decision must be made, ethical decision-making requires engaging as a human being. As this study will reveal, this step is fraught with challenges.

While the text-books recognise the ubiquitous nature of the ethical dilemma in critical care, and proffer ethical decision-making frameworks, (Hudak, Gallo & Benz, 1990; Thelan et al., 1990; Romanini & Daly, 1994; Pace & McClean, 1996), this dissertation contends that the environment in its present set-up does not facilitate the considered discussion necessary for these frameworks to "work". Further, I argue that it is relatively rare for ethically laden decisions to be recognised as such. Most clinical decisions have an ethical dimension but these are generally glossed over.

1.4.3 My background

I am a nurse with more than twenty years continuous practice experience. During that time I have worked in a wide variety of health care facilities both in Australia and abroad. I am the daughter of a doctor and a nurse and so I have had a long interest in and association with the health care professions. That my father is a medical specialist has presented me with a double-edged professional sword. On the one hand I grew up realising that doctors were humans with all the virtues and faults that being human entails. On the other hand, my direct and forthright approach, developed as a result of long and comfortable association with my father's colleagues, was not appreciated by many other doctors with whom I worked.

At eighteen, I chose nursing as a profession because I wanted to care for and help people and, trite as it may sound, this has been my objective ever since. For the last eighteen years my studies and practice have been in the area of critical care nursing. Throughout my nursing training at a major level three facility I was occasionally troubled by the effects of medical interventions on patients and my part in them. When I started working in the critical care area my value of "nursing to help people" was significantly challenged because of what I perceived to be the negative outcomes for many of the people, both patients and relatives, I 'cared' for.

My own experience of becoming an expert critical care nurse (CCN) is likely to be reflective of how other non-specialist nurses make the transition to expert CCN; certainly it is reflective of the experiences of my friends and colleagues. It is my own experience that the CCN's professional development encompasses a series of transitions as one moves from novice to expert in the field (Benner, 1984; Benner, Tanner & Chesla , 1996) Novices in the area are first overwhelmed by technology and information as they learn to function safely by following rules and procedures. Then as they develop knowledge and experience in the area, they may be confused by what they perceive to be inappropriate medical interventions. Unsure of this knowledge base, however, they do not question these incongruities. Then, for some critical care nurses, a day arrives when, sure of their knowledge and reasoning, they are disturbed enough by the actual or potential suffering they see to attempt to advocate for their patients.

When I first started as a novice in critical care, I was overwhelmed by the technology, the apparent amazing knowledge level of my colleagues and peers. I rapidly made the transitions outlined above. I became a source of stress for my charge nurse and colleagues as I frequently and vociferously questioned medical treatments which, in my view, caused inappropriate suffering. I was particularly troubled by the extra-ordinary measures taken to prolong life in the face of what appeared to me to be insurmountable odds. It seemed to me that such measures only prolonged individuals' suffering while fostering false hope in families who would naturally grasp at each new minute of life as a sign of potential recovery in their loved ones. My colleagues, it appeared, were not as troubled as I by these situations. These were the same people who appeared to me to be awesomely knowledgeable. This led me to believe that perhaps it was a knowledge deficit on my part that contributed to my perceptions of patient and family suffering.

To address this deficit I undertook post-graduate studies in critical nursing care. The knowledge I gained from this course allowed me to understand my patients' problems and potential interventions more thoroughly. This understanding enhanced the level and quality of nursing care I could provide. It did not change my previous perceptions of patient suffering. Instead, my deeper knowledge of physiological and pathophysiological mechanisms caused me to question rationales for many medical interventions even more. It has always been my practice in all areas of my life to "champion" the cause of what I perceive to be the undefended sufferer. I started this project from the position of angry patient advocate, convinced that I held the moral "high ground". During this study, while my values have not changed my appreciation of and approach to similar situations has matured. This evolution will be discussed later in this dissertation in conclusions and recommendations.

My early formative years left me with the double legacy of a strong personality and a sensitive nature. Thus my early efforts to challenge the irregularities I saw were often confrontational rather than diplomatically assertive. Even when my communication style improved and I learnt to be more gently assertive when advocating for my patients, my failed attempts were frequently unsupported (by nursing colleagues who privately agreed with me). As I gained more experience in critical care nursing and thus assumed more senior positions with broader responsibilities I continued to attempt to advocate for patients. While many of these attempts were successful, more of them were thwarted - by both medical and nursing colleagues alike. Gradually it became clear to me that I could not effect the changes I sought as an individual practitioner within the present culture of nursing and health care. I therefore sought to address the problems I saw through research, theorising and raising consciousness through speaking and publication.

1.4.3.1 My Research Work to Date

"We don't have ethical dilemmas - we just have disagreements with the doctors."

The above quote comes from the introductory chapter of a study I completed in 1997. Then, I was investigating the responses of critical care nurses to suffering perceived to be the result of inadequate or inappropriate medical intervention. The "Uppity Nurses" project (Huard, 1997) theorised a link between repeated experiences of unsuccessful advocacy and suffering and burnout in the nurse. The findings from this study are reflected in the following excerpt from the abstract of that study:

> *The study has found that nurses suffer when they are not supported by a policy framework and their communication strategies are ineffective in the face of medical intransigence. Power differentials between health professionals and inadequate organisational support contribute to dysfunctional communication patterns within the critical care environment. Our attempts at communication tend to happen in inappropriate settings and under pressure of time with both parties feeling threatened and defensive. Moreover, seriously challenging medical decision-making invariably incurs retribution from colleagues, both medical and nursing. This responsibility without autonomy leads to an adversarial rather than*

> *collaborative relationships between health professionals, increased levels of stress in the critical care environment, and the loss of expert nurses through burnout. Ultimately, the loss of expert nurses threatens the quality of care offered to our critically ill patients.*

A limitation of the study was its examination of moral dilemmas from the perspectives of the nurses only which leaves out the perspectives of other central individuals i.e. medical officers and relatives.

Generally, critical care nurses receive no special training on the historical or political background of their speciality's development. While they may be versed in the principles of the ethical decision-making framework, generally they have no specialised training in ethical decision-making, especially decision-making under pressure (Corley & Selig, 1994). It became clear in my previous research that the nurses' focus tended to be on the immediacy of the situation for their patients. Generally, they were unaware of, or ignored the historical and cultural context of the situations in which they were working. The reasons for this lie in their own biographical histories and socio-cultural backgrounds. Like me, the reasons for the immediacy of their focus also lay in their very limited experiences of seeing patients who seemed "hopeless" recover. This is because specialist critical care nurses, in general, tend not to have the opportunity to follow up on the progress of those patients who do leave the unit for rehabilitation. A percentage of those patients we see leaving who initially seem to be very disabled subsequently do recover very well (Davis, 1996; Ferreira, Daliana, Bross, Melot, Vincent & Bota, 2001). Perhaps it is because these patients have left the unit and nurses don't hear of them again that they tend to imagine a "worst case scenario" when some one with similar clinical problems presents in critical care.

I came to believe that the examination of the problem from one perspective only could not fully elucidate the issues surrounding the management (or the lack of management) of the ethical challenges of critical care. A deep understanding of these issues and their impact can only be gained through investigation from the viewpoints of all the major players i.e. the doctors, the nurses and the family members. It is my intention to build on the knowledge gained in my earlier project by seeking the perspectives of those swept into the eye of the storm of end-of-life decision making.

1.5 AIM OF THE STUDY

This is critical research using qualitative methods. The primary aim of this project is the development of strategies which will facilitate the amelioration of avoidable suffering in the critical care environment when decision-making is required regarding the implementation, maintenance or withdrawal of life-sustaining treatment.

1.6 FOCUS OF THE STUDY

This study focuses around those hours or moments when an acutely ill individual's prognosis is so precarious that decisions must be made regarding the initiation, withholding or withdrawal of life-sustaining treatments. Such treatments might include chemical, mechanical and/ or transplant interventions or a combination of any of these. ELD's have been specifically selected as the focus of this project as it is my experience that the issues surrounding the ethical challenges associated with the critical care environment are crystallised in these situations. It is important at this juncture to distinguish ELD's from euthanasia. Invariably when I have been asked about my research topic, health professionals and lay friends alike assume I am delving into euthanasia. I feel there is a place for "the good death" and that well managed palliative care potentially fills it. I only wish it was universally available to people in need. This study and dissertation seeks a deeper understanding of the perspectives of those caught up at the centre of critical care ELD-making. It does not seek to investigate euthanasia. I am aware of the debate in the media and the literature related to this subject at present (Waddell, Clarnette, Smith, Oldham & Kellhear, 1996; Davies, 1997; Cartwright, 2000). The most striking differences between these two phenomena are in the areas of acuity and medical intent. ELDs generally centre on strikingly acute scenarios while consideration and requests for euthanasia attach themselves most often to the insidious disease states. I am aware that there are some doctors and some nurses who do provide the means to grant these requests. This, however, is not the focus or area of interest for this study.

1.7 SIGNIFICANCE

This investigation will be concerned with examining ELD-making processes from the perspective of the relatives, nurses, and medical officers of critically ill patients. The contemporary literature is rife with allusion to the inexactitude and complexity of these emotive, ethical challenges. This project seeks a deeper understanding of the impact of the issues surrounding end-of-life decisions so that strategies might be proposed and shaped to improve the manner in which these challenges are managed in critical care environments. Ultimately, these changes should lead to the amelioration of the avoidable suffering associated with end of life decision-making for:

1.7.1 Families of the critically ill:

The public media and nursing literature both provide examples of the strain placed on families maintaining vigils at a loved one's bedside, or outside in the waiting room (Benner, 1993; O'Brien, 1998). There is little contemporary literature, however, related to the families of critically ill unconscious patients and/ or their perspectives on the issues surrounding ELD's. It is my experience that the family of the critically ill individual often becomes peripheral to the concerns of the health care team as they focus on the immediate physical and technological needs of their patient. Nursing and medical education today advocate the inclusion of the family in their patient's care (Wright, 1993; Foley-Pierce, 1999). The "pragmatics" of critical care and the aftermath of end-of-life decisions, however, mean that patients' families do indeed maintain the lonely vigils referred to in the literature (Benner, 1993; O'Brien, 1998). This project seeks to develop an understanding of the families' perspective on the issues and challenges related to ELD-making so that specific organisational strategies may be developed to ameliorate the avoidable suffering associated with those factors and structures contextual to the family members' experiences of ELD-making.

1.7.2 The critically ill patient:

A deeper understanding of the issues related to ELDs will not directly impact the critically ill unconscious patient who is usually, by virtue of their defining condition, incapable of input into this decision. It should, however, lead to strategies that empower the patient's carers and family to advocate and provide for his/ her best possible outcome and optimum clinical care. Thus this study will have significance for all potentially critically ill patients and the community at large. For example, my own reading for this project has lead to consciousness-raising in the area of advance directives and living wills. This information has been shared formally with the community at our University's Open Days and informally with colleagues and friends.

1.7.3 The nurses:

Critical care nurses experience ethical challenges and dilemmas as occurring on a recurrent basis and these experiences are thought to be contributing to the stress of the critical care environment and burnout of experienced nurses (Wellard, 1992; Holly, 1993; Huard, 1997; Sundin-Huard & Fahy, 1999). Nurses' moral distress is a factor which has previously been linked to burnout (Kendrick & Cubbin, 1996). Burnout is linked to the national shortage of critical care nurses (Norrie, 1995; Smith, 1995; McLean, 1997). The average survival time of a specialist nurse in the critical care environment is not easy to accurately estimate because of the many variables associated with the part-time nature and portability of the profession. Smith (1995) estimated it to be less than two years in a particularly poignant discussion of the challenges of these specialist nurses' lot. The costs incurred in the training of specialist nurses in this area range from $10,000 to $24,000 per nurse (C.A.C.C.N. Queensland branch). Thus loss of these nurses and their expertise through burnout results in a heavy drain on the financial and expertise coffers of the health system. The previously mentioned "Uppity Nurses" study illuminated the struggles nurses are having with this issue today. Links between repeated experiences of unsuccessful advocacy, the resultant moral distress and burnout were identified (Sundin-Huard & Fahy, 1999).

Building on the foundations of the "Uppity Nurses" project, this study will provide insight into the perspectives of all the stakeholders in ELD's. It is the absence of such insight which contemporary literature suggests is responsible for the frustration and distress many nurses experience in these situations; (Spence Laschinger, Sabiston & Kutszcher , 1997; Manias, 1998; Rieth, 1999). This understanding will then lend itself to the development of strategies, which will improve the manner in which ELDs are managed. The development of organisational strategies, which enhance the participation, and experience of the critical care nurse should, in turn, reduce the level of burnout and the loss of specialist nurses which plagues critical care at present.

1.7.4 The medical officers:

The medical officer in critical care, it seems, can also be troubled and frustrated by the challenges of the critical care environment. The medical officer is stereotypically perceived as being knowledgeable, decisive and strong - the arbiter of all crucial and critical judgements (Pike & Corrigan Wandel, 1991; Robotham, 1999; Wicks, 1999). There is, however, extensive evidence that medical practitioners struggle with the concept of human suffering, and the challenges our increasing ability to extend life places upon them (Cassell, 1982 & 1991; Boyle, 1996; Lynch & Edwards, 1998; Permut, 1998). This literature indicates that, in some areas, medicine is struggling with the issues surrounding and influencing the ELD's - assessment of quality of life (Cassell, 1991); living wills and the inclusion of third parties (next of kin) in these decisions (Boyle, 1996; Lynch & Edwards, 1998; (Permut, 1998). Discussions about quality of life, its measurement, and the related decisions, reflect the weight of responsibility carried by medical officers involved in ELDs (Cassell, 1991; Grubb, Walsh, Lambe, Murrells & Robinson, 1996). The literature also suggests most medical officers perceive this responsibility to be 'rightfully' theirs alone (Grubb et al, 1996; Chen, 1997). The impact of this load is profound, with links made in the literature to loss of experienced medical officers through burnout, stress-related ill-health and suicide (Fallowfield, 1990; Chen, 1997).

Again, a deeper understanding of the issues from the doctors' perspective should suggest areas for change and improvement in the way that ELDs are managed. The development of these strategies will lead to medical officers feeling less alone and more supported in the complex challenges they face in critical care. Thus the loss of experienced medical officers through burnout and stress-related illness could be reduced. The retention of expert, experienced doctors will lead, in turn, to optimum clinical care in the critical care environment.

1.7.5 The health care system:

The strain placed on the health care system by the loss of expert staff through burnout threatens both its financial resources and its ability to deliver quality health care. The current relevant Federal Senate discussion paper: "*The Patient Profession: Time for action*" (2002-4) has focused the attention of government and major nursing bodies on the developing nursing shortage and the potential impact on quality patient care. This report recognises severe shortages in all critical care specialties in all states as a major cause for concern. The understanding generated by this project of the issues causing this distress should provoke the development of policies and procedures designed to support health care teams confronting the challenges of ELDs. The resultant reduction in stress upon the health care team should then reduce the incidence of burnout.

This is a project with potential significance for all stakeholders and the health care system as a whole. The development of a deeper understanding of the issues and interactions surrounding ELDs as they impact upon the key stakeholders represents a crystallised representation of the impact of the challenges of critical care. The lessons learned from this project may be able to be applied in other challenging aspects of critical care as well as other areas of health care where health professionals, patients and relatives caught up within the crisis of decision-making. An understanding of how they all react to one another and the crisis may allow us to help others ride out similar storms with a little more ease.

1.8 THE METHODOLOGICAL CHALLENGE:

How does one investigate what happens in a critical care unit when decisions must be made regarding the initiation, maintenance or withdrawal of life-sustaining therapies? In an "ideal world" the researcher investigating this problem would randomly choose one case study in one critical care unit and study the phenomenon from the perspective of the all the individuals involved. One would have access to all the relatives, all the nurses and all the doctors involved in and affected by the issues that arose in relation to decision-making regarding the critically ill patient. Thus, the researcher could compare and contrast the varying perspectives of all the individuals at crucial moments in the trajectory of the patient's care. To augment their own observations, the researcher would also have access to the case notes, and the results of all clinical investigations to facilitate full understanding of all explanations given by and to all parties.

This approach of course, is fraught with ethical and logistical minefields. For such an approach to be successful, the researcher would have to:

a. Obtain ethical clearance from the health care facility, which given the sensitive and political nature of the topic is not likely to be given.
b. Meet with the medical and nursing directors of the unit in which he or she wishes to conduct said research project, ensure their understanding of, and effectively obtain the permission of these two individuals.
c. Meet with the health care professionals working in the unit in; explain the project, its aims and obtain their cooperation.

Even were this entire framework to be put in place, this methodology requires the researcher to approach family members who are already stressed by the anguish of having a loved one so ill that they require life-sustaining treatment and/or the need to make decisions about continued use of that treatment. Any form of suggestion that they might like to participate in research about their particular experience would be entirely inappropriate at that juncture no matter how significant its contribution to the experience of others in the future.

Ethically, it is unlikely that this sort of project just would receive support. Any health care institution approached by a researcher proposing such a project would naturally raise issues of privacy and confidentiality. Development of pseudonyms and the obscuring of distinguishing features of particular cases can normally ensure the anonymity of participants in any project encompassing a number of different cases. If however, the researcher focuses on a single case study, the maintenance of anonymity and therefore privacy and confidentiality, while possible, becomes difficult. If the researcher is privy to all the salient facts of the case, health care institutions and ethics committees would require clear and 'unshakable' guidelines detailing how the researcher intends to maintain the anonymity and confidentiality of all parties concerned. As I shall reveal as this project unfolds, one can never anticipate and plan for all possible eventualities in a project with the dimensions and context of this one. Thus as a researcher, one could never give "ironclad" guarantees of anonymity. One could promise to place identifying data in a separate volume if it was needed for examination purposes - but in this case - this might turn out to be the entire case study and therefore useless with respect to maintaining confidentiality. Furthermore, the suggestion that my project might involve discussions with relatives regarding their understanding and/or opinions of explanations given to them during these challenging times might not be a concept that the health professionals concerned would welcome. Understandably, the medical staff in particular would not welcome the involvement of a participant observer who, in their eyes, complicated the situation further, asking questions during treatment.

Thus, while a single case study would have been the "ideal" strategy with which to investigate this problem, I have been obliged to develop alternative methods. Accordingly, in this project I have sought to speak to several cohorts of respondents about their experiences related to the same sorts of issues surrounding differing case studies.

1.9 PERSONAL VALUES

Throughout this dissertation I have worked to be mindful of the impact of my own values and experiences upon the product. Examination of the problems and issues this dissertation has undertaken can not be explored with an objective focus. I have endeavoured to present a balanced portrayal of the perspectives of the problem under investigation here as seen through the lens of experience of the participants. By the same token, subjectivity in the scientist is not necessarily bias. The investigator who acknowledges that all data is filtered through the lens of perspective and experience and then takes this into account is in closer touch with reality than the scientist who imagines that ignoring feeling and values is the same as excluding them (Alderson, 1990; McHaffie, 1996; Denzin & Lincoln 2000). Description and discussion of the background to this study has already revealed much about my personal and professional values. As these profoundly influenced my career and the eventual focus of my study, it is important that they be elucidated here.

Professionally I am committed to the delivery of safe, sensitive and nurturing health care. This commitment includes the promotion of quality of life for my patients. It is my belief that a person's quality of life is influenced by the extent to which she/he is able to comfortably participate in and have control over her/his life and important related decisions. For any individual, once any of these factors are threatened or impaired to any degree, then I believe that person's quality of life is correspondingly diminished. Responsibility for patient care, I believe, includes the discussion and questioning of medical orders and decisions, which concern or puzzle the nurse. Thus I feel it falls within my duty of care to advocate for my patients, particularly when a patient's quality of life is actually or potentially threatened by inadequate or inappropriate medical interventions.

I have always found it distressing to witness the suffering of any being. To witness suffering of an individual and be restrained by any means from interceding or assisting causes me physical discomfort - to the point of pain in extreme situations. This pain can best be described as a twisting tightness within my chest that leaves me breathless as I try to explain my concerns and feelings. This is consistent with the descriptions in contemporary literature of sensations brought about by stress (Wright, 1993; Ray, 1994).

The values that have guided my practice, initially as a nurse and lately as a researcher have been strongly influenced by Watson's value system (Watson & Ray, 1988) and include valuing:

1. the individual's right to dignity and self-determination
2. the promotion of holistic health or wellness (health in mind, body and spirit)
3. caring yet responsible human relationships (including the relationship between the researcher and the informant)

4. the internal subjective world (of both the researcher and the participant) as a way of understanding and knowing.
5. reciprocity (which balances the power in relationships and facilitates intimacy).

1.10 OUTLINE OF DISSERTATION

This chapter has introduced the reader to the researcher and explained the origins and background of the project. I have moved from my own experiences in critical care nursing to themes raised by both contemporary literature and the media to outline the study's thesis, aims and significance. The following chapter will review contemporary related research literature and then chapters three and four will review the contemporary literature as it pertains to the theoretical underpinnings of this dissertation. In chapter five, I will introduce and discuss the epistemology, ontology and methodology that under pins this study together with the research design developed to guide this project. Chapters six, seven and eight will present the analysis of the data from each group of participants. In these chapters, stories will appear as narrative vignettes. Within these, concurrent analysis of the intrapersonal processes and related potential suffering will be presented. The participants' full narratives will appear in Appendix one. Finally, chapter nine will discuss the findings of this dissertation, presenting models of the decision-making process from each group's perspective and a 'paradigm' example of ELD making in which avoidable suffering might be reduced to a minimum. In this chapter I will acknowledge limitations and make recommendations for practice, education and research. Chapter nine is followed by a reference list of all sources cited in-text and eight appendices.

Chapter Two: Review of the Related Research Literature

In this chapter I will be discussing those aspects of contemporary research with a direct bearing upon my area of research interest: End-of-life decision-making (ELD) in the critical care environment. There is a paucity of nursing research relevant to the critical care area at this stage and the majority of this tends to draw upon earlier medical literature. At the same time, most of the literature in this area still emanates from the United States. For this review relevant studies have been organised according to title of study and year of publication. The areas of interest for these studies fall into three main categories:

1. Decision-making related to the initial intervention;
2. Decision-making related to prognosis and ongoing treatment;
3. Decision-making related to the withdrawal or withholding of treatment

This chapter will review and summarise the related literature and critique the research of direct relevance to the research question:

> "How might avoidable suffering related to the process of decision-making that accompanies the implementation, maintenance or withdrawal of life-sustaining treatment in the critical care environment be ameliorated?"

2.1 DECISION-MAKING RELATED TO THE INITIAL INTERVENTION

> "Avoidance of unwanted and inappropriate treatment in ICU necessitates early communication about life-support preferences" (Cook et al, 2001).

Contemporary research investigating ELD's related to the initial intervention has tended to have two major but closely related foci. With the rise of consumerism and the recognition of patient autonomy, there has been increasing interest in advance care planning and the impact of the advance directive as a decision-making tool in this context, both for the patient and the health professional (The SUPPORT Principal Investigators, 1995; Cook, Guyatt, Rocker, Sjokvist, Weaver, Dodek et al, 2001; Gilbert, Counsell, Guin, ONeill & Briggs, 2001; Rutledge, Bookbinder, Donaldson & Pravikoff, 2001; Tilden, Tolle, Nelson & Fields, 2001; Taylor, Ugoni, Cameron & McNeil, 2003; Thompson, Barbour & Schwartz, 2003). Decision-making related to the initiation of CPR (cardio-pulmonary resuscitation) and the contrary but closely related DNR (do-not-resuscitate) decisions have also attracted close interest in the last decade (Eliasson, Howard, Torrington, Dillard & Phillips, 1997; Kerridge, Pearson, Rolfe & Lowe, 1998); Thibault-Prevost, Jensen, & Hodgins, 2000).

Very few of these studies apply directly to the critical care setting. Studies examining advance directives tend to be related to end-of-life care planning and so many of these have been conducted in palliative care venues; these have not been included here. Decisions related to initiation of cardio-pulmonary resuscitation (CPR) are generally made by medical officers in acute care settings and so this is where the relevant studies have been conducted. This review focuses on studies conducted in critical care venues but also includes several studies conducted in acute care settings where they illustrate the relevant points.

2.1.1 Advance Directives

Advance directives are supported by legislation in most Australian states and territories apart from New South Wales, Tasmania and Western Australia although these states have *Dying with Dignity* guidelines which direct respect for previous wishes (Biegler, Stewart, Savulescu & Skene, 2000; Cartwright, 2000) In the absence of an explicit advance directive, the "default" implicit directive is to perform cardiopulmonary resuscitation (Cook et al. 2001).

When a patient and their family first enter the critical care environment, clinical/ ethical decisions immediately start to be made. Some argue that the burden of this decision-making would be eased by the presence of a clearly elucidated advance directive. It is argued that the presence of such a document would:

a. clarify that the patient's wishes
b. ease the burden of decision-making for the family members
c. ease the burden of responsibility for medical officers involved

(Cartwright, 2000; Cook et al., 2001; Tilden et al., 2001; Taylor et al., 2003).

The subject of end-of-life care planning, and related issues of patient autonomy and communication between health care professionals and patients has received a great deal of attention in the United States in the last decade. The Patient Self Determination Act of 1991 which requires that all health care workers honour the wishes of the patient expressed in advance directives also requires that patients be informed of this right on admission to hospital and be empowered to make out an advance directive (Gilbert et al., 2001). Not withstanding this, research to date illustrates that knowledge of the advance directive is not well disseminated in the public arena or between health professionals. Nor, as research indicates, is patient's preference necessarily taken into account when health professionals make end-of-life-decisions. These points were clearly illustrated in the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (The SUPPORT Principal Investigators, 1995), the largest study to investigate dying in hospitals in the US (to be discussed later under point 2.2:decision-making R/T prognosis and ongoing treatment). Since 1995 and the findings of SUPPORT there has been a burgeoning discussion in the literature about the necessity and possible benefits of advance directives as care planning and decision-making tools. There is still however, little evidence in the existing research to suggest that clinicians are finding these tools useful or necessarily clear in their directions.

Determining the Relationship Between End-of-Life Decisions Expressed in Advance Directives and Resuscitation Efforts During Cardiopulmonary Resuscitation (Gilbert et al, 2001)

In this study, Gilbert et al (2001) aimed to determine the application and usefulness of the advance directive as a tool for the health professional making end-of-life decisions involving CPR. They used a retrospective review of the clinical notes of 135 patients who had undergone CPR in the previous year. Of these, only 35 had documented advance directives. Gilbert et al. (2001) classified 13 of these as 'independently directive' or clear in their meaning and therefore of some use to the decision-making health professionals. Of the remainder, however 8 were classified as 'vague and requiring further clarification' and a further 8 were classified as 'non-directive'. A directive that was "…judged to be nondirective and not at all useful …" asked for "…no life prolonging treatments" (p.89). While the study found that advance directives, when well thought out and clearly expressed, could be an aid in decision-making this was not happening in practice.

The authors discussed the many issues impeding the efficient application of the advance care directive in the US, finding that they lie broadly in the areas of

- Pressure of time in clinical decision-making;
- Lingering gaps in the education of the public;
- Communication difficulties for patients, medical officers & relatives R/T issues around dying

A retrospective audit of medical records is a poor design if the stated aim was to "…determine how useful patients' advance care directives were to members of the health care team in determining treatment and end-of-life decisions among patients who received cardiopulmonary resuscitation (CPR) effort (p87)." This would have required interviews and/ or observation of individuals involved in the decisions to capture actual experiences of the events or reflections on decisions. Significantly though, Gilbert et al. (2001) remark that there was no clear evidence in the charts they reviewed that advance directives were considered as decisions were made. This is an indication that reflects little improvement on the findings of the SUPPORT study (1995) and is supported by the findings of an international study of the prevalence, and development of cardiopulmonary resuscitation directives and their impact upon treatment in Intensive care Units (Cook et al., 2001).

Cardiopulmonary resuscitation directives on admission to Intensive care unit: an international observational study Cook et al (2001)

Cook et al. (2001) conducted a quantitative study involving 15 university-affiliated intensive care units (ICU) in Canada, the USA, Australia and Sweden. Their aim was to "…ascertain the prevalence, predictors, and procurement patterns of cardiopulmonary resuscitation directives within 24 hours of admission to an intensive care unit (ICU)) (p.1941)". The authors noted a 'strikingly' reduced pattern of explicit resuscitation directives written in Sweden and Australia compared to Canada or the USA though no hypothesis was offered to explain this cultural difference. Explicit 'not for resuscitation directives' were most consistently written for older patients in all categories researched (worryingly, this predictor included patients 50 and older).

The study enrolled 2916 patients consecutively admitted to closed ICUs in university-affiliated teaching hospitals, among whom 44% were unable to participate in decision-making during the first 24 hours in the ICU. Only 11% of patients across the study sites had an explicit resuscitation directive during this period; almost half of these directives were established by patients, who were more likely than the attending physician to establish directives to resuscitate than not to resuscitate. Among patients with explicit directives, the directive was do-not-resuscitate for 50%. Substantial variation was observed among countries, cities within countries, and individual centres within cities

The authors of this study indicate that the type of resuscitation directives written for ICU patients was strongly influenced by culture, the age of the patient, and by their time of admission to the unit. They also theorised that time of admission to ICU was a strong influence on the type of directive written as patients admitted after hours would have been seen or reviewed by the ICU residents whose tendency was more towards writing full resuscitation directives than ICU physicians. Cook et al. (2001) felt that this tendency to select differing levels of care for the same ICU patients on the part of physician and resident was a reflection of two major factors. The ICU resident, like the nurse, develops a close professional relationship with the patient and their relatives due to their ‘round the clock’ presence in the intensive care environment. ICU physicians are likely to treat older and more seriously ill patients, as was indeed the case in this study, and are therefore more likely to establish not-for resuscitation directives. Most significantly this study found that resuscitation directives were not influenced by patient preference in the main; that “…for most critically ill patients, preferences about resuscitation are not recorded within 24 hours of admission to ICU” (p1994).

While this was a rigorous and comprehensive study, being logico-empirical in design, it was also distanced from the context and experiences of the decision-makers. Inclusion of interviews and/ or observation of the decision-makers at some of the sites used in the study would have produced personal and contextual insight to the authors' recommendations for the development of 'culturally appropriate' and 'locally adapted' guidelines.

Research related to the issues surrounding the use of advance directives in the planning of care and decision-making at the end of life have focussed on the their value or usefulness in the decision-making context, acceptance and uptake by the general public and on their consideration or application in the clinical setting. One project examined the links between advance directives and stress for family members when making decisions at the end-of-life:

Decision-Making to Withdraw Life-Sustaining Treatments from Hospitalised Patients (Tilden et al., 1999)

As the members of this research team acknowledge, the decision to withdraw life-saving treatment from a patient can be fraught with stress for all concerned (Tilden, Tolle, Nelson, Thompson & Eggman, 1999; Prendergast & Puntillo, 2002; Way, Back & Curtis , 2002). These levels of stress have not been measured as yet, however. Tilden et al (2001) were interested in:

- assessing levels of family stress associated with decisions to withdraw life-sustaining treatments;
- assessing factors that affected that stress, and
- comparing families and clinicians on their reasoning about the decisions made.

Psychometric measures used during data gathering – the Horowitz Impact of Events Scale (Horowitz, Wilner & Alvarez, 1979) and the mental/emotional state scale of the Rand 36-item Health Survey (Ware & Sherbourne, 1992) – were clearly described by the authors and demonstrated to measure the concepts of interest.

Information was sourced from hospital decedent charts, family members of the deceased, and clinicians who cared for these people. The research for this project was carried out at four urban tertiary hospitals (>350 beds) in Portland, Oregon, USA. Data were collected from families in individual interviews, shortly after decedent death and 6 months later, using the psychometric measures discussed and semi-structured interviews. Clinicians were interviewed once shortly following patient death (Tilden et al, 2001). The researchers indicate that ethical approval was obtained from the relevant health care institutions prior to data collection.

The study sample included 51 decedent individuals, 74 family members (more than one member of some families were interested in participation) and 45 clinicians. Tilden et al (2001) found that family stress associated with the withdrawal decision was high immediately following the death of the decedent and, while it decreased over time, stress remained high six months later. Most notably, stress was highest in the absence of patient advance directives. In reaching their decisions, both families and clinicians prioritised what they thought patients would want, although families, more strongly than clinicians, endorsed doing everything medically possible to prolong the patient's life. Perhaps the most significant contribution this rigorous work was the link demonstrated between the absence of advance directives and elevated levels of stress for the family member.

As in the rest of the world, the pressures of an aging Australian population and improving health care suggest that advanced care planning and the acceptance of and ownership of advance directives (AD’s) are of increasing importance. One recent Victorian study (Taylor et al, 2003) set out to examine the ‘ownership’ rates of advance directives amongst patients admitted to one particular emergency department of a large metropolitan hospital:

Advance directives and emergency department patients: ownership rates and perceptions of use Taylor et al (2003).

In this study, Taylor et al (2003) sought to determine patient knowledge, perception and ownership rates of advance directives (AD’s) for patients admitted to the emergency department of one particular hospital. They also aimed to ‘…determine the factors that impact upon these variables’ (p.586). The main outcome measures used in the study were (i) prior discussion about the extent of medical treatment and AD’s, (ii) knowledge and perceptions of AD’s, (iii) present AD ownership rates and (iv) likelihood of future AD ownership. The authors state that “generalized linear models" were used for analysis though this statement was not expanded upon for the uninitiated, limiting the study's clarity applicability (Taylor et al 2003).

These researchers addressed their goals using a cross-sectional survey of 403 emergency department patients. The mean age of patients was 73 years and 239 (59.3%) were male. Two hundred and forty patients (59.6%) had discussed the extent of treatment. Only 81 patients (20.1%) had discussed the use of an AD. One hundred and thirty-seven patients (34.0%) knew of one type of AD and 333 patients (82.6%) thought some sort of AD were a good idea. Only 32 patients (7.9%) owned an AD, although 276 (68.5%) would consider owning one. The main reason for never obtaining an AD was 'always wanting full treatment' (93 patients, 23.1%) – it would seem that some patients did not clearly understand the significance of the AD as a 'care planning' tool rather than an 'intervention proscription' tool. Level of education was the characteristic that impacted most significantly upon an outcome measure. Patients with a higher level of education were more likely to have known and spoken about AD's, to own an AD and to consider owning one. Ethnic origin was a significant factor impacting upon ownership of an AD with individuals of Greek or Italian background significantly less likely to have talked about or have considered owning an advance directive. These results led Taylor et al (2003) to conclude that AD knowledge and ownership rates were low. However, most patients perceived them favourably and many would consider owning one.

Taylor et al. (2003) provides useful information to the health practitioner with respect to ownership of AD's and measures that need to be put in place to enhance this in the current health context. As a quantitative study though, it is limited in its ability to achieve its stated aim with respect to perceptions of patients about AD's and the factors impinging upon ownership. Multivariate and Univariate analysis of statistical data provided beginning analysis of probable factors affecting ownership rates: age, ethnicity, and extent of illness. Understanding of these issues would have been enhanced with qualitative data obtained from the same participants who had completed the questionnaires. The study is also limited in that it was conducted at one site only. Data from this study is thus not truly reflective of the health care system as a whole and cannot therefore be generalised.

As the review of this literature has indicated one of the major concerns associated with advance directives appears to be related to their actual use or application in practice:

Adherence to advance directives in critical care decision-making; vignette study Thompson et al (2003)

Thompson et al (2003) attempted to gauge the impact of advance directives upon decision-making in a recent Scottish study. By title and aim, this qualitative study purportedly strove to '…explore health professionals' decision making in a critical care scenario when there is an advance directive' (p.1011). Perusal of the study methods revealed that the researchers had in fact examined these issues in a palliative care rather than critical care setting. A brief examination of this study is warranted here in light of the insight given into the influence of advance directives upon decisions made by health professionals. Thompson et al (2003) presented a hypothetical vignette involving an advanced directive to health professionals and explored the responses of general practitioners, hospital specialists, and nurses through interviews. The views of general practitioners, geriatricians (consultants and specialist registrars), hospital nurses, and hospice nurses were then explored through six focus groups. The hypothetical vignette used centred around the case of a 78 year old lady with progressing dementia who had drafted a living will when lucid dictating that she did not want any form of life-saving treatment in the event of her losing her mental faculties and needing such treatment. The lady in the vignette developed pneumonia & 'requiring' antibiotics. When presented with this scenario health professionals raised a variety of issues for debate and came to divergent conclusions as to the most appropriate course of action. Arguments opposing treatment tended to focus on the supremacy of the patient's autonomy in this instance. Arguments for treatment cited the impact of this chest infection on her hitherto good quality of life, the non-onerous nature of antibiotic treatment, questions around the 'currency' of her directive, and their obligation to treat a 'treatable' condition. The study report offers quotes from health professional illustrating how arguments from both perspectives are 'rationalised'.

This study offers the insight that advance directives are open to widely varying interpretation. Thompson et al (2003) suggest that some of this variability is related to the ambiguity of the directive's terminology (not included in full in the report) and that some of this is related to the willingness of health professionals to make subjective value judgments concerning quality of life. The value of the insight offered by this study is reduced however, in that it was based around a 'hypothetical' case. The use of a hypothetical vignette and its associated dilemma divorces the participants from the reality and context of a situation, which has a profound impact on a person's action in any given situation.

In summary, research to date would seem to indicate that while most health professionals and patients view advance care planning and the advance directive as an admirable tool and aspiration in the optimum care of the acutely or critically ill, this is not happening in practice for the reasons outlined by Gilbert et al in 2001:

1. Pressure of time in clinical decision-making;
2. Lingering gaps in the education of the public;
3. Communication difficulties for patients, medical officers & relatives R/T issues around dying

These issues have been addressed with limited success in those states of Australia, which have legislated in favour of advance care planning. Here in Queensland, for example, passage of the *Powers of Attorney Act* in 1998 has seen progress in the form of recognition of advance directives as well as enduring power of attorney for personal/ health matters (Cartwright, 2000). Since 1998, as a result of community debate and health professional input, a comprehensive but clear advance directive form has been developed to facilitate discussion, planning and documentation of planned advanced care by members of the public and their general practitioners. The associated legislation also covers protocols related to communication and storage of the document to ensure that the information in the directive reaches the appropriate health professional when necessary. For example, when an individual initially completes an advance directive, that person should discuss their wishes and related issues with their General Practitioner and the directive should be stored with their medical records (Biegler et al., 2000; Cartwright, 2000). The forms for advance directives (and living wills) and related information is freely available within Queensland at newsagents, post offices and from the Web. Active education about advance care planning tends not to occur however unless an individual is associated with the health care system in some capacity.

Under the current Australian and US legislation , treatment of a patient against their wishes as expressed in a directive constitutes battery (Permut, 1998; Biegler et al., 2000). The challenge remains though: the treating medical officer is also required to ensure that the advance directive is current and no suggestion is given as to how a directive might be obtained and its currency ascertained promptly when time-critical decisions must be made about a person's life (Biegler et al., 2000).

2.1.2 CPR and DNR decisions

One of the key aspects of advanced planning that must be covered in advance directives invariably relate to cardiopulmonary resuscitation. Cardio-pulmonary resuscitation has now been used in health care institutions for about four decades. Early studies of the effectiveness of this intervention (using highly selected samples) demonstrated its effectiveness and implementation of CPR soon became the routine for all patients who died in hospital (Robertson, 1993; Kerridge et al., 1998; Cook et al., 2001). Accumulating experience and evidence has demonstrated however that many patients do not 'ultimately' benefit from CPR- this is particularly so in the case of patients with chronic disease (Kerridge et al., 1998; Ryan, 1998).

Health care institutions and health professionals have responded with the development of not-for-resuscitation orders: 'DNR's. These decisions were originally made unilaterally by the medical officers responsible for the particular patient. Improved public education and increasing medical consumerism appear to have been the driving factors in changing attitudes to the patient-doctor relationship in recent years. Recognition of patient autonomy in the area of decisions about one's own heath and especially in the matter of the end of one's own life have been the catalyst for the development of advance directives and related legislation (Kerridge et al., 1998; Cartwright, 2000). If patients are to have some input into decision-making regarding their end-of life care, knowledge of patients' perceptions and attitudes to these decisions and related issues would be of use to guide care planning, communication and decision-making. At the time of the study reported below (Kerridge et al, 1998), no Australian studies had examined patient preferences with respect to CPR decisions. A search of CINAHL and Medline indicates this remains the only study of its kind today.

Cardiopulmonary resuscitation directives on admission to Intensive care unit: an international observational study Eliasson et al (1997)

Eliasson et al (1997) sought to address issues of disagreement between nurses and physicians over goals for critically ill patients in a specific unit by addressing the following questions:

1. When do physicians and nurses arrive at the DNR decision?
2. How often do physicians and nurses disagree about DNR decisions?
3. How often do patients or their surrogates disagree with the recommendations of the medical staff?

These questions were answered in the form of a quality improvement study, which enrolled all patients admitted to the medical ICU at the Walter Reed Medical Centre in the US. Demographic data, Glasgow coma scales, and Apache II scores (assessment of illness severity, which is by inference a reflection of prognosis) were calculated on all patients on admission.

The medical team and nurse assigned to each patient were independently surveyed each day for their opinions regarding DNR issues related to the patient under their direct care (interviews used the same objective verbally administered questionnaire). Differences from admission to decision for DNR/ or decision that DNR or would be appropriate was calculated in the case of each patient admission over a 10 month period. 368 consecutive admissions were included in the study and DNR orders were written for 84 of these patients. Comparison of DNR opinions of nurses and physicians were correlated against the patients' survival rates and showed no statistical differences. Eliasson et al (1997) felt that the nurses' impression that they were frequently ready to designate patients as DNR earlier than physicians probably related to their generally long-term one-on-one care of the patient. This aspect of the ICU nurse's practice results in both the tendency to develop relationships with patients and families and in the witnessing of fluctuating clinical courses with these patients and family members. These findings reflect the findings from my honours work and early experience in critical care. This study has also been of particular interest as its findings have resonated with the data and findings arising from my current dissertation.

These researchers also report that patients or families in their medical ICU "… infrequently disagreed with the medical recommendation for a DNR order" (p.5). Eliasson et al (1997) report correlation between nurses' and doctors' opinions related to timing of DNR designation; appropriateness of DNR designation and death of patients in both Doctors' and nurses' opinions. There was no statistical evidence supporting the researchers claim regarding patients' preferences for DNR orders apart from 24 patients who entered the unit with standing DNR orders. The claim that there was infrequent disagreement between doctors and patients in this respect in not supported in this report and is a flaw in this study. As Eliasson et al (1997) acknowledges the documentation of a DNR order for a patient is not equivalent to a decision to withdraw life-saving treatment. This study could have been extended to seek the opinions and feelings of nurses and physicians in relation to this issue as it impacts upon the documentation of a DNR order.

Decision making in CPR: attitudes of hospital patients and healthcare professionals Kerridge et al (1998)

Kerridge et al (1998) addressed the issues of 'opinions and attitudes' with respect to decision-making in some measure when they sought to "…examine the opinions of patients and health care professionals regarding the process of decision making about cardiopulmonary resuscitation" (p.128).

These researchers carried out a cross-sectional survey of 511 health care professionals (doctors, nurses and allied health professionals) and 152 patients

Hospital a metropolitan, University-affiliated hospital in NSW, Australia in an effort to measure:

- opinions on those who should be involved in CPR decision-making;
- the important issues when making these decisions; and
- how such decisions should be communicated.

A self-report questionnaire was developed with the assistance of consultants and expert clinicians, piloted and administered following ethical approval. Analysis of the data obtained during this study (carried out over two weeks) indicated that the majority (80% of patients; 99% of health care professionals) felt that the patients' views should be taken into account when making CPR decisions and that patient diagnosis and quality of life were important factors in the decision. More patients (29%) than health professional (14%) indicated that they felt the doctors should be the main decision-makers. Most respondents reported feeling comfortable discussing the topic of CPR and related issues (82%) but only 29% of patients reported having discussed CPR with others. When questioned about advance directives, a large proportion of patients (47%) and the majority of health professionals (69%) preferred to express their wishes in writing before or soon after admission to hospital - the remainder preferred to tell close family members of friends. Unsurprisingly, the majority of respondents (60% of patients, 95% of health professionals) wished to have their views/ preferences recorded in their medical records.

Interestingly, only 36% of patients were of the opinion that nurses should be involved in these decisions (Kerridge et al, 1998). The authors expressed the opinion that nurses were independent moral agents and that there were 'good reasons' for their inclusion in decisions about CPR but they felt that there were considerable difficulties associated with this. Providing round the clock bedside care, nurses work in shifts. The inclusion of all potential decision-makers is a logistic challenge- Kerridge et al suggest it is not possible, but perhaps the adoption of daily 'grand rounds' could achieve the input and consensus they strive for. The authors also suggest that their findings challenge the notion of "nurse as patient advocate" in that the image of nurses as moral agents in their own right has not yet been adequately communicated to the public, patients or other health professionals (Kerridge et al, 1998). This is not an opinion I share but perhaps this is the challenge for the next generation of nurses.

These results led Kerridge et al (1998) to conclude that most patients wanted to be involved in decisions about CPR and that many wanted some form of advance directive. They further concluded that though there was some disparity in the opinions between patients and health care professionals, both groups were of the opinion that decision-making about CPR should be a shared process, including both patient and doctor.

This study was limited in several respects. The respondents completing the questionnaire represented a response rate of 64% for the health care professionals and 58% for the patient cohort. As previously mentioned, data from the self-report questionnaires were collected within a two week time frame only. The sample used in this project was not homogenous and the findings from this study represent a ‘snapshot’ rather than representation of the patient population as whole. As the authors acknowledge, the use of self-reporting questionnaires is likely to have biased the study towards individuals keen to discuss the issue of CPR (Kerridge et al, 1998). Finally, the quantitative nature of this study has not facilitated exploration of participants’ feelings and values as they influence their ‘attitudes’ about CPR decision-making. The findings gleaned from this project’s data with respect to the correlation (or not) between the opinions of patients and health professionals about the decision-making process around CPR would have been enhanced with information about the values and contextual influences upon those opinions.

2.1.2.1 Discussion of advance directives/ CPR and DNR studies

The decision to designate do-not-resuscitate status for a patient has bioethical as well as clinical dimensions. When this decision is made, health professionals, especially nurses, are left to deal with its implications. The legal definition of DNR: not to initiate CPR at the time of cardiac or respiratory arrest, remains ambiguous in practice leading to confusion and anxiety (Pace & McLean, 1996; Wallace, 2001. Also misunderstood is that DNR allows for other medical and nursing interventions

(Eliasson et al., 1997; Thibault-Prevost et al., 2000). What needs to be emphasized in practice is the distinct rationale, which leads to a DNR decision (Thibault-Prevost, 2000). When this involves a quality-of-life issue for a patient, decision-making for care should where possible, be determined by the patient or the family and this is where clear advance directives can be of assistance. Educational programs and increased dialogue may facilitate understanding of the DNR designation and promote participation in formulating policies related to this complex issue (Ivy, 1996). This in turn may assist health care professionals in providing care to meet the needs of critically ill patients and their families (Larsen, 1999). In effect, the literature seems to indicate that the following strategies are required if the stress and anxieties related to end-of-life care planning and decision making are to be reduced:

- development of clear advance directives
- education of the public about their usefulness and use
- education of health professionals about the legal requirements R/T advance directives, and the formulation of DNR designations
- formulation of clear policies related to their use

2.2 DECISION-MAKING RELATED TO PROGNOSIS AND ON-GOING TREATMENT

Prediction of a patient's probable outcome or mortality once admitted to intensive care is an important tool with respect to clinical management both from clinical and administrative perspectives (Ferreira, Daliana, Bross, Melot & Vincent, 2001). Outcome prediction, calculated in terms of trends in organ dysfunction in the critically ill patient is also a useful tool when communicating to relatives and trying to give concrete or objective explanations of their loved ones' chances, prognoses or improvements during care (Knaus, Harrell, Lynn, Golman, Phillips, Connors et al., 1995). Doctors interviewed during the current ELD's project spoke frequently of explaining things to relatives in terms of percentages. It is from the outcome predictors discussed below that these percentages are drawn.

A major study, the SUPPORT Project (SUPPORT Principal investigators, 1995) aimed to enhance quality of life for patients in acute and critical care settings by examining advance care planning and the correlation between patients' treatment preferences and decisions made. Sensing the central importance of an objective tool to clinical decision-making, part of the SUPPORT project was devoted to the development and validation of such a prognostic tool (Knaus et al., 1995). For coherence, this study is discussed below:

The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) (The SUPPORT Principal Investigators, 1995).

Motivation for this project was two-fold: 1) an increasing sense that services provided to people who are dying overemphasized heroic, high-tech innovations at the expense of caring and comfort and, 2) increasing societal demand for something tangible in return for dollars spent (especially in such high-tech, high-cost areas as critical care) The project's long-term goal was to: improve end-of-life decision-making and reduce the frequency of a mechanically supported, painful, and prolonged process of dying (Tobin & Luce, 1996; Rutledge et al., 2001).

The SUPPORT group studied over 9000 seriously ill hospitalised patients in five U.S. teaching hospitals in a "two-phase" process. Phase one of SUPPORT involved a two- year (1989-1991) prospective observational study of 4816 patients in an effort to investigate and 'characterize' the care, treatment preferences, and patterns of decision-making among critically ill patients (The SUPPORT Principal Investigators, 1995; Tobin & Luce, 1996).

Phase 2 was a two year controlled clinical trial (1992 – 1994) involving 4804 patients and their physicians; 2652 of these randomly assigned to an intervention group in which physicians were provided regularly with accurate predictive information on patients':

- Future functional ability
- Survival probability to six months (derived from the prognostic scoring systems developed during the SUPPORT study);

- Preferences for end-of-life care

Skilled nurses 'specially trained' for the project were attached to the intervention group in the hopes of enhancing physician-patient communication. These met with patients, relatives and physicians 'several times' to elicit patient preferences, provide prognoses, enhance understanding, enable palliative care, and facilitate advance planning and pain control (Tobin & Luce, 1996; Rutledge et al., 2001).

Data collection in both phases of SUPPORT consisted of questionnaires administered to patients, their surrogates, and physicians, plus chart reviews for eliciting clinical, treatment, and decision information. Phase II also collected information regarding the implementation of the intervention from patient-specific logs. SUPPORT patients were followed for six months after inclusion in the study (The SUPPORT Principal Investigators, 1995).

Contrary to expectations, these intensive interventions did not influence physician-patient communication and patient outcomes noticeably (Tobin & Luce, 1996; Rutledge et al., 2001). These discouraging results might be explained by the use of nurses in the intervention group. These nurses took the lead in promoting patient-physician communication but did not have authority in direct clinical care. Tobin and Luce concurred that this was a difficulty in the methodology because "… physicians are not known for listening to nurses' advice" Tobin & Luce, 2001, p.2. This is an opinion that while honest, may be reflected by their own professional persuasion as physicians. It is also reflected in the research of Rowbotham (1999) and Wicks (1999) which indicates that while we have moved on from the patriarchal physician/ handmaiden nurse stereotypes, there still remains some tension in the physician-nurse relationship which creates a need for nurses to 'facilitate' the decisions they perceive to be necessary for optimum patient care (Rowbotham, 1999; Wicks, 1999). It is also significant that most of the physicians in this study were specialists supervising care and not 'primary-care' physicians or registrars with their 'own' patients. This might have affected the tenor and reduced the frequency of their communication with patients. It is also possible, as Tobin and Luce (2001) suggest, that the physicians in this project were still just developing trust in the prognostic scoring systems being developed for this project.

This prognostic tool was developed during both phases 1 and 2 of the study. The researchers' objective in this aspect of the study was to develop and validate a prognostic model that would estimate survival over a 180-day period for seriously ill hospitalised adults (during phase 1 of SUPPORT) in a prospective cohort study and then compare this tool with pre-existing models-specifically the APACHE III (*Acute Physiology, Age, Chronic Health Evaluation* prognostic system) and physicians' own judgments in phase 2 (Knaus et al., 1995). A survival prediction tool was developed based upon: diagnosis, age, number of days in the hospital before study entry, presence of cancer, neurologic function, and the combined with 11 physiological measures (not listed). This formed the SUPPORT physiological score which was recorded on day 3 after patients entered the study. Physicians were also interviewed on day 3 with respect to their estimations of patients' conditions and prognoses. Reliability of the APACHE III and SUPPORT models were compared using the "areas under receiver operating characteristic" (AUROC) curves. Both tools were reported to be equally reliable during testing in Phase 1 of the SUPPORT study (variance of 0.78 for both) (Knaus et al., 1995). During phase 2 as physicians' judgment/ estimation of mortality was compared with the support tool, both were found to be equally discriminating (Knaus et al., 1995). These findings led the research group to conclude that prognostic tools developed from readily available and accurate clinical information can provide the basis of accurate clinical predictions of survival estimates. They sagely suggested that the best of these combines objective prognosis with a physician's clinical estimate.

Caring for the critically ill patient Ferreira et al (2001).

Ferreira et al. (2001) noted that the outcome prediction models available at the time, eg APACHE and SAPS (Simplified Acute Physiological Score) were statistical in nature, not taking into account the dynamic tendency of a critically ill patient's condition to change from day to day, or even minute to minute. This study aimed to take that dynamic aspect of critical care medicine into account by assessing the usefulness of repeated measurement of the Sequential Organ Failure Assessment (SOFA) score for prediction of mortality in intensive care unit (ICU) patients. The researchers conducted a prospective, observational cohort study conducted from April 1 to July 31, 1999 using 352 consecutive patients admitted to ICU in a Belgian University hospital. SOFA scores were calculated for these patients on admission and then every 48 hours during their stay in ICU. The main outcome measures calculated were:

- Initial SOFA scores (0-24),
- -SOFA scores (differences between subsequent scores),
- The highest and mean SOFA scores obtained during the ICU stay and
- Their correlations with mortality.

Statistical analysis of the data obtained from these measures lead Ferreira et al (2001) to conclude that use of sequential assessment of organ dysfunction during the first few days of ICU admission gave a good indicator of prognosis. Both the mean and highest SOFA scores were thought to give particularly useful predictors of outcome. Independent of the initial score, an increase in SOFA score during the first 48 hours in the ICU predicts a mortality rate of at least 50% (Ferreira et al., 2001).

The Multiple Organ Dysfunction Score (MODS) versus the Sequential Organ Failure Assessment (SOFA) score in outcome prediction (Peres, Melot & Vincent, 2002)

The same group of researchers compared the MODS (*Multiple Organ Dysfunction Score)* prediction model with the SOFA scale during the same study but reported their findings later in 2002 with a different first author (Peres et al., 2002). Similar outcome measures were used and the Areas Under Receiver Operating Characteristic (AUROC) curves used in statistical analysis. This aspect of the study led the researchers to conclude that MODS and SOFA are both reliable outcome predictors in the management of the critically ill patient. They found though that there was a tendency to more accurate prediction of outcome in patients with cardio-vascular dysfunction if SOFA scores were used than if the MODS tool was used (Peres et al., 2002). The authors thought that this difference might be explained by the stronger focus on variables of cardiovascular function in the SOFA tool than in the MODS tool (Peres et al., 2002).

These three studies have an entirely medical focus but have been included here because of their direct relationship to and importance in the area of clinical decision-making in critical care. All three studies have a logico-empirical focus, which is appropriate to their aims but ignores the context and impact of the decisions resulting from the application of these tools. There has been one study recently that has recognised this gap in the research:

Negotiating natural death in intensive care Seymour (2000).

In this study, Seymour (2000) used fourteen case studies to examine the way in which the problem of predicting and negotiating the trajectory of various patients' illnesses from admission to recovery or death was handled by the within the intensive care unit. The impetus for this study lay in Seymour's observation and empirical evidence that dying patients in acute care settings still tended to receive invasive medical treatments immediately before death, in spite of evidence of their poor prognosis being available to treating physicians (Tobin & Luce, 1996; Brody, Campbell, Faber-Langendoen & Ogle, 1997).

The data that arose from Seymour's investigation suggested that clinicians engage in a process of 'timed' treatment withdrawal of treatment so that the appearance of a natural death is negotiated and allowed to occur as much as is possible (Seymour 2000). She also suggests that analysis highlighted the existence of two potential divergent trajectories for the dying process: 'technical' and 'bodily'. These, she suggested might be aligned for death to occur at the 'right' time. The containment or alignment of these two processes to facilitate 'natural' death might be explained within the framework Seymour (2000) developed to explain the social interactions between physicians at times of end-of-life decision-making:

1. The establishment of a `technical' definition of dying- informed by results of investigations and monitoring equipment - over and above `bodily' dying informed by clinical experience;
2. The alignment of the trajectories of technical and bodily dying to ensure that the events of non-treatment have no perceived causative link to death;
3. The balancing of medical action with non- action, allowing a diffusion of responsibility for death to the patient's body;
4. The incorporation of patient's companions and nursing staff into the decision-making process.

This was a well-designed study, offering significant knowledge and theorizing supported by the data. This study has been of particular interest due to the quality of the data and because of its resonance with my own experience and the data from the ELD’s project.

2.3 DECISION-MAKING RELATED TO WITHDRAWAL OR WITHHOLDING OF TREATMENT

The decision-making process related to the withdrawal or withholding of life-supporting treatment needs to be better understood in terms of the values and beliefs of the peoples making these decisions, the issues affecting their decision-making and the impact of these decisions upon those involved. Current research in this area falls into two broad categories at present: The challenges related to the decision (Heide & Maas, 1998; Dickenson, 2000); and the impacts of the decision (Viney, 1996; McHaffie & Fowlie, 1996; McHaffie, 2001).

2.3.1 Challenges of the decision

The Role of parents in End-of-life Decisions in Neonatology: Physicians' Views and Practices (Heide & Maas, 1998).

End-of-life decisions for newborns are usually made in consultation with the child’s parents. These discussions may result in disagreement about the ‘best’ course of treatment and ‘decision’ for the neonate. Such situations may be resolved by parents’ acquiescence to the ‘superior’ knowledge of the physician or following consultation with the pediatrician involved. Researchers Heide and Maas (1998) were interested in investigating the extent to which parents were actually engaged in making end-of-life decisions for their infants and understanding the background behind differences in opinions between physicians and parents when decisions to hasten death or not prolong life were not considered. This study was part of a larger Dutch study into euthanasia and related issues being conducted at the time (Maas, Wal & Haverkate, 1995).

In this study, face-to-face interviews were held with a ‘stratified’ sample of 31 neonatologists and paediatric intensivists from 8 university and 2 non-university hospitals in the Netherlands together with 35 general paediatricians. Experienced physicians ‘extensively trained’ for the interviews conducted semi-structured interviews. These discussed whether the participants had been involved in end-of-life decisions concerning neonates, what the role of the parents had been in these decisions, and whether their decisions had been influenced by disagreements with parents. Paediatricians were asked to discuss their most recent cases but a time frame was not mentioned in the study report (Heide & Maas, 1998).

This study presented the prospect of insight into the impact of attitudes of senior clinicians on one of the most challenging areas of decision-making in critical care. There was also the opportunity here to develop an understanding of the issues involved in these decisions for both the paediatricians and the parents. These opportunities were not explored however. This study was limited in that the parents were not interviewed and instead of exploring the meaning and contextual input from the interview data, four categories were developed which were then converted into quantitative findings. These categories were:

1. An end-if-life decision was made because the infant had (virtually) no chance of survival;
2. An end-of-life decision was made because the child had an extremely poor prognosis for quality of life;
3. An end-of-life decision was not made because the parents did not consent to such a decision;

4. An end-of-life decision was not made because the respondent could not consent to the parents for such a decision.

The researchers reported that parents had usually been involved in the decision-making process but that general paediatricians were less likely than neonatologists to include parents in such decisions. The only quote from an interview to support an argument appears in this part of the discussion: when asked why parents were not included in decision-making at these times, general paediatricians apparently most commonly replied that there had been no time for discussion or that "… it had so obviously been the right decision" (p.3). It is possible that much rich insightful text flowed from the interviews with these Dutch doctors but it was not reported. The tenor of the report matches the quote above and is reflected by the conclusions drawn:

> *The opinion of parents about which medical decision is in the best interest of their child is for paediatricians only decisive in case it invokes the continuation of treatment. The principle of preserving life is abandoned only when the paediatrician feels sufficiently sure that the parents agree that such a course of action is in the best interests of the child (Heide & Maas, 1998, p. 1).*

The focus of this report seems to have a definite paternalistic flavour arguing that paediatricians concede that the views of parents should be taken into consideration when making end-of-life decisions, but that, in the end, the paediatrician 'know best' and is most capable of making these decisions for the good of the child. It is possible that this interpretation of results and viewpoint is an expression of the Dutch society in which the study was carried out; it may also be a reflection of the standpoint of the researchers, both physicians themselves.

This study was funded by the Dutch Ministry of Health, Welfare and Sports, and the Ministry of Justice. The interests of Medicine and Capitalism are closely intertwined and as any Western government has to manage its economy, it is reasonable to assume that the state is much more likely to fund research that is conducted in the interests of Medicine and would rarely fund research that is likely to undermine medical interests (Willis, 1990). Medical dominance has allowed the development of what Willis (1990) called the '*Corporatist*' mode of medical production, which results in a form of public passivity, acceptance or fatalism as they feel unable to challenge the medical knowledge. The medical interest is to maintain medical power, i.e. “doctor knows best”. Thus, this study is biased towards presenting doctors making ELD’s as wise and benevolent.

With the evolution and application of technological innovations that require us to make decisions about the appropriateness of withholding or withdrawal of such treatment comes many vexed ethical and legal questions: When is the intervention overly-burdensome for the patient? Should the question of futility in such care enter discussions (Carnevale, 1998; Parmley, 1999; Burt, 2002; Clark, 2002; Glare & Tobin, 2002) or is such a concept anathema in the context of critical care and to intensivists (Ardagh, 2000)? One of the most contentious issues in the area of withdrawal of treatment is that of double-effect. There remains little clarity around this issue. The debate related to the use of narcotic analgesic at the end of life hinges on the issue of intention. The difference between relieving suffering and shortening the dying process is cloudy at best. Studies investigating the intentions and attitudes of surgeons in Australia (680 surgeons) by Douglas, Kerridge, Rainbird and McPhee (2001) and intensivists Europe-wide (31, 417 patients and their physicians) by Sprung and colleagues in 2003 (Sprung, Cohen, Sjokvist, Baras, Bulow, Hovilehto, Ledoux, Lippert, Maia, Phelan,Schobersberger, Wenberg & Woodcock 2003) suggest that the intention more often than not may be towards the latter of these two. Similar arguments can be raised about intentions when life-supporting treatment is withdrawn in cases where prognoses are considered futile (Truog, Burns, Mitchell, Johnson & Robinson, 2000; Douglas et al., 2001; Sprung et al., 2003). The decision-making process needs to be understood in terms of the values and belief systems of the individuals working in critical care. Dickenson (2000) developed a study with this intention:

Practitioner attitudes in the United States and the United Kingdom toward decisions at the end of life: are medical ethicists out of touch? (Dickenson, 2000)

Dickenson (2000) set out to asses whether UK and US health care professional shared the views of medical ethicists about issues such as medical futility, withdrawing or withholding treatment, ordinary or extraordinary interventions and the doctrine of double effect. She administered similar 138-item attitudinal questionnaires (details not given) to 469 UK nurses studying the Open University course on "Death and Dying" and 759 US nurses and 687 US physicians taking the Hastings Centre course on "Decisions Near the End of Life" and compared their responses.

Analysis of the responses to these questionnaires led Dickenson to conclude that there was a wide disparity, "a gulf" between the beliefs and ethical values of professionals in the field, and majority opinion in bioethics. She also concludes that there was disparity between the recommendations of the professionals' various national regulatory bodies but this was not borne out in the study report – it may have been supported but data from the larger study. The majority of health professionals indicated that they accepted the relevance of concepts such as: double effect, medical futility, and the distinctions between heroic and ordinary interventions and withholding and withdrawing treatment; concepts described as widely disparaged by bio-ethicists by Dickenson (2000). UK nurses in the study tended to take a more rationalist stance than their US colleagues, describing themselves as having 'no religion' and being closer to the bioethics consensus on withholding and withdrawing treatment.

Dickenson (2000) uses the information drawn from this study to support a discussion about the application of bioethical principles in practice, suggesting that while practitioners may accept the concepts and principles of bioethics, they don't necessarily have to apply them. She makes a good case for her argument that medical ethics is in danger of becoming a self-regarding activity if it does not consider and incorporate the opinions and input of practice. Medical ethics she argues essentially is out of touch with practice and ethicists have a narrow philosophical and analytical approach to the problem that could be enhanced by the clinical focus. These criticisms may be warranted (Jennings 2000). They are not however, justified by the data presented in this study. This study did not aim to examine the application of any particular bioethical model in practice- though Dickenson revealed an interest in a naturalistic model of decision-making in her discussion. The participants in this study were asked rather about their own attitudes in these matters and here the study was flawed in that participants were pre-sensitised by participation in relevant courses and so data would have been skewed towards acceptance of the concepts and issues under investigation.

Dickenson betrays a certain bias towards 'right' and 'wrong' in her perception of ethical decision-making in her description of the relevant bio-ethical concepts as "widely disparaged" (p.254). There is no ethical consensus reached around these issues at present- for example ethicists are virtually split 50/ 50 over futility and its utility in decision-making (Carnevale, 1998; Ardagh, 2000; Burt, 2002).

2.3.2 Impact of the decision-making

There has been increasing evidence in the research that decision-making at the end-of-life should be shared, at least by physician and patient or surrogate. There is also a burgeoning body of evidence to suggest that this time is fraught with ethical, legal and emotional anxieties. There is little empirical evidence as yet though to help us understand how these issues affect the all those potentially affected by the decision: the relatives, doctors and nurses. I have described the research, which was the foundation for this study: The Uppity Nurses project (Huard, 1997). The limitation of that project was that it did not explore the perspectives of the families or doctors involved. The following studies examined the perspectives of the various stakeholders but not necessarily in the same study:

A phenomenological study of ethical decision-making experiences among senior intensive care nurses and doctors concerning withdrawal of treatment Viney (1996).

Viney (1996) sought to compare the experiences of senior doctors' and nurses' ethical decision-making experiences concerning withdrawal of treatment. Using unstructured interviews, stories were collected from 5 nurses and 5 doctors all with an average of 10 years' experience in the same critical care unit in the UK. These stories were then converted into narratives. Interviews according to Viney (1996) last 30 – 90 minutes yet she describes her methodology as phenomenological. She legitimately argues that this is an appropriate methodology as it allows the researcher to interpret and understand rather than observe and explain. But the effective application of phenomenological methods requires the enmeshing of the researcher in the lived experience of the participant so that a deep understanding of their world is developed (Crotty, 1996). This is not an understanding that might be achieved in one 30-minute interview. Viney (1996) makes no mention of repetition of interviews. Using thematic analysis, Viney (1996) developed six categories from the narratives:

- Responsibility for decision-making
- Approach to decision-making
- Criteria for treatment withdrawal
- Caring for the relatives
- Coming to terms with the relatives
- Moral distress

Viney (1996) concluded that nurses suffered moral distress around perceived patient and relative suffering as well as disruptions in relationships with relatives or doctors related to the decision to withdrawal of treatment. Whilst doctors suffered moral distress related to patient suffering and quality of life, they also suffered moral dissonance around issues of power and control over the decision-making process. Viney also stated that doctors and nurses need to 'come to terms' with treatment withdrawal. No suggestion was made how this might be achieved was offered. Viney's (1996) study was also limited in that it did not include the perspective of patients or surrogates who may have been involved in and would have been affected by the decision making experience.

Life, Death and Decisions: Doctors and Nurses Reflect on Neonatal Practice McHaffie& Fowlie (1996).

McHaffie& Fowlie (1996) identified a gap in the literature with respect to knowledge about clinicians' decision-making practices. They were interested in exploring the thinking and practices among doctors and nurses and midwifes related to the withholding of treatment for neonates in intensive care units. Further to this they hoped to identify practices that would facilitate appropriate decision-making related to the care of these neonates, minimising tension, stress and conflict among caregivers and family members involved.

This was a well-designed study conducted across six Scottish neonatal intensive care units (NICU's). Following general discussion with staff in each NICU to outline the study and its aims there followed a period of participant observation and schedule of interviews, organised with management so as not to disrupt care. Individual interviews were carried out in which participants were asked to reflect on decisions made. The sample for this study included 76 midwives, 43 neonatal nurses (nurses managers, sisters and staff midwives) and 57 doctors (consultants, senior registrars and senior house officers. McHaffie and Fowlie's excellent entrée into these NICU's may be explained by their support at the time by the Scottish Department of Health. McHaffie was a research fellow, Department of Medicine, Edinburgh at the time, while Fowlie was Senior Registrar in Dundee. This research was funded by the Chief Scientist Office at the Scottish Health Department.

McHaffie and Fowlie (1996) have produced significant and valuable insight into the perceptions of the doctors and nurses involved in decisions related to the withholding or withdrawal of treatment from babies. These researchers found that the nurses and midwives in the study felt that their study or training had not prepared them adequately for the difficult ethical situations they confronted (only 3 out of 119 were satisfied with their preparation). These two researchers also found that most of the nurses and midwives (55%) in this study perceived that the doctors tended to 'routinely treat' neonates, thereby giving themselves time to make decisions later on based on investigations and observation-only 35% of doctors were of this opinion. McHaffie and Fowlie (1996) thought this practice might have been explained by decisions made during antenatal visits. This might be the case for pre-diagnosed chromosomal abnormalities such as Down's syndrome or severe physical abnormalities.

McHaffie and Fowlie (1996) also found that the majority of nurses and midwives experienced difficulties expressing their concerns about these ethically challenging situations in practice. Some of the nurses had developed comfortable working relationships with the medical officers in the NICU's and felt they were able to discuss their concerns. Many said, however, that despite many years working with their medical colleagues, their opinions were neither sought nor offered. Nurses and midwives chose 'consultation' with their peers and if a consensus of concern was reached, then rather than using their agency, silence was chosen over direct approaches to senior registrars or consultants. Their preferred approach when concerned was to pass these up the line of management. As a consequence, nurses' opinions were underrepresented despite their unique and valuable insight into family dynamics and parents' wishes and these nurses and midwives feel undervalued. (McHaffie & Fowlie, 1996). McHaffie suggested this reluctance on the part of nurses and midwives to communicate their concerns had a profound influence upon the care given to children in the NICU's observed. She went so far as to suggest in an précis of the report that the nurses and midwives set limits on their accountability; that they were professionally responsible for the care of the child but that "…when it came to whether a child lived or died, they often remained silent" (McHaffie, 1997, p. 94). This is a strong and disturbing statement, not necessarily backed up by other findings in the study, for example, participant observation had revealed that some consultants had fully involved nurses in decision-making, while others had had merely 'gone through the motions'. Some senior medical officers had admitted that they would not be influenced by anyone else's opinions and made unilateral decisions, only paying 'lip service' to the concept of collaborative decision-making. It is not surprising then that in this atmosphere, many of the nurses and midwives would seek alternative paths for addressing their concerns or had given up trying.

McHaffie and Fowlie (1996) acknowledge the responsibility of care and decision-making that appears to delegate to the medical officer caring for the child and that this becomes part of the 'vicious cycle' of the technological imperative: once we have started with the highly specialised knowledge and high-tech expertise we can offer, we have a responsibility to keep trying as hard as we can to do as well as we can for this infant. They suggest that there is a sense of pride and a sense of guilt associated with the technological imperative: even if death occurs, if all possible interventions were tried in the treatment of the child, the medical officer discharged his responsibility for the child: 'did the best he could' (McHaffie & Fowlie, 1996).

The suggestion is made by McHaffie (1997) though, that by remaining silent in some circumstance, nurses and midwives are **abdicating** their responsibility to their patients.

This may well be one interpretation of the data collected but it is not the only one. McHaffie and Fowlie (1996) have been at pains to understand the doctors' point of view in these challenging situations, offering possible explanations for their behaviours and decisions that reflect them in a compassionate light. The same cannot be said of discussion of the nurses' actions and decisions. This tends to suggest a bias from the perspective of the researchers. This suggestion of bias is echoed from another perspective of presentation of the data. McHaffie and Fowlie (1996) spoke to more nurses than doctors (119 nurses: 57 doctors). Rich and interesting quotes are used in many interesting instances to support their arguments, but while there are 107 (178.71%) of these from doctors there are only 61 (51.26%) from the 119 nurses interviewed. This bias towards the doctors' perspectives may be explained by the fact that one of the researchers was a senior registrar with an interest in paediatrics himself. It is possible that his input into discussions during analysis may have coloured interpretations. Finally, this study was funded by the Scottish Department of Health. As has been previously argued, in a Western Capitalist economy, research reflecting the interests and/ or perspective of Medicine is more likely to attract funding than research which undermines or detracts from medicine's interests or image (Willis 1990). The reporting of results from this study might be viewed as a reflection of the higher social value accorded to medicine and the tendency to recognise doctors as the group with the specialised knowledge and that somehow this, ipso facto, leads them to be in the best position to make these moral decisions at the end-of-life. This study explores, in part, how true such a faith in medical moral decision-making may be.

This study had one further limitation. It examined the perspectives of the doctors and nurses only, leaving out the parents of the children. These stakeholders in these emotive and challenging issues were included in a further study by McHaffie in 2001:

Crucial Decisions at the Beginning of Life (McHaffie, 2001)

In this study McHaffie and her research team interviewed 81 recently bereaved couples accessed via referral from 3 regional Scottish NICU’s. Parents were included if there had been any discussion of treatment limitation during their child’s time in ICU. They were then approached at their first ‘bereavement’ visit and possible interviews discussed. With permission, in-depth interviews were conducted at 3months and 13 months. Data was coded using the SPSS package. Results from this analysis was summarised as follows:

1. Nurses play a key role in providing emotional support for families during the process of treatment withdrawal;
2. Information should be consistent and honest, helping parents towards an acceptance of the bleak prognosis;
3. Every care should be taken to respect parents’ preferences and ensure care is tailored to their tolerances and wishes;
4. Known nurses should attend the funeral (half the families said this was gesture they appreciated since very few people had known the baby);
5. Contact should be maintained to ensure that families are coping appropriately with their loss.

In this study, as in the last, McHaffie (2001) emphasised the role of the nurses as information broker and support-person for the parent coping with an extremely challenging time- what McHaffie called a ‘special place’ in the lives of families at these times. As she says further, nurses in these NICU’s care intimately for these fragile babies at these times understand their individual characteristics and needs and develop close attachments with the child and their family. McHaffie (2001) suggests that teamwork and a collaborative atmosphere in decision-making will offer support to the parents involved in these tragedies. She suggests though that the parents will look to the consultants for information and direction and to the nurses for reinforcement and reassurance. It is disappointing that McHaffie, a nurse with NICU expertise herself, sees the scope of the nurse as so limited. This project was also funded by the Scottish Department of Health.

2.4 CONCLUSION

Research related to end-of-life decision-making has only begun to develop in the last ten to twelve years and has had three main foci:

- Decision-making related to the initial intervention (and who should have input here), which in summary shows that advance directives are not generally considered and that dying in hospital generally means CPR and technological intervention.
- Decision-making related to prognosis (and tools that help here), which in summary shows that several reliable prognostic tools have been validated to aid the clinical decision-making related to maintenance or withdrawal of life-sustaining interventions.
- Decision-making related to the withholding or withdrawal of treatment, which in summary shows that doctors do not want the death to have any presumed link with the withdrawal of treatment. Doctors like to feel that their decisions will be supported by family and by nurses but they are unlikely to ask their opinions directly.

As this review has demonstrated, no research has answered the question:

> "How might avoidable suffering related to the process of decision-making that accompanies the implementation, maintenance or withdrawal of life-sustaining treatment in the critical care environment be ameliorated?"

A number of the issues around end-life decision-making have been investigated peripherally, from a logico-empirical perspective and in Europe and the United States of America. There have been no studies to date in Australia which have investigated how these issues affect all the stakeholders involved in the decision-making when a person is critically ill and in need of support or in need of judicious consideration of its withdrawal.

CHAPTER THREE: SUFFERING

The concept of suffering is central to this dissertation, which seeks to explore ways to ameliorate avoidable suffering in the critical care environment. Suffering is part of the human condition (Travelbee, 1971), yet the concept is difficult to capture in a definition. Suffering has an entirely negative aspect for many people, while others view it as a challenge, a potential path to enlightenment or existential growth. Suffering is often defined in terms of one's relationship to God: many believing that whatever suffering is dealt their way comes from him and is not to be questioned but learned from. Many religions and cultures accept suffering as a part of life and as a means of atonement for an evil committed. These theological and philosophical questions are complex and interesting but they are not the focus of this discussion, which is the suffering that occurs in health care, specifically the critical care environment and how that might be best understood and, when appropriate, alleviated. To eliminate suffering entirely would be to remove a meaningful portion of many people's lives. Since suffering is part of the human condition we all must accept some suffering in our lives eg pain in birth, loss and death bring suffering that really cannot be avoided. In this chapter I will focus upon suffering as it relates to loss and threats to a person's integrity. I am particularly concerned with recognising and ameliorating avoidable suffering i.e. that suffering that occurs in addition to that, which is inherent in dying.

3.1 WHAT IS SUFFERING?

The Everyday Oxford Dictionary recognises suffering as the noun drawn from the verb 'suffer'. To suffer, according to the dictionary, is "… to undergo or to be subjected to pain, loss, damage, grief; to feel or bear pain or grief; to be subjected to damage or disadvantage" (Hawkins, 1981, p.710). It is in these negative contexts that the term is most frequently used today. According to the same dictionary, the word also means "…to allow, to permit or tolerate" (p.710), which reflects the original meaning of the word drawn from the Latin, "*sufferre*" - meaning to bear or support (Annandale, 1931). Hence the unattributed and oft-quoted: "She does not suffer (tolerate) fools gladly", or the more reassuring biblical citation: "Suffer (permit) the little children to come unto me…" (Mark10: 14).

Suffering is personal, intimate and contagious. It often entails exposure of our innermost selves (Younger, 1995). As such it is an experience many would rather avoid, forget, deny or hide. Suffering is also a particularly human experience which brings with it a feeling of loneliness or alienation from others (Younger 1995). Indeed, it has been argued that suffering is an inherent aspect of the human condition, a universal human experience, in that the history of mankind and the history of suffering are intertwined (Travelbee, 1971; Cassell, 1991; Pollard, 2002).

3.2 THE NATURE OF SUFFERING

Suffering is recognised as the subjective and complex response of the individual to stressful events or perceived threats to the person's integrity (Cassell, 1991;Rodgers & Cowles, 1997). This response involves the assignment of intensely negative meanings to these threats and consequently results in the distress that is commonly associated with suffering (Kahn & Steeves, 1994). Suffering can occur in relation to any aspect of the person. It can impinge upon the individual in relation to their body and their relationship with their own persona, as well as any aspect of their social or family relations. Perhaps most importantly, suffering can threaten the psyche which is experienced as a symbolic threat to existence (Lindholm & Eriksson, 1993; Younger, 1995;Clark, 2002).

Suffering reduces and can eliminate a person's sense of value, purpose and hope; in extreme cases this can lead to suicide. It has at its core the sense of loss of control or being forced to admit to the existence of a set of circumstances outside our control and to which one might feel that one has to submit. The intrusion of this event or activity, operating outside our control makes us aware of our vulnerability and thus becomes a threat to our autonomy and integrity (Younger, 1995). Allied to this threat to the individual's autonomy is the private nature of suffering. While it is possible to know the suffering of others, to come to their aid and to relieve their distress to some extent it is never possible to share their torment with them. Indeed, the natural human response is to withdraw from a suffering other. It takes compassion and ethical commitment to stay with the suffering other (Younger, 1995).

3.3 SUFFERING AND PAIN

For some time, suffering has been discussed and conceptualised in conjunction with pain. Definitions of pain commonly link the concepts of mental suffering or anguish and physical distress or agony (Kahn & Steeves, 1986; Cassell, 1991; Brown & O'Toole, 1992). It is interesting that even the Oxford dictionary seems to use the words “pain” and “suffering” interchangeably defining suffering as “…undergoing pain, grief or damage, or experiencing or being subjected to pain or loss, defeat grief or change” (Allen, 1990, p1219). This seeming confusion does however reflect the common usage of the terms in society today. While these are concepts that are ubiquitously linked within the literature, it is important to understand their relationship: though linked one may not necessarily be the cause of the other. Pain is fairly easily understood, while suffering, the emotional response to that pain is a more subtle concept (Cassell, 1991; Pollard, 2002). Suffering is recognised as a negative response to a perceived threat to the individual’s integrity. Pain may cause suffering if its source is not understood or has dread significance, if it is chronically unrelieved, or if it is not paid appropriate attention. But pain that is accepted (understood), eg labour pain, and a degree of post-operative pain, need not cause suffering (Pollard, 2002).

Pain is ego-alien, meaning that in managing pain, the ego seeks to hold the pain apart from itself and the pain is often experienced as ‘not self’: something happening to the body (Seamon & Kenrick, 1992; Younger, 1995). Suffering, however is deeply, and intrinsically related to the ‘self’ and what the self makes of life’s situations. Suffering may not occur, even in the presence of severe or acute pain, if the person is aware of its source, and does not perceive the pain as a threat to their continued existence. Individuals in great acute pain or chronic pain, often come to experience their own bodies as if they were external agents causing the suffering they are experiencing. However, if the person identifies ‘self’ as the cause of their suffering, this may result in the self-hatred, self-alienation and self-betrayal that is so damaging to the psyche of the sufferer (Lindholm & Eriksson, 1993; Younger, 1995).

3.4 SUFFERING IN THE HEALTH CARE SYSTEM

The health care system has in some senses been developed to oppose suffering. Yet suffering is often an unfortunate but unavoidable result of the interventions we provide in our efforts to save lives and cure disease. The reasons for this would seem to lie with two closely linked facets of health care: medicine's historical background and the twofold impact of this history on the professionals who practice the science and art of health care. The present day biomedical model remains rooted, as Cassell (1991) suggested, in Cartesianism and the mind-body dichotomy of the 17th century. This philosophical split between body and mind made it possible for science to escape the control of the church by consigning the non-corporeal, spiritual side of the person to the church, leaving the body and the physical world to science. The legacy of the continued acceptance of this philosophical dichotomy is that physical disease is viewed as objective, measurable, 'true' and the proper focus of the attention of health care providers. Conversely emotional distress, seen as more rightly the focus of the church, becomes obscured or dismissed. Suffering, however, is an experience of the whole person; body, mind and spirit (Cassell, 1991; Corr, C, Nabe & Corr, D, 1996; Rodgers & Cowles, 1997; Clark, 2002; Jezuit, 2000).

This anachronistic division of the human condition into what is medical (having to do with the body) and what is non-medical (the rest) perpetuates, some would argue, too narrow a focus for medicine (Cassell, 1991 & Clark 2002). The tendency to focus on the cure of bodily ills without consideration of the person or person's contextual to the illness or trauma risks adding unnecessary, meaningless suffering, causing the patient as a person to suffer emotionally (Cassell, 1991; Bracken & Thomas, 2002; Clark, 2002). True, in many of the interventions and treatments we use in health care there is some inherent suffering, particularly in those we have developed to prolong life, but I would argue that in the forgetting of the psycho-social aspects of the person upon whom the interventions are performed, sometimes much additional suffering is caused, not just for the person but also for the family.

As health care professionals, we generally acknowledge aims and desires that include the reduction of suffering. Thus it is hard to talk and hear about suffering and to acknowledge that as health care professionals we are responsible for a large proportion of the iatrogenic suffering inherent in the interventions we put in place. As a result we sometimes miss (find it even harder to acknowledge) the extrinsic suffering occurring around these situations – additional suffering that might be avoidable. I will be arguing that all health professionals need to recognise suffering in all its manifestations: physical, emotional and spiritual, equally and that we need to find strategies to promote and support the voice of all those who are suffering within the health care system.

3.5 STAGES OF SUFFERING

In this section I will outline the stages of suffering and Younger's (1995) theory of suffering. This theory has particular resonance for this study as it speaks of and elucidates society's response to the suffering individual. It has been especially useful in the development of understandings of the repercussions of the crises for the participants in this study and their own responses to the events that unfolded

Communication is a key element in the resolution of suffering, particularly isolated suffering. Sharing the suffering with a compassionate fellow human being may allow the sufferer to articulate their grief, work through and interpret their suffering and find meaning (Jezuit, 2000). Sharing with a compassionate other may also add an element of acceptance, radically transforming the isolated nature of the suffering experience.

Younger (1995) extended Reich's (1989) work suggesting that suffering silences the afflicted individual. She argued that while the individual is suffering acutely whether their wounding be due to crisis, loss or injury to the flesh, suffering damages the ability to communicate. She argues that regaining this voice reflects the mastery of suffering and takes place over several stages: mute suffering, expressive suffering and finding one's autonomous and authentic voice (their real self) (p.55). Passage through these stages will take varying times and have varying manifestations both positive and negative for the individual. If suffering is to be mastered, however, Younger insists no stage can be bypassed.

Mute suffering: Overwhelmed by the sheer force and unexpectedness of the event, the sufferer may be rendered inarticulate-struck dumb at this stage. Alternatively, the only expression they may be able to lend to their experience of the event to this point is to scream or cry. This is an expression of the 'unspeakable anguish' of the event for the individual. At this stage everything but the suffering loses importance and recedes into the background. The individual becomes focused in the moment only and loses the ability to articulate their relationship with self and the rest of society (Wright, 1993; Younger, 1995). A sense of overwhelming meaninglessness is likely to permeate the prevailing situation. Autonomy and a sense of control of one's destiny are deeply challenged at this stage but Younger suggests it cannot be bypassed if the individual is to successfully work through the suffering with their psyche intact. It is the challenge to the person's sense of control of the situation that renders them mute just when they need to speaking up. This stage of mute suffering is reflected in the relatives who sit silently by their loved one's bedsides with eyes full of tears, asking few questions and yet agreeing to any intervention proposed. One reads, "I just didn't think it was my place to ask…" in the transcripts of relatives interviews when they are asked about how they responded when concerned about the treatment loved ones were receiving. Similarly, this phenomenon can be seen reflected in the behaviour and words of critical care nurse who responded: "I just didn't know what to say" when discussing their frustrations when trying to reduce patient or family member suffering.

Expressive suffering: As they move out of the acute phase of their affliction, suffers will, according to Younger (1995), begin to construct a story that is both a lament and way of attaching some meaning to their suffering. She also suggests that the construction of this narrative and its telling serves the purpose of drawing support and affirmation from the listener or listeners as the sufferer starts to re-engage with society. Thirdly, Younger suggests, the sufferer may use the narrative to find the interpretation that fits his or her own understanding of how this suffering has come about. This interpretation may draw from religion or mythology as the sufferer uses the intervention of a higher being to explain this awful occurrence. Thus one might hear relatives explaining the loss of a loved one with words such as "It was God's time to take her/him". During this study many of the health care professionals appeared to use the experience both to construct some clear meaning for themselves and to draw some affirmation from me in the process. As this was the first time many of them had told their stories to another, there was also a cathartic element to the process.

Finding an autonomous and authentic voice: For some individuals, if they move successfully and gradually through the stages that Younger describes, they reach a stage where they are able to find a language that interprets their experience and gives meaning to their suffering. Then they may be able to communicate with others in a voice and using a language that is mutually understood. At this stage some sufferers may reach a turning point where they realise they can achieve change and move beyond their suffering. This is the stage at which Younger suggests a sense of protest arises within the sufferer: "This must not go on!" (something must be done!). It is at this point that some individuals gain the freedom and energy to 'liberate themselves or others' from the painful conditions contributing to their suffering. This was not a manifestation of suffering seen in this dissertation (Younger, 1995)

3.6 THE ALIENATION OF THE SUFFERER (YOUNGER'S THEORY)

Younger intimately tied the sufferer's loss of voice to the profound experience of loss of connectedness that may occur for some individuals. The experience of suffering and the associated loss of voice predispose some individuals to a state of alienation. Younger (1995) described the alienation of the sufferer as one of the greatest paradoxes of the human experience. The suffering that accompanies adversity, she suggests, is accompanied by a second type: loss of connectedness to one's community. Just at the time when one needs support, in one's suffering the realisation of one's aloneness becomes most acute.

Younger describes alienation as a state of disconnectedness with one's self, with others, and one's God (p.57.). This loss of connectedness is the result of the tendency of human beings to recoil from the contemplation of suffering: our own or another's. When affliction is seen vaguely from a distance, it engenders emotions of sympathy and pity. But when people are confronted with it suddenly in all its intensity and vulnerability, their tendency is to recoil and retreat. This visible, obvious suffering causes friends and acquaintances to retreat as it strips away the socially acceptable persona and makes normal social interaction problematic. While happy to offer solicitude and sympathy, society views the afflicted individual as different and as a potential source of contagion: close association may pass on the feelings. This perception of 'contagion' often tends to stigmatise the afflicted and suffering individual (Younger, 1995).

As previously discussed, the afflicted themselves feel the same horror at their own condition. Aware that their suffering will or does not make others comfortable, the afflicted experience a feeling of shame that comes from a sense that their obvious suffering exposes their intimate, sensitive and vulnerable aspects (Younger, 1995). In response to this 'shame' and aware of society's reaction to their affliction the sufferer contributes to their own marginalisation and alienation by withdrawing and retreating within themselves. It is this spiral of affliction, stigma, shame, separation and withdrawal that Younger suggests produces the alienation of the sufferer. We see this alienation, I believe, occurring for the suffering families in of patients in critical care. They sit together but alone in waiting rooms-mostly in silence (1995).

3.6.1 The alienated individual

The stigmatised individual is expected by the rest of society to behave as if the burdens laid upon them by their suffering and the related stigma are no heavier than usual and have not made them different. At the same time the afflicted individuals are also expected to keep themselves at a distance from the rest thereby confirming this belief and easing their own stigmatisation. The psychologic component of this process is self-estrangement: a dissonance between the person's authentic emotions and feelings and their publicly projected reality or persona (Younger, 1995).

While alienation causes an altered relationship with the self, the individual's connection with society is concurrently affected as the alienated individual no longer experiences them self as being at the centre of their community, the arbiter of their own fate. The alienated individual, therefore, is no longer able to be genuine or authentic in their interaction or participation with other members of society (1995). While the suffering, the alienated individual still feels as if they have been robbed of control of their fate or robbed of their voice – silenced by their suffering, then such individuals will not be able to interact authentically with the rest of the society which might be causing their suffering. Until they have worked through their suffering and found their autonomous voice, these individuals may not be able to genuinely and clearly interact with those around them (Younger, 1995) I would argue that while individuals are still suffering acutely, they need someone, either to intercede on their behalf (to be their voice) or help them find their own authentic voice. They may need assistance, then, both to work through the stages of suffering and to communicate with all the important individuals vital to their own or related decision-making.

3.7 CONCLUSION

Suffering is an inherent aspect of the human condition, a universal human experience, in that the history of mankind and the history of suffering are intertwined (Travelbee, 1971; Cassell, 1991; Pollard, 2002). For the most part, such experiences are unpredictable and unavoidable. I would, argue though, that it is when predictable additional suffering is not avoided or ameliorated, for instance in critical care situations, that frustration, anger and despair add to the suffering which is inherent. All health professionals need to recognise suffering in all its manifestations. We need to find strategies to promote and support the voices of those who are suffering within the health care system and as far as possible we should avoid or eliminate unnecessary suffering.

3.8 DEFINITIONS*:*

In light of the preceding discussion and for the purposes of this study, the researcher has developed the following definitions of suffering:

3.8.1 Physical Suffering:

Physical suffering is the individual's response to a perceived or actual threat to the body's integrity. This is a subjective experience and response. It does not necessarily relate to actual physical injury or disease.

3.8.2 Holistic Suffering

Holistic suffering is a complex and subjective response to an intensely negative experience, which may threaten the individual bodily, socially, spiritually, or in all of these spheres. It has at its core the sense of loss of control over some aspect of one's life.

3.8.3 Avoidable Suffering

Avoidable suffering is an additional and increasingly intense response individuals may have to a potentially negative or threatening situation. It occurs when those aspects of the human condition, contextual to their experience or illness, but important to them as persons are forgotten or ignored.

CHAPTER FOUR: DIAGNOSIS OF BRAIN DEATH

> *"If there is one issue within health law and bioethics which can be said to be both well settled and persistently the source of unresolved debate, it is how to determine when death has occurred.*" (Capron, 2001, p 1244)

The advent of the first heart transplant towards the end of the 1950's precipitated recognition of the need for the development of a clear clinical and legal framework to guide decision-making related to death. The intimate relationship between the declaration of brain death and the removal of organs for transplantation has been the source of philosophical, clinical and ethical debate ever since the earliest formulation of the term. Many of the clinicians involved in these discussions express the opinion that the sole purpose a neurological definition of death serves is the facilitation of the procurement of fresh viable organs for transplantation. Most importantly, recent years have seen impassioned debate around the world about the validity of the concept of brain death. This debate can be followed at the bmj.com website/ rapid responses for the last two years. This discussion has been precipitated by research demonstrating the viability of areas of the brain for much longer than suspected when appropriately treated (Coimbra, 1999). Increasingly there are calls for a return to a definition of death based on the cessation of blood flow in the interests of honesty and scientific clarity (Truog, 1997; Shewmon, 1998; Lock, 2001; Coimbra, 2002; Evans, 2002; Potts, 2002; Woodcock, 2002) . It would seem then that in less than half a century we have come full circle in our understandings of death.

This was an issue I was confronted with during data collection for this project. It was not an issue I had actively sought to include in this investigation but one that I recognised as pivotal to the project when it arose. Since the middle of the twentieth century criteria have been developed and used for the diagnosis of brain death and, following refinements, these have remained relatively settled since the early 1980's (Capron, 2001;Wijdicks, 2001). My faith that these criteria were clear and easily followed was shaken as I heard some challenging stories from participants.

One of the doctors who shared his experiences with me (a neurologist with over 30 years' experience) expressed his dissatisfaction with the manner in which testing for brain death was being carried out. He supported this opinion with examples from his clinical practice of a dozen cases of patients who had been diagnosed 'brain dead' but were to his knowledge now living fruitful lives. Furthermore they had expressed the opinion to him that they were contented with the quality of their lives. I was also told a story by a relative about her experiences as she watched her father 'fight' for breath when he was extubated following the diagnosis of 'brain death' by two specialists presumably following the criteria for diagnosis discussed above. It became apparent that a review of the contemporary knowledge and practices surrounding the diagnosis of brain death was vital to this project.

This chapter begins with an overview of the historical and political background to the evolution of the concept "brain death". This development includes the evolution over the last half century of the criteria used in the clinical diagnosis of brain-**stem** death. Next the current practices used in the diagnosis of brain death in Critical Care units will be described. Thirdly there will be a critique of both the concept of brain death and the current practices used in the determination of brain death. This will set a foundation for analysis of some of the stories about the maintenance and withdrawal of life support that are presented in chapters six, seven and eight. The final section of the chapter will include a critique of the protocols and guidelines currently in place in health care to support the accurate and safe diagnosis of brain death.

4.1 THE HISTORY AND POLITICS OF 'BRAIN DEATH'

For centuries, as both Pallis (1987) and Evans (1995) illuminate, people have been legitimately fearful of premature declarations of death and being buried alive. This is not a fear that escapes members of our more' modern' societies today. A gentleman of Uttar Pradesh, India was awarded the Ig Nobel peace prize in 2003 for his efforts and experiences in this area. Mr Bihari received the award for "…leading an active life even though he has been declared-and remains-legally dead." (p. 813). The citation was also for waging a lively posthumous campaign against greedy relatives who had him declared dead in order to steal his land and for creating the Association of Dead People (Lenzer, 2003).

For much of history, the absence of respirations has been the standard determinant of death, an assessment as often performed by the lay public as by physicians (Evans, 1995; Capron, 2001). The invention of the stethoscope enhanced this diagnostic measure to include the beating heart and until the middle of the 20th century, death was diagnosed on the basis of the irreversible cessation of circulatory and respiratory functions (Jennett, 1981; Chaloner, 1996; Sullivan, Seem & Chablewski, 1999; Capron, 2001; Wijdicks, 2001). Since the middle of the 20th century advances in medical knowledge and intensive care therapeutics have facilitated the rescue and support of many people who would previously have died. This has coincided with the ability to perform organ transplants on an increasingly larger scale. Indeed there is much to support the assertion that:

> ***"****The only reason to diagnose brain death is to legitimise the procurement of top-quality vital organs for transplantation. A doctor does not need to diagnose brain death for any other purpose, including discontinuation of ventilation. If I just want to turn off a ventilator, I can do it on the grounds that it is no longer in the patient's interest to continue****"*** *Woodcock, T (Personal communication 22/04/02)*

The pre-morbid syndrome, *coma dépassé*, literally 'a state beyond coma' was first described in 1959 in the French neurological literature by two Parisian Neurologists, Mollaret and Goulon. When, in 1968, the first reported heart transplant occurred in Japan, the surgeon was accused of unlawfully killing both donor and recipient. The response of most policy makers and clinicians to the spectre of litigation foreshadowed in this early incident was an insistence that the donor of organs be declared dead before their organs are removed for transplantation. This has become known as the "dead donor rule" for major organ donation (Kerridge, Saul, Lowe, McPhee & Williams, 2002).

The AD Hoc committee of the Harvard Medical School endorsed the concept of 'brain death as death' in 1968. They made the proclamation that "…life support could be withdrawn from patients with irreversible coma or brain death"

(Hoffenberg, 2001, p1480) and provided the first criteria for diagnosing brain death. Conjoined legal opinion offered at the time of the report advised that patients satisfying the criteria for brain death be pronounced dead before organ removal was considered or attempted (Hoffenberg, 2001). Thus organ donations proceeded on this basis without legal impediment even though the law that defined brain death as the permanent cessation of respiration and circulation was not changed until 1981 to allow for the concept of 'brain death'.

While the tests for the diagnosis of brain death listed by Harvard ad hoc Committee included the EEG, this has not been the case in the UK and Australia. The development of the UK criteria was strongly influenced by the work of Mohandas and Chou (1971). A small study (25 cases) by these two specialists focussed attention upon the 'importance' of physiological loss of brain-**stem** function as the 'point of no return' in the diagnosis of brain death. Specific criteria, for determining this 'point of no return were listed (discussed in section below), accepted within the USA and underpinned the 1976 UK criteria. These were dubbed the Minnesota criteria. The aim of the development of these criteria was to dispense with the EEG as a tool in the diagnosis of brain death. This is what has come to pass for, if one uses the Minnesota criteria, which have been worked into the British Criteria and the Guidelines published in the 1981 President's Commission, then "… it is not necessary to include EEG evaluation in determining death" (Byrne & Nilges, 2001)

The law in the USA was changed to reflect the 'brain death as death' diagnosis after a report of the medical consultants to the US Presidents Commission (1981) recommended that the diagnosis of 'brain death' be seen as synonymous with death of the organism as whole. Following this commission, a Uniform Determination of Death Act, which insisted upon "whole brain death" as a *sin qua non* of brain death was enacted into law and accepted in most of the United States of America. This insistence upon "whole brain" death as criteria for death has itself been a source of controversy in the US, raising as many problems as it seeks to solve. If taken literally, the detection of any residual electrical or neurohormonal activity in any part of the brain at all would preclude the diagnosis of brain death (Truog, 1997; Shewmon, 1998; Capron, 2001; Evans, 2002).

The Conference of Medical Royal Colleges and their Faculties in the United Kingdom developed the UK criteria in 1976 and defined 'brain death' as the complete and irreversible loss of brain **stem** function. A 1995 review by the Conference of Medical Royal Colleges preferred the term 'brain stem' death but otherwise found no need to modify their original diagnostic criteria. While a further review in 1998 linked the process to procurement of organs, it was of a similar confident view regarding the original diagnostic criteria for brain stem death (Black, Balderson, Gadd, Bates, Falvey, Gaffin et al., 1998).

In Australia in 1977, the Law Reform Commission drafted legislation for *the Transplantation and Anatomy Ordinance*. The definition of death was:

a. Irreversible cessation of all function of the brain of the person; or
b. Irreversible cessation of circulation of blood in the body of the person. (Law Reform Commission, 1977, p136).

How "irreversible cessation of all function of the brain" is to be determined is not codified in law. As intensivist and adviser to the NH&MRC on the topic of brain death, Ray Raper, outlined in a recent Radio National discussion:

> *…the definition of death doesn't require us to test all brain functions. The definition of death requires that we certify that all brain function is irreversibly ceased. How that was to be certified was not prescribed in law, and neither was it prescribed by the Law Reform Commission when they drafted this definition of death originally. That was left up to professional consensus. (Carlisle et al., 2002)*

Table 4.1 A summary of the historical development of brain-stem death as death and its diagnostic criteria:

Author/s & year	**Significant Events**	**Characteristics**
Mollaret & Goulon **1959**	First Definition *(coma dépassé)*	▪ Loss of brain stem reflexes ▪ Loss of capacity to breath spontaneously (apnoea) ▪ Absence of tendon reflexes in limbs (spinal cord function had also ceased) ▪ EEG was 'flat'
Harvard ad hoc committee **1968**	Linked irreversible coma with death	▪ Unresponsive/ unreceptive & apnoeic for period of 24 hrs +Absent brain stem reflexes
Mohandas & Chou **1971**	Minnesota Criteria (identified importance of preconditions i.e. irreparable intracranial cause of coma)	Called for: No observed spon. m'ment For 12 hrs rather than 24 At least 4 minutes' apnoea No brain stem reflexes
Conference of Medical Royal Colleges & their faculties **1976**	**Publication of UK Code** Reviewed without alteration 1995 & again in 1998 (DoH) with links to organ donation protocols	Identification of coma Clinical evidence of cause Exclusion of drugs & hypothermia Absent motor response Absent brain stem reflexes Apnoea
President's Commission for study of Ethical Problems in Medicine **1981** **Uniform determination of Death Act**	<u>US Code Published</u> Reviewed 1995 – Recommendations: Confirmatory testing& Practical guide to apnoea testing	Follows same criteria as UK Code

(Conference of Medical Royal Colleges and their Faculties in the United Kingdom, 1976); (Pallis, 1987); (Black et al., 1998); (Jennett, 1999); (Wijdicks, 2001);

4.2 CURRENT PRACTICE FOR DETERMINING 'BRAIN DEATH'

Clinical neurological examination remains the standard for determination of brain death. The declaration of brain death involves the combination of a series of neurological tests with the establishment of:

- the cause of the coma.;
- the ascertainment of irreversibility of the cause;
- the resolution of any misleading neurologic signs;
- the recognition of possible confounding factors;
- the interpretation of findings on neuroimaging;
- the performance of any confirmatory laboratory tests deemed necessary

(Crippen, 1991; Black et al., 1998; Sullivan et al., 1999; Sahni, 2000; Lazar, Shemie, Webster & Dickens, 2001; Wijdicks, 2001).

4.2.1 Prerequisites for the diagnosis of brain death

Before the clinical neurological examination of the patient in whom brain death is suspected can proceed, certain initial prerequisites must be met. These are perhaps best conceptualised as essential preconditions and necessary exclusions. The individual for whom a diagnosis of brain death is being considered will typically present with clinical or neuro-imaging evidence of an acute, catastrophic cerebral event. The cause of this event must be established as irremediable and this cannot be done on theoretical grounds. In other words, all attempts to correct potentially treatable problems must have been undertaken as an essential precondition to assessment for brain stem death (Pallis, 1987; Crippen, 1991)

All potential metabolic and/or pharmaceutical influences on the patient's condition have been excluded prior to testing. Thus necessary exclusions prior to assessment for brain stem death include:

- Extremes of metabolic or endocrine disturbance.
- Drugs (i.e. sedatives, muscle relaxants) or poisons in the system.
- Hypothermia (must have a core temperature ≥ 32° C)

(Pallis, 1987; Hudak, Gallo & Benz, p. 530, 1990; Dorr, 1997; Black et al., 1998; Sullivan et al., 1999; Lazar et al., 2001; Wijdicks, 2001).

The **cardinal** findings in brain death include

- coma or unresponsiveness,
- absence of cerebral motor responses to pain in all extremities,
- absence of brain stem reflexes and apnoea

(Mollaret & Goulon, 1959; Mohandas & Chou, 1971)

Current practice for the determination of brain death is essentially a three step process involving examination and documentation that the patient meets the above criteria.

4.2.2 Coma

Coma has been defined as

> "…deep sustained unconsciousness that results from dysfunction of the ascending reticular activating system in either the brain stem or both cerebral hemispheres. The eyes remain closed, and the patient cannot be aroused. To be distinguished from syncope, concussion, or other states of transient unconsciousness, coma must persist for at least one hour" (The Multi-Society Task Force on PVS, 1994, p1452).

Characteristically, such patients will have been in a comatose state as a result of their injury for a prolonged period. Although there is debate about how long this period of unresponsiveness need be, a minimum period of observed unconscious was set at 6 hours in the 1983 review of the UK Code of Practice (Evans, 2002). In most patients with brain death, the reason for this period of unresponsiveness will have been established with neuro-imaging (Sullivan et al., 1999; Schubert, Trantor & Chapranka, 2001). In rare cases of brain death due to ischaemic-anoxic cerebral injury, the patient may have normal neuro-imaging studies (Sullivan et al., 1999;

Wijdicks, 2001). In such cases, where the patient's coma is of indeterminate origin, determining brain death remains difficult and presents increased difficulties for the patient's family (Evans, 1995).

4.2.3 Motor Responses to Pain

The depth of the individual's coma is assessed through the documentation of the assessment of the cerebral motor responses to pain. These are elicited through the use of "standardized" painful stimuli such as pressure applied to the finger nail beds, supraorbital nerves or to the temporomandibular joints. Purposive or cerebrally modulated motor responses to painful stimuli will be absent in all peripheries in brain death. (Mollaret & Goulon, 1959; Mohondas & Chou, 1971;Black et al., 1998; Sullivan et al., 1999; Lazar et al., 2001; Wijdicks, 2001). It is noted that spontaneous motor responses (eg twitching, small arm or leg movements) may occur during apnoea testing as a result of hypoxia or hypotension. These movements are considered to be due to spinal cord reflexes and noted to be a potential source of concern for relatives and inexperienced staff (Black et al., 1998; Sullivan et al., 1999). They do not include attempts to breath or voluntary purposeful movements. Once the absence of motor responses has been documented, the examination next considers the assessment of brain stem reflexes.

4.2.4 Assessment of Brain Stem Reflexes

4.2.4.1 Functions of the Brain Stem

Autonomic and involuntary functions such as cardiac response, respiratory drive and blood pressure are centred within the medulla oblongata of the brain stem. The senses (other than sight and smell) pass to the brain via the brain stem and motor output to the muscles leaves the brain via the brain stem. Importantly, the brain stem mediates all the cranial nerve reflexes. The brain stem is also thought to have some role in the mediation and integration of consciousness. For a fuller discussion of the functions of the brain stem see glossary (appendix viii).

The assessment of brain stem reflexes is the assessment of the lower brain's ability to sustain basic life. For example, such functions as the ability to cough, gag, withdraw from noxious stimuli and breathe are the supported by the brain stem. All brain stem reflexes will be absent in brain death (Mollaret & Goulon, 1959; Mohondas & Chou, 1971; Conference of Medical Royal Colleges & their Faculties in the United Kingdom, 1976; Jennett, 1981; Pallis, 1987; Sullivan et al., 1999; Lazar et al., 2001; Wijdicks, 2001). If brain stem reflexes are absent then the examination should result in the doctor documenting:

- Absent pupillary response to bright light
- No grimacing or purposive motor response to painful stimuli
- Absent corneal reflex
- Absent ocular-cephalic reflex (doll's eye movement)
- Absent oculo-vestibular reflex (cold caloric test)
- Absent pharyngeal (gag) and tracheal (cough) reflexes

Assessment of many of these reflexes becomes problematic in the case of severe head injuries and facial trauma as indicated in the table below. A more extensive discussion of this diagnostic process may be found in Appendix v: Determination of Brain death.

Table 4.2 Summary- Brain stem reflexes (Sullivan et al., 1999; Wijdicks, 2001)

Brain Stem Reflexes assessed	**Findings in Brain Death**	**Cranial Nerves Tested**	**Reliability in massive Brain Injury**
Pupillary reflexes	Absent response to bright light (pupils at midpoint with respect to dilatation 4-6mm)	II and III	Dependant amount of swelling and access to eyes
Facial sensory & motor responses	Absence of grimacing or eye opening in response to pain, eg deep pressure on temporomandibular joints	Afferent V & Efferent VII	Problematic in presence of facial swelling
Corneal Reflexes	Absence of grimace/ pain response when edge of cornea is touched	V and VII	Dependant on access to eyes
Oculo-Cephalic reflex (problematic)	Absence of deviation of eyes to opposite side following rapid head turning 90° (doll's eye phenomenon)	III, VI and VIII	Problematic in presence of unstable cervical spine

			– not recognised as reliable
Oculo-Vestibular reflex (caloric test)	Absence of response (deviation of eyes towards side of cold stimulus provided by introduction of ice water)	III, VI and VIII	Problematic in presence of facial/jaw/temporal area trauma
Pharyngeal (gag) reflex	Absent – elicited by stimulating rear of pharynx with tongue depressor	IX and X	Difficult to assess in the orally intubated patient (often the case in the first 24-48 hrs with head injuries).
Tracheal (cough) reflex	Absent – elicited by inserting a suction catheter deep into the trachea.	IX and X	Most reliable

4.2.5 Apnoea Testing

Apnoea testing requires the induction of hypercarbia to a level that it would be expected to stimulate the patient to inspire if the respiratory centre in the brain stem was intact (Sullivan et al., 1999, Wijdicks, 2001). Apnoea testing requires disconnection from the ventilator for a period long enough to satisfy the testing physician that the patient is not going to breathe spontaneously and to allow the patient's PCO_2 to rise to 60mm Hg (Wijdicks, 2001). If inspiration does not occur, the inference drawn is that irreparable damage has been done to the patient's brain stem. To satisfy the current criteria for brain death, this process should be repeated by a second qualified medical officer (Wijdicks, 2001). Research and refinement has instituted such safeguards as apnoea diffusion oxygenation and streamlining of the process by raising the patient's $PaCO^2$ to 40mmHg before disconnection from the ventilator (to reduce the period of disconnection) (Roper & Zisfein, 1990; Benzel, Mashburn, Conrad & Modling, 1992). Nonetheless, apnoea testing requires the patient to be disconnected from the ventilator twice.

4.2.6 Confirmatory testing

In situations where components of the clinical evaluation for brain death cannot be reliably evaluated (see table above), then the physician may have to turn to confirmatory testing. The confirmatory tests discussed in the literature include Electroencephalography, Cerebral Angiography, Transcranial Doppler Ultrasonography, Somatosensory-evoked Potentials, and Cerebral Scintigraphy (Nuclear imaging) all of which of have relative use and accuracy depending on the clinical scenario (Pallis, 1987; Bates, 1997; Jenkins, Reilly, McMahon & Hawthorne, 1997; Zandbergen, deHaan, Stoutenbeek & Koelman, 1998; Litscher, 1999; Carter & Butt, 2001; Wijdicks, 2001; Hankey, 2002). For example there has been on-going debate about the usefulness and applicability of the electroencephalogram in the diagnosis of brain death and in some cases, eg MRI or Cerebral Scintigraphy, the sheer logistics of transporting patient and for testing becomes a consideration. The details of the performance of these confirmatory tests are discussed at length in the glossary.

The use of confirmatory tests to augment the clinical determination of brain stem death is mandated by law in several European, Central and South American and Asian countries (Wijdicks, 2001). Conversely, confirmatory testing is perceived and discussed as ‘optional’ corroboration of the diagnostic process in the literature emanating from the United States and Britain where the use of such tests is left to the discretion of the physician (Litscher, 1999; Sullivan et al., 1999; Swinburn, Ali, Bannerjee & Khan, 1999; Wijdicks, 2001). As the diagnosis of brain death is intimately linked to the procurement of organs for transplantation, some of the discourse centres on how confirmatory testing might facilitate a speedier process so that ‘fresher’ organs might be obtained for harvest and transplantation or indeed how the charges for care might be minimised if this process were ‘streamlined’. For example one study suggested the determination of brain death could be speeded up using just one clinical examination together with a nuclear medicine brain flow scan (Jenkins et al., 1997).

The Jenkins study reported improvements with respect to the numbers of organs procured per patient, reduction in costs for care, and reduction in complications while these patients were being cared for. There was, however, no discussion of the relative accuracy rendered by this ‘speedier’ method of determination of brain death. As this method depends on one clinical examination only, the validity of the diagnosis of brain death depends upon one physician’s expertise and opinion. Although this examination is supported with a recognised confirmatory test, this testing method is seriously flawed in that it does not allow for the passage of time for the patient’s condition to alter or for the value of a second opinion. Although costs are a concern both to the consumer and the health care system, accuracy in diagnosis should be the prime consideration in light of the impact of a finding of brain death upon the patient and loved ones left behind (Evans, 1995; Inwald, Raper, Jakobovits, Petros & Fisher, 2000; Pugh, Clarke, Gray, Haveman, Lawler, Bonner, 2000).

4.3 CRITIQUE OF THE CONCEPT OF BRAIN DEATH

The critique of the “established” practices in the diagnosis of brain death has two main elements:

1. Brain death cannot be reliably determined using the current diagnostic tools and techniques.
2. Procedures to diagnose brain death are sometimes performed either by inexperienced doctors who may leave out or misinterpret vital steps, or without due diligence by experienced doctors.

Research concerning the pathophysiology of raised intracranial pressure (ICP) has improved our understanding of the types of support a severely neurologically compromised individual may need and the time frames for recovery that are involved. Indeed this research (described below) challenges the very basis of brain death diagnosis and implies that patients who are diagnosed too early after cerebral insult may in fact have lived had they not had their organs removed or their ventilators prematurely turned off.

In a multi-centre blinded assessment of 136 patients randomly assigned to undergo therapeutic hypothermia following successful resuscitation after cardiac arrest due to ventricular fibrillation, Safar and Kochanek (2002), found this intervention increased the rate of a favourable neurologic outcome and reduced mortality in 55% of cases. Research has demonstrated that induced hypothermia (with or without use of thrombolysis) has had positive results in outcomes for patients who might have otherwise been diagnosed with brain death (Coimbra, 1999; Bernard, Gray, Buist, Jones, Silveter, Getteridge & Sith, 2002). Bernard et al (2002) compared outcomes in 77 adult patients (males > 18years, and females> 55years) who remained conscious after resuscitation from out-of–hospital cardiac arrest. These researchers found that 21 of the 43 patients (49%) assigned hypothermic intervention survived to go home or to a rehabilitation facility (classified as ‘good outcome’ p.557). Of the 26 assigned to normothermic intervention, nine (26%) progressed to a good outcome. These observations prompted Bernard et al (2002) to conclude that induced hypothermia ‘…improves outcomes in patients with coma after resuscitation from out-of-hospital cardiac arrest” (p.563).

Recent research has cast further doubt over the worth of the EEG as part of the diagnostic criteria for Brain Death (Facco, Munari, Gallo, Volpin, Behr, Barrato & Giron, 2002). These researchers tested the effectiveness of auditory brain-stem responses (ABRs) and somatosensory evoked potentials (SEPs) on 130 patients. They submitted 81 male patients and 49 female patients (aged range 8-77 years) to serial recordings of ABRs and SEPs in the same session. The use of these tools was able to confirm brain death in all but 7 cases. However, in these 7 cases, despite a clinical and EEG picture of BD, diagnosis of BD was deferred due to detection of the brain-stem evoked potentials and responses monitored.

Significant is Coimbra’s description of the syndrome of “global ischaemic penumbra” (GIP) which may last hours or several days (Coimbra, 1999). He describes this state of ‘brain shock’ occurring as a result of raised intra-cranial pressure (ICP) potentially impairing blood supply to the whole brain or solely to the infratentorial structures. This ischaemic state in the brain will then lead to the absence of the ‘synapse-dependent’ functions, which are tested in the diagnosis of brain death. The person’s brain in these cases, he argues, is deeply comatosed and areflexic, not dead (Coimbra, 2002). This means that for patients who have raised ICP the diagnosis of brain death should not be attempted until the ischaemic penumbra has subsided which takes about 36 hours. Evidence of hypothalamic secretory action may be used as a means of indirectly inferring a blood supply to deep cerebral tissue above 10ml 100g $^{-1}$/min^{-1} (Coimbra,1999). Measuring specific hormonal release (hypothalamic-pituitary hormones, thyroid hormones and cortisol, Gramm and colleagues (1992) followed 32 adults listed as potential organ donors following cerebral damage from trauma or sustained anoxia during resuscitation attempts. These patients displayed deep coma and concomitant cerebral areflexia. While 78% of patients developed diabetes insipidus, no other hormone concentrations were found to be subnormal over the 80 hours they were monitored. Arita and co-workers (1993) monitored the release of the hormones ACTH, Luteinizing hormone-releasing, and Growth hormone releasing hormone in 24 thermoregulated adult patients, previously diagnosed as brain dead, over a 3 day period. In this study “… one or more hypothalamic hormones were detectable in every case”(p.1482).

Drawing on these and similar earlier studies, Coimbra (1999) argues that this sustained hypothalamic circulation (implying circulation above 10ml 100g $^{-1}$/min^{-1} when concomitant with deep coma and cerebral areflexia, suggests that the neural structures with higher metabolic demands (those assessed for the diagnosis of brain death) may be under GIP. Preservation of brain blood flow in these patients is crucial and yet may be compromised by hypercarbia, hypertension, or hypotension as a result of the very tests we carry out:

> “…*apnoea testing may induce rather than diagnose irreversible damage to brain tissue, and the results of all confirmatory tests carried out thereafter may reflect the deleterious effects of induced apnoea with or without hypoxia*.” (p. 1483),

If apnoea testing is performed during this period of ‘ischaemic penumbra’ and the patient is disconnected from the ventilator twice, then as they areflexive, even with appropriate pre-oxygenation, this testing is likely to produce a self-fulfilling prophecy. This is the argument put forward by the many clinicians calling for a halt to apnoea testing (Truog, 1997; Lock, 2001; Evans, 2002; Coimbra, 2002; (Woodcock, 2002). Indeed many clinicians are calling for an abandonment of the neurologically based definition of death altogether (Truog, 1997; Shewmon, 1998; Potts et al., 2000); Evans, 2002; Kerridge et al., 2002; Woodcock, 2002).

As the main reason for a neurologically-based definition of death is the obtaining of viable organs for transplantation, and there can be no advantage to the patient in inducing apnoea, clinicians around the world are asking their colleagues to recall their first ethical imperative: “Primum non nocere” – first do no harm, in the care of the defenceless comatose patient, and abandon apnoea testing (Lock, 2001; Coimbra, 2002; Evans, 2002; Potts, 2002; Woodcock, 2002).

4.3.1 Lack of consensus about diagnostic criteria

In this matter, medicine tends to operates at the edges of the law because the law does not specify how the diagnosis of brain death is to be made. Instead, when the definition of death under Australian law was drafted by the Law Reform Commission: “That (how diagnosis should be reached) was left up to professional consensus” (Carlisle et al., 2002). This lack of consensus relates, in part, to whose interests are being promoted and protected by varying claims about what the criteria for ‘brain death’ should be. As the diagnosis of ‘brain death as death’ is intimately linked to the procurement of organs for transplantation, some of the discourse related to confirmatory testing centres on how this might facilitate the ‘speeding up’ of the whole process so that ‘fresher’ organs might be obtained for harvest and transplantation. This point is illustrated by a neurologist’s experience in the early days of heart transplantation. Time taken to declare the comatosed individual ‘brain dead’ may have damaging impacts upon the organs that transplant surgeons are hoping to use. Anxiety about such ‘wastage’ may tempt them to bring pressure to bear upon the physicians performing assessment for the determination of brain death.

This was indeed the experience of one physician in the early days of heart transplant who insisted upon a third, later set of tests for brain stem reflexes in a patient before authorising the harvesting of that individual's heart. For his delay he was greeted with the exasperated: "God, Bill, what sort of heart are you going to give us?" (Hoffenberg, 2001). As previously mentioned, discussion of minimisation of costs related to this diagnostic process, for example using one clinical examination and a nuclear medicine brain flow scan (Jenkins et al., 1997), is also used as an argument. Such an approach would not be valid given the discussion of ischaemic penumbra and the continuation of brain stem function which cannot be clinically evaluated even with the direct scanning of cerebral blood flow (Coimbra, 1999).

The guidelines for apnoea testing insist upon the exclusion of respiratory depressants from the patient's system i.e. muscle relaxants and sedatives. The literature indicates however that it is not uncommon for these not to be ceased thus masking and 'smothering' spontaneous attempts to breathe should they occur. Indeed the issue of double-effect is raised in relation to the maintenance or even initiation of muscle relaxants and sedation as the patient is extubated (Swinburn et al., 1999; Truog et al., 2000; Street, Edwards, Henderson, Inwald, Vandyck & Grieg-Midlane 2001). The fact that this possible aberration from established practice is canvassed in the contemporary literature must be disturbing for the majority of health practitioners in the critical care field. It does indicate though that what this majority feel to be 'established practice' is not necessarily so.

While the criteria for the determination of brain death have been well researched and documented, it cannot be said that they are always uniformly and rigorously followed (Jenkins et al., 1997; Sahni, 2000). As this review and discussion has illustrated, neither are they without their problems. As Wijdicks acknowledged, there are concerns about the use of 'adequate' precautions when apnoea testing and until recently, there had been no audits of the competence of physicians in the determination of brain death (Goudreau et al in Wijdicks, 2001). It would seem therefore, that the only really reliable test of brain death is whether the person breathes when the ventilator is turned off

4.3.2 Expertise and experience of those diagnosing brain death

As discussed, the law in the UK, US and Australia does not specify the skill, training or advanced qualifications of the doctors who diagnose brain death. Just who performs the clinical neurological examinations leading to the determination of brain death depends upon each hospital's protocols and upon its locality and resources. It has been convincingly argued that because of their expertise, only neurophysicians and neurosurgeons should perform these examinations and make the related determination (Wijdicks, 2001; Baumgartner & Gerstenbrand, 2002), but in practice there is a wide variation in the experience and qualifications of the doctors involved in diagnosing brain death. As the current NH&MRC discussion paper on "…the diagnosis and certification of death with respect to brain function criteria" acknowledges, the procedure varies from hospital to hospital. The authors of this paper felt that the practices have however, become 'fairly standardised', being guided by codes of professional conduct and the statutory definition of death (where applicable) National Health & Medical Research Council, 2002). This statement is not supported by a meta-analysis of practice guidelines for brain death diagnosis within 80 countries. Wijdicks (2002) carried out a systematic investigation of the practices related to the diagnosis of brain death in 80 countries, reviewing the guidelines and legal standards, obtained through literature searches and personal contact with physicians. This investigation led Wijdicks to conclude that while there was uniform agreement on the neurologic examination with the exception of the apnoea test, "… this survey found other major differences in the procedures for diagnosing brain death in adults. Standardization should be considered" (p.20) (Wijdicks, 2002).

Policies do not usually require credentialing of the diagnosing physicians and do not usually rule out inexperienced doctors from decision-making. The lack of credentialing means that the public are supposed to believe that all doctors currently involved in the diagnosis of 'brain death as death' are adequately skilled in neurological examinations. Given the evidence of people surviving the diagnosis of brain death we reject this belief.

4.3.3 Who should be diagnosing brain death?

As Wijdicks (2002) has asserted, the issue of quality assurance in relation to the diagnosis of brain stem death in clinical practice needs attention. Ideal practice standards recommend that such testing, if it is to proceed should be carried out by specialists only (Wijdicks, 2001; Lazar et al., 2001; National Health & Medical Research Council, 2002; Baumgartner & Gerstenbrand, 2002). If the discipline is to develop such specialists this standard should include registrars (senior training medical officers) under direct specialist supervision. The constraints of distance and/ or resource mean though that not all health care facilities have adequate numbers of specialist staff available to facilitate this standard. In some cases, general physicians or training medical staff are required to perform one or both of the assessments for certification of brain death. While Baumgartner & Gerstenbrand (2002) argue cogently that any physician trained in the use of a ventilator should also be trained in the diagnosis of brain death, the reality is that one or both of the tests in the procedure for the diagnosis for brain death may be carried out by a medical officer without sufficient expertise, experience and supervision leading to the missing of vital steps in the procedure or the misinterpretation of those steps which are performed. Indeed in 1989, Younger et al reported that only 35% of a sample of medical practitioners concerned with diagnosing brain death could accurately identify the legal and medical criteria for determining brain death.

It is imperative, then, that all units have clearly outlined protocols guiding the assessment process and documentation for the determination of brain death. These protocols would encompass the following issues:

- Credentialing of assessors;
- the time frames involved;
- recommendations related to confirmatory testing and;
- documentation of assessment.

While there is little in the literature that addresses the specifics there are some generally accepted norms. For example it would seem to be accepted that two different physicians/specialists perform the examinations and that these examinations should be delayed, not for the standard six hours, but for 36 hours when ischaemic penumbra may be contributing to the coma state. It is accepted that these two physicians/specialists should not be treating the individual for assessment and should have no interest in the treatment of the potential recipient/s of organs (Romanini &Daly, 1994; Nimmo et al., 1994; Schubert et al., 2001).

To address this deficit with respect to specifics and to acquire an understanding of the 'state of play' with respect to diagnosis of brain death within the region I wrote to all the critical care units in South-East Queensland likely to be ventilating (13 in all) and thus requiring a protocol for the determination of brain death (see appendix v).

I received replies from two major critical care units who informed me that they both follow the National Guidelines for Organ and Tissue Donation (last updated in 1999, see Appendix x). This document does indeed include specifics and guidelines about the level of expertise of the physicians performing this testing as well as degree of interest in the patient and outcome of the diagnosis. It clearly outlines the criteria for the diagnosis of brain death previously discussed, together with the essential preconditions and necessary exclusions that must be met before testing. It does not outline how these tests are done however so that there is no confidence of uniformity of testing even if all units throughout Australia are following these guidelines. The paper does make recommendations with respect to documentation of testing procedures and provision of supporting information to relatives and staff in an understandable format. One is encouraged that there are measures of quality assurance and family support already in place.

One of the replying units informed me however that they had "no specific policies" as they followed the aforementioned guidelines. The second informed me they documented both assessments (completed by two specialists at least four hours apart) on a summary sheet, which was then included in the patient's chart. This summary sheet is entitled "Brain Death Certificate – Queenslanders Donate August 2000" once again underlining the close links between diagnosis of brain death and the procurement of organs for transplantation. A death certificate is also placed in the chart and a copy issued to the family (or police) as appropriate. Once a patient has been identified as deceased the issue of organ donation is raised. The author of this letter ensures me that families of deceased patients are treated with "…empathy and courtesy, taking into consideration social, religious and cultural issues".

4.4 CONCLUSION

The advent of critical care units, mechanical ventilation and related advanced therapeutics challenged our long-held understandings of death. This was most severely challenged with the advent of heart transplantation and the need to take living, beating hearts from a people. The diagnosis of brain death and its legal definition is intimately linked to this new technology and legal challenges it presented. The determination of brain death hinges upon the accurate performance of a series of clinical neurological examinations. This may or may not be augmented by the use of confirmatory testing. With the advent of improved understandings, the validity of the concept of brain death is now increasingly questioned with the validity and ethical value of apnoea testing receiving particular scrutiny. This section of the literature review has discussed the problems that exist with the tool that is used for the diagnosis of brain death today and supports the argument that we should return to cardio-respiratory criteria for the diagnosis of death.

CHAPTER FIVE: METHODOLOGY

This chapter opens with discussion of the background, strengths of Interpretive Interactionism and the major methodological elements, which continue to form the foundations for Critical Interpretive Interactionism. The limitations of Interpretive Interactionism and proposed modifications are then outlined in table format to enhance the reader's understanding of the methodology's evolution proposed here. Next, the changes to Interpretive Interactionism to develop the research design "Critical Interpretive Interactionism" will be outlined using examples from the study to demonstrate the methodology's development. The final section of this chapter will address issues of praxis, academic rigour and accountability as they relate to this project.

5.1 OUTLINE OF INTERPRETIVE INTERACTIONISM

Denzin's original model of Interpretive Interactionism aimed to render 'understandable' epiphanies in the lives of ordinary people, those moments that "…rupture the routines and lives and provoke radical redefinition of the self: turning-point experiences" (Denzin, 1992, p26). Denzin (1989) suggested that by locating epiphanies-those moments in which personal troubles become public issues, then the personal is "…connected to the structural, through biographical and interactional experiences" (p.27). Involvement in end-of-life decision-making is just such a turning-point event for each of the relatives involved in this study and every nurse and doctor has had at least one epiphany experience related to ELDs in their practice though they take most in their stride on a day-to day basis. In this model, understanding is reached through the interpretations or meanings placed on interactions by the participants themselves. The methodological framework as outlined in 1989 by Norman K Denzin has several strengths including that Interpretive Interactionism:

1. Facilitates focus on the interactional processes between individuals in problematic situations and on deconstructing these processes in order to better understand them.

2. Focuses on the epiphanies or turning point experiences in a person's life, those moments when people's lives and routines are ruptured to provoke radical changes and a redefinition of the self. This focus allows the researcher to develop an understanding of those moments in ordinary people's lives when their private tribulations can be seen to be 'caused' by or 'contributed to' by the way in which social organisations are structured and function.
3. Describes clearly articulated steps in the interpretive research process, giving the researcher guidance on how to proceed in the collection, interpretation and analysis of data.

Using Denzin's (1989) model, there are six phases or steps to the interpretive process, which form the basis for the revised Critical Interpretive Interactionism.

Table 5.1 Steps of Interpretive Interactionism (Denzin, 1989)

- Framing the Research Question:
- Deconstruction and Critical Analysis of Prior Conceptions of the Phenomenon
- Capturing the Phenomena within the Social World through study of multiple naturalistic examples of the process or interaction under investigation
- Bracketing the Phenomenon: reduction of the process or interaction being examined to its key elements or features
- Construction: an attempt to interpret the interaction more fully through the "putting together" a model or single case of the process being studied.
- Contextualisation: locating the 'phenomenon' under examination within the social world by demonstrating how individual experience shapes and is shaped by the process being studied.

5.2 LIMITATIONS OF INTERPRETIVE INTERACTIONISM

In an earlier study, (Huard, 1997) Interpretive Interactionism (Denzin, 1989) was used to guide the research design. The earlier project found a theoretical correlation between repeated experiences of unsuccessful advocacy and burnout in critical care nurses (Sundin-Huard & Fahy, 1999). In that dissertation the nurses' experiences of ethical dilemmas in critical care were presented without moving beyond the participants' own understandings of the situations to incorporate critical insights of the researcher or insights that could be gleaned from the literature. This limit on interpretation was necessary to adhere to the interpretive methodology (Denzin, 1989). Importantly, how power is currently used was not addressed in the earlier study because the interpretive paradigm tends to focus on the lived experience and does not specifically focus upon power (Habermas, 1987). I have since come to realise that issues of power are central to understanding how ELD's are made and how nurses and relative may exercise more power in their own interests. To achieve this, the ontological and epistemological principles of the Critical Paradigm (Habermas, 1987; Fay, 1995) needed to be added to Interpretive Interactionism. In addition, some of the key insights of post-structuralism needed to be explicitly included (eg critique of rationality, autonomy, integrated subject, grand narratives) (Smart, 1995; Agger, 1998; Taylor, 2002). The way in which Interpretive Interactionism (II) has been modified is shown in the table below. The implications of these modifications will be explicated in the discussion of the research design, which follows this table.

Table 5.2 Interpretive Elements requiring modification:

Symbolic Interactionist premise guiding Interpretive Interactionism	**Modification for CII**	**Application in current study**
Humans are **rational** in their social interactions, using reason to explain and guide the worlds they live in. (Mead, 1954; Blumer, 1969)	Modify to recognise and incorporate emotional element of human behaviour in data collection and analysis. (Johnson, 1994); (Fahy, 1997)	Sought participants' reflections on emotions/ feelings during data collections. Recognised impact of emotions upon decision-making, interactions and suffering during analysis
Humans are **autonomous** in their actions (Mead, 1954; Blumer, 1969)	Autonomy implies separateness from individuals and the ability to make decisions in one's own best interests. As members of society, humans are too inherently dependent on the actions of others/ events outside themselves for the idea and ideal of autonomy to be appropriate (Fay, 1987;	Sought participant's reflections on, recollections of interactions with others during decision-making. Analysis specifically focussed upon degree and quality of interactions between/ interconnectedness of decision-makers.

	Johnson, 1994). Modify to acknowledge the inherent interconnectedness of all human beings.	
Although the self is 'multi-layered' the ego is in control thus the self is seen as **integrated** (Garfinkel, 1967; Goffman, 1985; Denzin 1989, 1992)	Modify to acknowledge **split subjectivity** and multiple selves each with their own discourse and that people do not always behave in an integrated way (Butler, 1995; Johnson, 1994; Smart 1995)	Analysis examined participants' narratives for varying roles adopted at different stages during their experiences together with the influences/ constraints responsible for these variations in 'behaviours'.
The focus of investigation and analysis is at the **micro-level** of society: local narratives at the intersubjective level (Denzin, 1992): "… locked into first-order, primary, lived concepts of everyday life" (p.25).	Modify to acknowledge the impact of the **macro-social** world upon the 'micro-situations' that are the focus of the person's suffering (Fay, 1995; Habermas, 1987; Stevens, 1989; Ray, 1995; Agger, 1998; Taylor, 2002).	This study specifically examined participants' narratives for the wider influences upon their behaviours as well as the inter and intra-personal; i.e. structural, procedural and policy supports or constraints
Emic perspective only in analysis: thus analyses reflect the views of the individuals being studied (Denzin 1989). The implication is that issues of **power** may not specifically be addressed.	Modify to retain the Emic perspective but include **Etic** perspective. This allows issues of power to be specifically addressed. (Fleming & Moloney, 1996; Kincheloe & McLaren, 2000; Taylor, 2002).	Analysis of the participants' narratives included examination of social issues and forces within the health care system which impacted upon decision-making experiences (ranging from seniority of the health care professional to impact of the 'medical establishment' upon doctors' decision-making.
Focus on **spoken word** in analysis. (Denzin, 1989)	Modify to include what is unsaid, what might have been said (i.e. the gaps and silences in narrative texts). Analysis should also include the 'gaps' in social context that are currently constraining participants acting in their own best interest.	Analysis of narratives examined the spoken interactions between key players. It also identified silences and absences such as absence of spiritual support for families; missing collegial support between health professionals.

The need to develop Interpretive Interactionism from critical and poststructural perspectives is not a new idea. Interestingly, in 1997 Denzin advocated: "An emancipatory critical interpretive Interactionism" (Denzin, 1997, p250). Denzin called for the Symbolic Interactionist to become more self-consciously interpretive, to adopt the "...insights from poststructural philosophy, principally work in cultural and feminist studies" (Denzin, 1992, p96). Essentially this is what the modifications, proposed here, are intended to do. Poststructural critical studies, Denzin points out, direct the researcher to regard the language and behaviour of participants in an interview as "... gendered, existential, biographical and classed..." (p161). Denzin argues that it is for these very reasons that issues of power, ideology, and how human individuals place themselves in relationship to each other, are of interest to the Interactionist (Denzin, 1992). These are all 'critical' notions indicating Denzin's own moves away from a purely interpretive paradigm. He has not specifically provided an outline suggesting how his 1989 model of Interpretive Interactionism might be adapted to develop Critical Interpretive Interactionism.

5.3 RESEARCH DESIGN FOR THIS STUDY:

Using Denzin's (1989) model, there were six phases to the interpretive process. With modification at several of these stages as outlined, the principles of critical post-structuralism can be incorporated into these steps to develop a design that allows the aims of this study to be met. This section of the chapter will outline each of these phases and illustrate how they have been modified for Critical Interpretive Interactionism.

5.4 CRITICAL INTERPRETIVE INTERACTIONISM

5.4.1 Framing the Research Question:

The first step in framing a question is that the researcher is and able to think critically, historically and comparatively as they examine issues close to their own biography in relation to the research topic. As Hanisch (1969) asserted, 'the personal is political'. The next step in is to discover how the researcher's interest or problem is relates to a public issue that affects multiple lives, institutions and social groups. The question should locate the site of these problems and frame their enquiry to ask "how" rather than "why' is this happening (Denzin, 1989). The question should focus on the <u>process</u> of interaction with attention to the contextual factors such as venue, organisational structures and policies. The steps in framing the research question were addressed in chapter one where I outlined the background to this study and presented the question driving this project:

> *"How might avoidable suffering related to the process of decision-making that accompanies the implementation, maintenance or withdrawal of life-sustaining treatment in the critical care environment be ameliorated?"*

5.4.2 Deconstruction and Critical Analysis of Prior Conceptions of the Phenomenon:

This step requires the researcher to locate previous conceptions of their problem as revealed in contemporary literature (Denzin 1989, p.51). Previous theories, observations and analysis of the phenomena under study have been critically examined in the literature review chapters. Previous biases and possible misconceptions surrounding existing understanding have also been presented. Researchers follow this step to identify problems and gaps in present knowledge to demonstrate the need for their study.

5.4.3 Capturing the Phenomena within the Social World:

Capture involves locating multiple cases of the phenomenon under examination. In this study the researcher secured personal stories from people who have experienced "epiphanies" or turning points in their lives in relation to ELD's. This step of the process occurred during data collection - the narratives themselves appearing in Results- Appendix II.

5.4.4 Bracketing the Phenomenon:

In "bracketing", the researcher inspects the data for examples of the phenomenon within the participants' broader narratives. At this point the researcher's focus of attention was limited to ELD's in the Critical Care setting. Previous understandings reached through deconstruction of the literature are suspended and the participants' narratives are inspected and dissected purely as examples of <u>their</u> experiences of the phenomenon. In this step the researcher reduces the phenomenon to its "essential elements" in an effort to elicit its key features and structures (Denzin 1989, p.55). The terms 'essential elements' are problematic from a post-structural perspective, suggesting that a clear, basic truth might be arrived at here. The alternative terminology "key factors" will be used in Critical Interpretive Interactionism and these factors will be identified as either:

1. **Interactional Process Factors (IF):** Used when referring to factors/ aspects of "… the interaction itself" (Denzin 1992, p. 59).
2. **Personal factors (PF):** Used when referring to intrapersonal, biographical, gender, race and class related factors inherent within the individual which impact the interactions (Denzin 1992).
3. **Contextual factors (CF)** Used when referring to those circumstances or "…factors surrounding a particular interactional situation" (Macquarie Dictionary 1991, p.96). For the purposes of this project, analysis will consider the micro, organisational, and broader historico-political context which is potentially impinging on the interactional situation.

This project aimed to understand how avoidable suffering was produced for the individuals telling their stories and then to offer recommendations to ameliorate this suffering where possible. The development of a theory which demonstrates where suffering is increased for an individual and thus, how that suffering might be reduced requires the 'measurement' of the factors impacting on the suffering. To that end, the key factors identified during analysis were also ascribed descriptor weightings signifying the potential impact on the experience/s of the individual/s involved in the interaction. In effect, key factors were made variable eg: 'seniority of staff member' (RMO, Registrar and Consultant) OR 'timeliness of decision-making' (timely, delayed, too late). Specifically, making the factors variables allowed me to identify which factors were related to the most suffering which in turn influenced the recommendations arising from this project.

Bracketing the phenomena involves several distinct yet inter-related sub-steps: -

i) *Examination of text of narratives for key phrases, silences or gaps which highlight and 'locate' the epiphany / crisis for the decision-makers.*

This step required the investigator to search the interview texts, which will appear in the font 'times new roman', for recurrent phrases or meanings that seemed to exemplify significant moments of the process of interest occurring within the interactions under investigation. This project focussed upon **key decision-making events** within each narrative and the interactions occurring around them:

Sandra continues, We waited from 9 o'clock to I think about 1 or 2 o'clock in the morning. The surgeon came back and was absolutely exhausted because he had been working all day.

ii) Interpretation of these moments as an informed reader;

I then interpreted these key moments and their importance as an informed reader. This was done by inserting my interpretations directly into the unfolding stories, `using courier new to make it clear to the reader when the researcher's etic perspective was being added`. During this stage of analysis, concept names were given to the factors identified, this time with an `COURIER NEW FONT ALL CAPS and brackets around the named factor (IF)`, in the key moments of interactions:

`Sandra spent at least four hours waiting to see Grant or hear news about his progress: BEING SEPARATED (prolonged) (IF); WAITING for NEWS (4+ hours) (IF). While there is nothing that can be done about the length of time taken to attempt to correct Grant's problem, Sandra should have been provided with regular updates on his progress. The absence of news during this long separation would have unnecessarily increased her anxieties: WORRYING (high) (PF). She had no feedback from theatre or intensive care staff until the surgeon spoke to her: BEING KEPT IN THE LOOP (Absent) (IF). There is no indication of a dedicated comfortable being provided for Sandra (she` `mentions having to go away for a cup of tea earlier): WAITING AREA (PUBLIC, NON-SPECIFIC) (CF).`

In this step the analytical focus was on the process of interaction with attention to the venue and the organisational, biographical, gender, and class related factors that may have been influencing the way the interactions occurred.

iii) *Solicitation of the informant's understandings or interpretations of these moments, if possible;*

This was done in a two-step process. During the interview, as key phrases occurred that seem to crystallise or speak to the phenomenon under investigation, I sought the participants' reflections on the meaning of the phrases to them at the time of the event and then at the time of the interview. When a tentative understanding of meaning of the key phrases "bracketed" from interview texts had been established, the interpreted story and list of key factors and emerging concepts was then returned to participants to seek their validation of the interpretation of the data. 14 of the 18 participants responded to my request to validate interpretation and indicated agreement with my interpretation of their interview texts.

5.4.5 Construction:

The penultimate phase of this design, construction, involves the reassemblage of the previously identified factors so that it can be conceptualised as theory (Denzin, 1989). In effect this step involved the 'reconstruction' of the identified key factors into a model theoretically explaining the phenomenon under investigation – in this instance, ELD making. 'Construction' follows upon and yet integrates with analysis. Construction too, has a number of distinct sub-steps:

i) Listing and Tentative ordering of 'bracketed' key factors in process for individual;

At the end of each interpreted narrative the key phrases, gaps and silences were listed together with tentative conceptualisations of the significance of each factor in the process of ELD making. All factors were listed at this stage and grouped under their analytical classifications: Interactional Process Factors, Context and Personal Factors,

Contextual Factors	
Waiting area	Public, non-specific
Personal Factors	
Worrying	High
Interactional Process Factors	
Waiting for news	4+ hours
Being separated	Prolonged
Being kept in the loop	Absent

ii) Ordering of key factors as they appeared within the process;

At the end of each sub-group of interpreted narratives, the key phrases, gaps and silences were listed together under their analytical classifications: Contextual, Personal and Interactional Process Factors. Factors were then sorted, subsumed and organised to reflect a tentative temporal and semi-constructed process explaining ELD's from the perspectives of the relevant group. This was done by comparing factors across cases within each sub-group. Factors were examined for similarities and like factors were grouped together and given a conceptual label. Any factor that was not recurrently reported was examined for theoretical relevance and was either subsumed or eliminated. This step is reflected in the discussion section of each analysis chapter.

iii) Tentative development of temporal and contextual ordering of key factors in process for each sub-group;

Following 'listing' of the 'bracketed' factors, Denzin suggests that the various factors be examined for some indication of how they all interrelate with one another and the process being studied (Denzin, 1989, p. 57). In the present study, the collected key factors were examined by the candidate and her supervisor together and organised into a tentative modelling of the process of ELD making from each group's perspective. The emerging theory was then compared and validated against two stories: one which the researcher felt represented a situation in which a high degree of avoidable suffering had occurred and one in which it was felt the participants had experienced the 'least' avoidable suffering.

iv) Production of concise statement/ model of process

Finally, according to (Denzin, 1989, p.59), the researcher needs to produce a statement or model that indicates how the constituent analytical elements cohere into a totality. In this project, the aim was to recreate the process as represented by the participants. The process outlined above in sub-steps i to iii will produce three models of ELD making, one from each group, and these will appear in conclusions to be discussed again in the context of the world in which they happened.

5.4.6 Contextualisation:

Contextualisation seeks to add depth of meaning to the constructed theory arising from analysis by finally laying aside the 'bracketing' of Critical Interactionism and '…relocating the major analytical concepts of the phenomenon within the social world' (Denzin 1989, p. 60). Contextualisation occurred in two phases in conclusions. As the three models of decision-making are discussed, examples drawn from each groups' narratives will be used to illustrate concepts and points made. To facilitate discussion, the researcher will develop a model of the ideal decision-making environment, drawing upon the models of ELD making from each group together with the experiences and remarks of the relatives, nurses and doctors in this project. This section of the design appears in the final chapter of this dissertation as findings are discussed, conclusions reached and recommendations for change are considered.

5.5 DATA COLLECTION

5.5.1 The Research Sites

Discussion and disclosure is most likely to be facilitated if the informant is allowed to choose the venue in which they feel most comfortable and relaxed (Yeandale, cited in Reinharz 1992). As informants were discussing experiences and feelings, which are deeply personal, these interviews were best conducted in a non-threatening environment. I offered firstly to travel to the informant's homes to save them any inconvenience. Aware of the potential intrusion, I offered my own home as an alternative venue. Interestingly, although I offered these options to the medical officers in this study, the majority of them chose to be interviewed at their place of work. Whether or not this was a reflection of the long hours these individuals work or their true comfort zone, I was unable to ascertain.

Additionally several interviews were carried out by telephone at my expense. This was due to the participants' distance from me and my own personal difficulties with long-distance travel. In all cases, the same interview format was used, I made sure that participants were aware that our conversations were being taped and that they were comfortable with this.

5.5.2 Participants

5.5.2.1 Selection and Recruitment Strategies

Ideally, this study would have focused on the perspectives of all parties in the same clinical case. The political, ethical and logistical ramifications of arranging such a study, while maintaining privacy and confidentiality presented an insurmountable obstacle. Theoretically this could have been an observational study but again, legal, ethical and time constraints made this impractical. Thus a more feasible approach was to seek separate groups of participants and ask them to talk about "similar" cases and their experiences in relation to these. To pursue this study I sought three separate groups of participants - each group: family members, nurses, and doctors, having very special characteristics of its own. The participants and the stories they told came from a variety of critical care units throughout South-East Queensland and New South Wales.

5.5.2.1.1 Family Members

Criteria for selection included that they a) have had a family member in critical care requiring some form of life-sustaining treatment, b) be willing to talk to me about that experience in an audiotaped interview.

Recruitment for this group of participants was a difficult process-it transpired that contrary to this researcher's assumptions, this was the most difficult group of participants to recruit. This is understandable given the subject matter that participants were being asked to consider disclosing and the potentially sensitive circumstances surrounding the events they were going to have to recall in this disclosure. A variety of recruitment strategies were tried before one was applied which met with success. Given that end-of-life decisions in critical care would have often ended in the death of their loved ones, I initially thought to enlist the aid of funeral directors as third parties in the recruitment of family members. I sought these parties as I thought they would be able to a) identify appropriate potential participants given clear outlines from myself; b) with their counselling skills, identify if and when the time was right to suggest that a family member contact me. My initial meeting with the funeral directors was met with enthusiasm and helpful suggestions together with agreement to post a notice about this study in the funeral homes' waiting rooms. Unfortunately, despite regular follow-ups this strategy was not successful. Both managers revised their enthusiasm regarding the posting of the notice in the waiting rooms and no suitable participants were ever identified via this strategy.

It became clear that I would need to advertise for family member participants for this study. I originally placed a small advertisement in the local newspapers to 'test' the waters. This met with absolutely no response. 'Lay' friends suggested that this poor rate of response might have been due to the absence of any information about me or the aims of the study. Accordingly, I used a brief piece in the local press to achieve those ends (see appendix III). This strategy did indeed achieve the desired outcome by a circuitous route. The piece in the paper did not result in approaches from the general public but rather from colleagues all around the University alerted to the aims and interests of my study, who then approached me with references to friends, acquaintances or family members they felt might be willing and able to contribute to this study. The participants in this group come from diverse educational and socio-economic backgrounds. Two of them are nurses with their own experiences as relatives. Consequently, their knowledge base and understanding of the events they narrate is stronger that the other participants. The stories told by family members come from within the private and public Health Care Systems in South-east Queensland and NSW. The participants and the loved ones they talk about come from both genders and represent a broad age-span.

5.5.2.1.2 Nurses

These nurses must have had at least five years' experience in the critical care area for two reasons. Firstly, nurses with this level of experience would be most likely to have had the opportunity to accrue the knowledge, which could illuminate the research question. Secondly, experienced nurses are more likely to have a sound knowledge base from which to evaluate treatment regimes and so are most likely to understand the clinical issues surrounding end-of-life decisions.

The nurses' stories in this dissertation were drawn from data gathered from my earlier research which was a pilot study for this larger project. Although ELDs were considered in the Honours dissertation, the focus of analysis was what happened to the nurses who advocated for patients or family members. This PhD project involved a secondary analysis of these nurses' stories. This time the stories were examined from the perspective of ELD-making and the interactions around these decisions in order to better understand the issues producing the anguish for the nurses in the previous study; particularly, this time including and considering issues of power and social structures. This was described in the original proposal which gained ethics approval.

I had initially and unsuccessfully attempted to recruit for this group of participants also using newspaper and journal advertisements. While this advertising campaign was not successful, I was able to draw on a number of colleagues who were aware of and interested in my project. Thereafter word of mouth and self-referral produced a snowball effect and informants sought me out. Nurses were generally eager to talk to me of their experiences and the interviews invariably were a cathartic experience for participants. I was therefore mindful of the potential Hawthorn effect that might be elicited from participants with vested interests (Denzin & Lincoln, 1994).

5.5.2.1.3 Doctors

The skills mix of medical staff in critical care facilities is usually varied including a number of specialist intensivists and any number of younger medical officers training and working towards "membership" of the specialty. It is my observation that the gender mix of these medical officers is invariably towards the masculine. In the interests of verisimilitude and richness of representation I have tried to reflect this skills mix in selection of participants.

I had initially assumed that this group of participants would be the most difficult to recruit. With this in mind I started recruitment and data collection with this group first. I had anticipated the need for advertisements in newspapers and journals as a means of recruitment. This strategy proved unnecessary however. I work as a critical care nurse in the university semester breaks. Medical and nursing colleagues always expressed interest in my research whenever I do so. A small number of medical colleagues agreed to consider participating in interviews for this project. Happily, they followed this consideration with agreement to participate. Thereafter, the medical officers recommended possible participants to me along the lines of: "You should talk to so-and-so. I know they've been having trouble with this sort of thing. They might talk to you". Invariably, the individual mentioned did want to talk and used the interview as a catharthsis. Further to this, I made contact with the Doctor's Reform Society and was able to elicit the participation of several of their members in this project.

The doctors contributing to this project represent a diverse range of expertise and experience, ranging from registrar to consultant neuro-physician. They narrate stories from a variety of critical care contexts in both public and private facilities in NSW and South–East Queensland. As mentioned above, the gender-mix in this group leans toward the masculine. Although I was always mindful of trying to represent the feminine voice in this group, the opportunity did not arise.

5.5.2.2 Generalisability/ Verisimilitude

As discussed, the participants in each group contributing to this study come from diverse backgrounds and reflect a broad range of age, gender, socio-economic backgrounds, experience and knowledge. The stories they tell are drawn from a wide variety of critical care units, large and small, public and private. While it is not possible to generalise from a study of this size or design, the diversity of these participants and the contexts of their stories lends the study verisimilitude – a quality to be discussed shortly in rigour.

5.5.3 Methods for acquiring data

5.5.3.1 In-depth interviewing

Individual unstructured interviews were conducted. The open-ended, unstructured interview provides for greater breadth of interaction because it provides opportunities for clarification and discussion as the researcher - researched partnership explores views of reality (Reinharz, 1992; Fontana & Frey, 1994). If a rich, detailed account of events is to be obtained using this technique, as Yeandale (cited in Reinharz 1992) outlines, the person being interviewed must be put at ease. To this end, I spent time, usually over a cup of tea or coffee, allowing the participant and myself to "get to know one another". The swapping of demographic data, memories of nursing/medical training or similar experiences rather than anything to do with the intended interview were the topics of conversation during these preparatory preambles. Thus, when the participants and I began to talk in an audiotaped setting, they were at ease, relaxed and used to talking to me. The potential intrusion of the audiotaping itself faded from the participants' consciousness as they explored the different aspects of their experience.

The participants in this project were asked to recall and describe the particular critical incident, which involved their participation in end-of-life decision-making for a patient or a loved one. Invariably some discussion and clarification of the term end-of-life decision would follow. Interestingly, many of the family member participants commenced their interview with the conviction that they had not been involved in ELD's but as their stories unfolded, the opposite became clear. In the interview participants were then asked to describe their feelings during and as a result of the incident in as much detail as they were able to remember and were prepared to relate. I used gentle probing questions to encourage participants to reflect upon the important meanings to be drawn from these events and feelings. The interviews were audiotaped and then transcribed. I took additional notes or cues related to the participants' body language, facial features and emotions during the interview. Copies of these transcripts were given to the relevant participants and their validation of the transcripts' authenticity sought and received.

5.5.3.2 Reflection:

5.5.3.2.1 Personal

Throughout data collection and analysis I have kept a reflective journal, entering my feelings and interpretations of the interview processes and progress together with my feelings in relation to the incidents described. The practice of reflection leads to a greater insight into the social issues under investigation (Lather, 1991). It requires researchers to deconstruct complex, political and value-laden concepts. This deconstruction becomes a learning process, which, in turn, becomes personally emancipatory for the researcher (Lather, 1991). With respect to this project, personal reflection has enhanced my understandings of the issues under investigation, in turn enhancing my own personal and professional development.

5.5.3.2.2 Feedback from industry

At the same time, during this project, I have had many opportunities, both formal and informal, to speak with colleagues in the industry, medical and nursing, about the issues under investigation, emerging themes and theories and possible recommendations. For example, presentations to and participation in the local Clinical Unit for Ethics & Health Law provides a fertile ground for such discussion. These conversations often provided a foundation for further reflection and/ or modification of work in progress. They have also ensured that my emerging work and recommendations resonate with contemporary practice.

5.6 DATA ANALYSIS METHODS

5.6.1 Analytical Methods

Analysis of the data in this project will focus upon:

1. Identification of avoidable suffering within the narratives of all the participants as they tell their stories. This stage of the interpretive process occurred in the first results chapter – chapter six.
2. Deeply interpreting key moments of decision-making in the stories of the participants for Interactional process factors, Personal factors, Contextual factors that impact upon the process of decision-making. These key moments of decision-making are the 'epiphaneal moments' in the various participants' stories. They focus and illustrate the key interactional factors that were present (or absent) in the experiences that were to change the lives of the individuals in this study. The steps in this analytical process have been outlined in the discussion of the development of Critical Interactionism.

5.6.2 Interpretive methods

5.6.2.1 Use of the Literature

As explained in discussion of the design, Critical Interactionism requires the researcher to 'bracket' or suspend their understandings of the phenomenon in terms of the contextual and contemporary world. No specific theory will be used to drive interpretation.

5.6.2.2 Critical Reflection

As outlined in 5.5.3.2, critical reflection formed a conscious aspect of data collection in the knowledge that this 'step' would contribute significantly to analysis. As outlined previously, this step in the methodology allows for a deeper understanding of the informants' experiences of "being in their world" (Walters, 1994). It is this understanding which is essential to the process of social change (Stanley & Wise, 1995). I recognised when planning this project that the issues raised during interviews were likely to raise personal and ethical issues, which would be challenging and painful for me. Accordingly, I made arrangements to explore these issues when they arose using an independent counsellor. The combination of this self-exploration and journaling has allowed me to develop a complex understanding of the issues surrounding the informant's experiences and ELD's generally. At the same time the process has contributed to the personal growth alluded to in chapter one. Where these reflections coincide with interpretation and analysis, they appear in a contrasting typeface to distinguish them from the informants' stories (Denzin & Lincoln, 1994).

5.6.3 Presentation of analysis

As outlined in description of this study's design, analysis of data requires the researcher to distinguish the "analytical concepts" of the phenomenon being studied and then reassemble or contextualise these factors (Denzin, 1989). Presentation of information derived from this project will involve thick description and interpretation. Thick description requires a dense recording of the informant's experience; all that surrounds it (the events, emotions and sequelae), and its meaning to the person who lived the experience (Denzin & Lincoln, 1994). Thus the informants' stories will appear as narrative 'vignettes' designed to give the reader a sense of seeing the experiences through the eyes of the informant (Van Manen, 1990; Denzin, 1997).

Using this method of analysis, the final interpreted scenario becomes a lengthy document. With some license, the philosopher, Bertrand Russell (1961) expresses the dilemma faced here best: "The problem of selection, in such a *dissertation* as the present is very difficult. Without detail, a *dissertation* becomes jejune and uninteresting: with detail, it is in danger of becoming intolerably lengthy" (p.8). In the interests of maintaining this dissertation within a manageable length, I originally planned to present the analysis of six narratives, two from each group, with representation of participants from both genders and different cultures. As analysis progressed however, it became clear that such selective presentation would not permit legitimate and accountable development of the theories arising from this analysis. I have chosen instead to present the analysis of each group of participants' scenarios and experiences in separate chapters (six, seven and eight), focusing on the key decision-making moments that crystallize the issues most pertinent to the subject of this dissertation.

5.7 Methodological Rigour

Now that this research model has been revised with a post-structural, critical consciousness, I turn to the notions of 'validity' and textual authority. As post modernism tangles with and moves further away from the positivist idea of validity, researchers are challenged by the 'crisis of legitimation' (Denzin & Lincoln, 1994). How does a qualitative researcher defend their knowledge claims? How does the researcher deal with issues of truth both in respect to the researcher's own aims and perspective and, simultaneously, respect the perspectives and political interests of the participants? Critical post-structural research at once recognises and respects the complexities of the social world whilst aspiring to change an aspect of that world in order to reduce suffering or promote happiness. Unlike positivistic, narrow-focussed reductionism, the critical researcher acknowledges, even welcomes these complexities as their impact upon the researched and the researcher needs to be considered in order to understand as fully as possible the real world situation of research concern (Lather, 1991; Kincheloe and McLaren 1994). The post-structural researcher recognises that their work will never represent the truth (no single truth is possible in the realm of the social) but seeks instead some measure of a true descriptor of reality from the perspective of all key participants including the researcher's perspective. Kincheloe and McLaren (1994) use the term *trustworthiness* meaning that the reader is able to develop trust in what is being read because of the authenticity of the words and the closeness of interpretation to the actual research data. Denzin (1997) refers to the same measure as *verisimilitude.*

5.7.1 Verisimilitude

In his discussion of the validity debate following the post-structural turn of the human sciences, Denzin (1997) expanded upon the concept of *verisimilitude* or the ability to simulate the real and suggested that we dispense with the quest for a single ‘truth’. He argued that this measure has been the most important criterion of validity as it asks: “Are the representations in the text consistent with the real? Is the text telling the truth (sic)?”(Denzin, 1997, p10).

In his earlier discussion of this issue in 1989 and 1992, Denzin averred that ‘verisimilitude’ could not be achieved in the absence of ‘thick’ interpretation; supported by ‘thick’ description (the lesser alternatives were ‘glossed’ or ‘thin’). It is this ‘thick description’ that assists the reader to recognise the true to life nature of the research report.

Denzin’s (1989) criteria/ characteristics for thick description that were used to guide analysis and interpretation in this study include that descriptions:

1. builds on multiple, triangulated, biographical methods
2. connects biography to lived experience
3. is contextual, historical, and interactional
4. captures the actual flow experience of individuals and collectivities (communities) in a social situation
5. captures the meanings that are present in a sequence of experiences
6. allows the reader to experience vicariously the essential features of the experiences that have been described and are being interpreted
7. attempts not to gloss over what is being described.

His characteristics for thick interpretation require that interpretation:

1. rests upon and interprets thick description
2. assumes that meaning is symbolic and operates at the surface and at deeper levels
3. attempts to unravel the multiple meanings that are present in any interactional experience.

Denzin (1997) appends a second level of meaning to verisimilitude-the measure of the relationship of a particular text to some agreed upon opinion held by a relevant community. In this sense, Denzin refers to the opinion held by a relevant community of scientists and gives the exemplar of epistemological validity, but it is my opinion that this measure would apply equally well to a community of participants in a research project and their opinion with respect to the theorising arising from the data. In this project there are three groups or communities of participants, relatives, nurses and doctors. This criterion was met in this study by taking the emerging theory back to the participants and seeking their endorsement and enhancement of the analysis and theory development.

The third level of meaning that Denzin applies to verisimilitude refers to the ability of the text to permit "naturalistic generalisation" (Denzin, 1997, p10). In Denzin's opinion a project that has generated high verisimilitude facilitates an opportunity for the reader to vicariously experience the situation at hand. If the reader of critical research is able to vicariously experience the situations under investigation then this should facilitate an understanding of the reasons behind the recommended changes arising from the research. While the post-structural researcher acknowledges the existence of multiple realities (perspectives) in any given situation and thus cannot expect any text to be telling the truth, the criteria of "community agreement" and "naturalistic generalisation" within verisimilitude are both useful measures of quality and usefulness within the critical paradigm. My intention is that the reader of the participants' *voices* in appendix one will vicariously experience the situations under investigation in this present project. The reader of the models arising from analysis of this data will, I believe, be able to vicariously experience the process of ELD-making and appreciate the usefulness of recommendations being made.

5.7.2 Further measures

For the critical researcher, with an agenda for social change, measures of research rigour raise special concern. How can one demonstrate that one's research has had an impact and is likely to do so in the future - that it is likely to have some impact upon the social phenomenon investigated? Catalytic validity as recommended by Lather (1991) provides a means of demonstrating this impact as it points towards the degree to which the project moved those studied to understand their world and/or transform it (Kincheloe & McLaren, 1994; Pierce, 1995; Denzin, 1997, p10). In this project many participants unveiled and explored issues and aspects of experiences, which they had kept hidden for some time (even from significant others). When I returned transcripts of interviews, participants invariably expressed the view that it had been *"good to talk about this"* or *"to get this off my chest at last"*. Discussions of the transcripts with participants, particularly nurses and doctors, invariably resulted in insightful comments, which added to the data and analysis. Participation in these discussions indicated general agreement with major themes arising from analysis. More importantly it moved members from all groups to contribute to the recommendations arising from this study. All of which suggests that this project had strong catalytic validity for those involved. The ultimate catalytic validity lies beyond this dissertation and will be attested to after papers are published in the international journals when the recommendations should be taken up in critical care units.

5.8 Research Ethics

Ethical approval was granted for this research project by the University of Southern Queensland Human Research Ethics Committee. A copy of the letter conferring approval is included as appendix 1.

5.8.1 Consent

Prior to participation in the project, all informants were furnished with an information sheet/ consent form outlining this project's purpose (see appendix IV). The information sheet included an area for the informant's signature so that agreement to join the project and an accompanying signature on the information sheet constituted informed consent of the informants. This information sheet notified informants:

- Of their right to withdraw from the project at any time.
- That I, as researcher, would ensure confidentiality, anonymity and security with regard to all information collected.
- That names of informants, patients, health care institutions and non-essential information would be altered to ensure anonymity.

- That all information collected will remain in the researcher's possession, kept in a locked filing cabinet at my home for five years.
- That some informants might find that revealing their stories causes emotional distress and that ongoing counselling could be necessary to assist them in dealing with this. Arrangements had been made for referral to a counselling agency should the need arise.

5.8.2 Confidentiality

I recognised the possibility that the stories revealed by informants might still reveal identities and yet be central to the dissertation for examination purposes. Informants were notified that in the event of this occurrence, the pertinent sections of the dissertation would remain closed. This consideration was explained to the informants to dispel any fear of retribution linked to disclosure of what may be ethically and politically delicate information.

5.8.2 Data

The computer I have been using for this process is connected to a modem but has been protected at all times by a firewall and is thus not potentially available to unauthorized access. To address the auditability requirements of this study, copies of all tapes and transcriptions will be kept in a secure area at my home for a period of five years after the completion of this project.

5.9 Conclusion

This chapter has discussed the philosophical foundations of the methodology underpinning this project and presented the research design that will be guiding the work. The chapter opened with a presentation of the philosophical debate and challenges that this researcher has considered in the development and adaptation of the framework of Interpretive Interactionism to include the strengths of critical poststructuralism. This discussion included a presentation of the core epistemological and ontological assumptions of Interpretive Interactionism and a critique of these in light of the postmodern critique of humanism. The chapter then moved on to suggest that critical poststructuralism would both address the limitations of ‘Uppity Nurses’ project and meet the postmodern critiques of humanism as they apply to Interpretive Interactionism. The adaptation of Denzin’s model, now incorporating the principles of critical poststructuralism was then presented. Finally the chapter concluded with a discussion of the praxis related issues of this project.

CHAPTER SIX- ANALYSIS OF THE RELATIVES' STORIES

The purpose of this chapter is to present the analysis of the relatives' stories which will allow this group of decision-makers to help answer the question:

"How might avoidable suffering related to the process of decision-making that accompanies the implementation, maintenance or withdrawal of life-sustaining treatment in the critical care environment be ameliorated?"

The thesis that this dissertation argues is that: Unnecessary suffering for relatives, nurses and doctors in critical care related to end-of-life decision-making can be minimised through a combination of structural, procedural and educational interventions.

In this chapter, analysis will focus upon the **key decision-making moments** in these stories, the interactions around them and the **key factors** impacting on the decision-makers. These key factors will be expressed for the most part as variables to demonstrate/explore their impact upon the families' experiences of decision-making in these stories. For example, a personal factor (PF) degree of `FEELING SUPPORTED` might range from low through moderate to high and therefore have varying impacts upon the family members' decision-making interactions. In the interests of parsimony, the words 'degree of' will not appear in the analysis. At the same time, the types of factors will not be fully identified each time they appear. To refresh the reader's memory, these are contextual factors (CF), personal factors (PF), interactional process factors (IF) and historico-political factors (HF). In the interests of brevity, the abbreviation only will appear in the text of analysis. Thus a section of analysis will appear in the following format:

`When Hannah did speak to someone about her father and his condition it was to one of the anaesthetists involved in Bill's resuscitation: SENIORITY OF CONTACT PERSON (consultant) (IF). The anaesthetist's detailed explanation of the resuscitation and description of its impact upon Bill seem to have prepared Hannah for her first sight of Bill: BEING ORIENTED TO UNIT (high) (IF).`

`Notwithstanding this, Hannah had some difficulty understanding the consultant's rationale for what seemed in her experience to have been extra-ordinary attempts to resuscitate her father: AGREEMENT WITH DECISION (low) (PF).`

As described in the methodology chapter, the stories will appear as vignettes intertwined with thick description and thick interpretation. The relatives' words will appear in times new roman. `My own words of interpretation will appear in courier new.` *Brief explanatory interjections or introductions to the scenarios will appear in times new roman italics.* At times, there are aspects of the nurses' stories or analysis which require extended explanation and clarification to facilitate analysis. These explanations appear in the glossary and will be signified in brackets (see glossary).

6.1 SANDRA:

Sandra's husband, Grant was to have elective surgery to release the trigeminal nerve causing his neuralgia. He had already had all the nerves in his teeth on the affected side of his face removed in an effort to thwart the pain but that had not been effective. The surgery was performed in a large private metropolitan hospital with intensive care facilities. Following the surgery, Sandra saw her husband briefly in recover:

Grant was nauseous, but that's a part of the deal when you have brain surgery - it's just like concussion-he was throwing up. [I thought] this was a great sign because that means he hadn't had a stroke and he didn't die on the table. I'd researched the chances for this: 2% for stroke or 1% for death on the operative table. I asked him "How are you?" and he said, "I've got a terrible headache Sandra." I said, "Be patient, wait for the pain killers to kick in." […] I said to his sister, "We can't do much here, let's go and have a cup of tea".

Grant's severe headache and vomiting, suggestive of rising intracranial pressure, were sinister symptoms in light of his recent surgery (see appendix VII). Despite her 'research', Sandra was not equipped to understand the significance of Grant's complaints: KNOWING or UNDERSTANDING (low) (PF). The nursing staff in recovery (this would have been a specialist recovery area) should have understood the significance of Grant's symptoms. Yet there was no attempt at this stage to clarify Sandra's misunderstandings. Most health professionals would argue that raising these concerns at this early stage may have unnecessarily increased Sandra's anxieties. Conversely, Sandra left the area happy that all was well with her husband. The tendency to 'shelter' relatives until a clear diagnosis is known, in this case, left Sandra with the false impression that all was well: BEING KEPT IN THE LOOP (absent) (IF). I will return to this in conclusions.

Sandra and Anna (friend) were having a cup of tea and discussing plans for Grant's expected discharge when a call was received from the intensivist asking them to meet the surgeon and himself in X-ray as Grant had taken a 'turn for the worse':

So we went down there and the surgeon met us. He told me: "Sandra there's something going on in his head, he's got a bit of pressure up there. I don't know if he's bleeding where I was today or if he's got brain fluid. So we're going to do a C/T scan and we're going to see what's up there".

There is no indication here of a nurse or any other support person being present for Sandra as she received this news: BEING EMOTIONALLY SUPPORTED (absent) (IF); HAVING SPIRITUAL SUPPORT OFFERED (absent) (IF). She received this news about Grant's deteriorating condition in or just outside the X-ray department: VENUE for INTERACTION (public) (CF). Sandra would have been feeling particularly vulnerable as she started to worry about Grant and the implications of this news: WORRYING (high) (PF); FEELING POWERLESS (high) (PF).

The literature suggests that at stressful times such as these, individuals' integrity is challenged most by a sense of waning control over the relevant situation (Wright, 1993; Mendonca & Warren, 1998; Kirchhoff et al., 2002). An enhanced sense of control could have been provided for Sandra and her family in the form of a liaison or 'primary contact' nurse. The potential benefits of and consideration for the development of this position in critical care units will be discussed further in conclusions.

Once the C/T scan was performed, Sandra was told by the surgeon that the surgery and 'handling of the brain' seemed to have caused a lot 'a lot of fluid' (cerebral oedema). She was informed that Grant was to be taken back to theatre for the insertion of a shunt.

Sandra continues, I said, "Well that's fair enough." And then I said, "You're not going to give him another anaesthetic and put him through that again, because he was very drowsy at six o'clock when I saw him after the first one." They said, "We'll only give him a very light one 'because he's still very drowsy from all the pain killers too." I thought that was good because another anaesthetic-that was going to take him longer to get over the surgery, you see.

The precipitating cause of Grant's intracranial hypertension was most probably vasogenic oedema (see appendix VII). Surgical intervention in this case is a possibility but is considered 'heroic' as the cerebral ventricular swelling makes the placement of the shunt so difficult (see appendices VII & VIII). The decision to take Grant back to theatre is the next **key decision** in this scenario.

It is interesting to see Sandra speaking up for Grant- attempting to advocate for him and yet her greatest concern is his ability to recover from a second anaesthetic. Rising intracranial pressure, unchecked, will result in infra-tentorial herniation and death (Hankey, 2002). Grant's clinical condition at this moment is most worrisome. Sandra's misdirected focus of concern here indicates that she had still not been altered to the severity of Grant's problem: KNOWING or UNDERSTANDING (low) (PF). In effect, she was not giving fully informed consent to this second operation: GIVING INFORMED CONSENT (no) (IF).

Sandra tells us, So as we were entering the unit, I saw him on the stretcher and he was snoring and I said to Anna, "He does that at home he must just be tired." He was going into a coma. I didn't realise that at the time

Sandra had formed the impression that her husband was sleeping peacefully and had a good chance of recovery following surgery. Grant's "snoring", however, is an indicator of partial upper airway obstruction. Grant had lost the ability to protect his own airway. This deepening level of consciousness is indicative of pressure on the reticular activating system within the brain stem (*indicative that herniation of Grant's brain stem was imminent if not already in progress*). Sandra was unable to grasp the significance of her husband's condition because she did not have the benefit of experience, relevant knowledge or timely explanations: KNOWING OR UNDERSTANDING (low) (PF).

When she mentioned Grant's snoring favourably, the health professionals present would have been alerted to the gap in her understanding. One of the nurses should have alerted the surgeon to this need before Grant was taken back to theatre: BEING KEPT IN THE LOOP (Absent) (IF). Respecting Sandra's need, indeed right, to be fully informed of Grant's condition, care and prognosis might have ameliorated some of the confusion and distress Sandra experienced when reality set in. I will return to this in conclusions

Sandra continues, We waited from 9 o'clock to I think about 1 or 2 o'clock in the morning. The surgeon came back and was absolutely exhausted because he had been working all day.

Sandra spent at least four hours waiting to see Grant or hear news about his progress: BEING SEPARATED (prolonged) (IF); WAITING for NEWS (4+ hours) (IF). While there is nothing that can be done about the length of time taken to attempt to correct Grant's problem, Sandra should have been provided with regular updates on his progress. The absence of news during this long separation would have unnecessarily increased her anxieties: WORRYING (high) (PF). She had no feedback from theatre or intensive care staff until the surgeon spoke to her: BEING KEPT IN THE LOOP (Absent) (IF). There is no indication of a dedicated comfortable being provided for Sandra (she mentions having to go away for a cup of tea earlier): WAITING AREA (PUBLIC, NON-SPECIFIC) (CF).

Grant's surgery happened overnight and so the staffing in theatre was probably reduced. It would have been possible though for ICU staff to call at 30-60 minutes intervals for updates to pass on to Sandra. The issue of relatives' long separation from their loved ones at various times during critical care interventions and possible strategies to address the resultant suffering will be addressed in depth in conclusions.

He said, "Sandra, that shunt in his head, it took me so long to get it in, but it's in there. We're going to monitor him and we're going to see if we can release all that fluid and we'll see what tomorrow brings.

Sandra continues, He was the only one in intensive care on the weekend. So he had all the care and attention. They said "We've put a breathing tube down there so when he wakes up-we'll give his brain a rest–he'll be tossing and turning [without it?] We need to give his brain the best chance." I said "Fair enough" So he's sort of breathing away there – they're breathing for him. I think Terry, his brother, stayed with him that night, and then I kept ringing the hospital during the night to see if anything had changed because one of the nurses had said, "I want him to rip this thing out (*the E-T tube*). ["I want him to say"] 'I don't want it any more- get it out of my throat - get it out' - we want him breathing for himself".

There is no mention of Sandra being introduced to the critical care unit although this may have happened prior to the conversation above: BEING ORIENTED TO CRITICAL CARE ENVIRONMENT (low) (IF); BEING ORIENTED TO PATIENT'S POTENTIAL APPEARANCE (moderate) (IF).

Sandra's recollection of the conversations with the nurses in unit caring for Grant, outline the next **key decisions** in his management – essentially to sedate and ventilate him for some time (usually two days); to let his brain rest and then assess his cerebral function after that. It is instructive that Sandra seems to have recalled those aspects of the conversation with the most hopeful overtones. The nurse probably explained that Grant would be sedated for a while to rest his head and to stop him trying to 'rip his tube out' in agitation. Sandra though has heard those aspects of the conversation most hopeful to her: her husband is on a ventilator and the health care professionals are still talking hopefully about his brain: HOLDING ON TO HOPE (high) (PF); FEELING DAZED (high) (PF).

An instructive silence in this scenario as it unfolds is the virtual absence of questions from Sandra. Apart from her expression of concern for Grant's ability to handle a second general anaesthetic, Sandra seems to have allowed the information and decisions roll over her when she does hear of them: "I said 'fair enough'…": QUESTIONING (low) (IF). It is my experience that the majority of relatives visiting their loved ones in critical care are overwhelmed by the technological environment of critical care and by the fact that their loved one is requiring such complex care. Unless they have an assertive personality, they tend to ask few questions. This is mostly related to the reverence and mystique which enshrouds medicine-especially the technologically specialised areas like neurology and critical care (Boyle, 1996; Moynihan, 1998): FEELING DAZED (PF). Strategies that might be implemented to ameliorate the impact of the critical care environment upon the patient's relatives will be discussed in depth in conclusions.

Sandra continues, Then the next day they did some tests on him – they tickled his feet, they tickled his fingers, they did all the tests, and he seemed to be coming in this way (*demonstrating decorticate gesturing which indicates hypoxic damage to the cerebral hemispheres*) instead of going the outward way. I said "That's good!" and the nurse said to me "No, not really, it should be the other way." [She didn't really explain what that meant.] - and I didn't sort of like to hear that negativity at that early stage because I said to her, "Any sign is a good sign", because I haven't got very much medical experience. So, that was on the Thursday, I guess, and he was still the same on the Friday […]. Nothing changed.

As Grant started to portray the signs of profound injury to the brain stem and higher brain structures (Sullivan et al., 1999), Sandra interpreted his movement as a positive sign. When the nurse present at the time begins to 'correct' this impression, Sandra tells us she cut her off in what appears to be denial of the significance of the information she is being given: EMOTION -Denial (High) (PF). This is a natural human response to potential bad news (Corr & Corr, 1996). It is also possible that she was still not understanding as a consequence of the quality of information she had been receiving.

The nursing staff would have had a strong indication at this stage that Grant's prognosis was hopeless. Sandra's words "Any sign is a good sign" would have indicated that she was in need of clear information and emotional support. The enlistment of assistance from a counsellor or pastoral care worker would have been useful both at this juncture and during the following days: HAVING SPIRITUAL SUPPORT OFFERED (absent) (IF). The issue of complementary support during end-of-life decision-making will be raised again in conclusions.

Saturday morning came and they called us all in. Another two neuro-physicians came in and he (*the intensivist)* said, "We've got to do two independent tests, an hour apart and we're going to see how he goes." One fellow did his test and then the next fellow did his an hour later. The first fellow came and he says. "I'm sorry, he's failed his exams." He just had this look on his face and when he said it this shiver just went up the right side of my body. I thought 'This is for real this time!' *(tears*) Because you hear of people being in comas and coming out it! I had had the music going - I had his favourite music going - I was talking to him. Then this other Neuro guy came in and did obviously the same tests but then he said "I'm sorry, he's failed the tests - at this stage he's brain dead". They more or less said that they had not much hope for him at that stage. While I'm getting this news there was always one nurse always standing around with her arms crossed as if she had to be there to "be a witness". She also patted Terry (brother) on shoulder when he was crying but she seemed more as if she was there to "witness" what the Neuro guy was telling us.

It is at this stage that the reality of Grant's condition and prognosis finally hit Sandra. She speaks of a visceral response to the neuro-physician's pronouncement: VISCERAL SHOCK (high) (PF). Her words: "This is for real this time!" and "...they had not much hope for him..." reflect that up until this point Sandra had been existing on hope that was not based in reality or on sound information. This was the stage at which the truth penetrated for her and her suffering started to take on another dimension: LOSS OF HOPE (high) (PF). She tells us that she had been playing music for Grant and talking to him: "Because you hear of people being in comas and coming out it!" Her words strongly indicate that Sandra had built up the hope that this might have been the case for Grant too: HOLDING ON TO HOPE (High) (PF). Had she been given clear and ongoing information from the start of Grant's decline, this would not necessarily have been the case and Sandra would have been better prepared for the decision-making to follow: BEING KEPT IN THE DARK (high) (IF). I will return to this issue in conclusions.

One is struck by the tenor of the exchange between the physicians and Sandra as they deliver their 'verdict' on Grant's diagnosis as well as Sandra's perception of the role of the nurse present at the time. Both the physicians in this story reported their findings to Sandra using blunt, almost confrontational language. Their expressions: "…he's failed his exams", or "… he's failed his tests" seem to lay the predicament at Grant's feet as if there is some blame in the matter: LANGUAGE

(Blunt); MEDICAL EMPATHY (low) (IF); QUALITY OF INTERACTION (low) (IF).

There are a couple of possible explanations for the harsh and seemingly blaming nature of the expressions used by the medical officers. Perhaps the physicians had interpersonal difficulties in dealing with telling a woman that her husband is brain dead. Secondly, this patient's brain death is the result of elective surgery. Should Grant die, the possibility of litigation would not have escaped the attention of the medical officers involved in the case. The attitude of the physicians here may be an early indicator of the fraternity of medicine adopting a united front in the face of "possible litigation" (Moynihan, 1998).

Sandra does not give the impression in her words above that she perceived the language the physicians used to be blaming but she was certainly struck by the attitude of the nurse accompanying the physicians as they delivered their news. Her perception that the nurse was a witness and not a support person is unusual here. It is my experience that in situations such as the one Sandra is describing it is usual practice to have a registered nurse accompany the medical officer. The registered nurse then knows exactly what has been said, can explain this information again in lay terms and, most importantly, can offer emotional support as the difficult news is being imparted. Sandra's experience though, was a nurse whose body language (crossed arms) for most of the exchange suggests separation from the relative concerned rather than empathy and support: BEING EMOTIONALLY SUPPORTED (low); FEELING SUPPORTED (low) (PF) (IF); NURSE AS WITNESS (high) (IF. It is possible that the nurse in this scenario was having difficulty dealing with both the challenging situation of Grant's 'brain death' and the dual roles she had to fill here. This may explain the withdrawn behaviour Sandra picked up during this exchange.

As Sandra relates the circumstances of these conversations with the neuro-physicians, she does not mention any efforts to move the family from the bedside, out of or away from the unit they had all been called into. One can infer then, that these conversations took place at the end of Grant's bed or at best in the waiting room outside the unit's doors. Such a venue would not have been conducive to privacy, clear explanation and the unburdening of grief that would have followed: VENUE for INTERACTION (public) (CF). A more appropriate venue and dialogue for these circumstances will be suggested and discussed in conclusions.

Sandra and family waited and watched Grant's progress for 'a couple of hours'*: […]* And then they [Intensivists] said, "I don't think there's anything we can really do and you'll probably have to make a decision. You don't have to make the decision right now - talk amongst yourselves. Sandra describes a relatively short period (a couple of hours) from the time of receiving news of Grant's 'brain death' until being asked to make a decision about his further treatment. It may be that this time-frame was telescoped in her memory as a result of her grief. Nevertheless, it seems that Sandra and the family are being asked to make this decision at a particularly vulnerable juncture in their experience: VULNERABILITY (high) (PF). In a few hours they have been told that Grant is brain dead and while the full significance of this is still sinking in, they are asked to make a decision about the continuance of his care. This conversation too seems to have happened in public, at Grant's bedside VENUE FOR INTERACTION (Public) (CF).

I went in and saw him again and thought, 'What will we do?' I thought 'is there any chance here? Is there any point in lingering? Is it going to change? And physiologically there wasn't any hope of change because his brain had died-his brain stem had died and he wasn't getting any nutrients so he was virtually–no he wasn't even a vegetable – he was dead. I thought I can't bring him back; no doctor could bring him back at this stage [...] well the nurses did it really. I asked, "How long would he last if we just left him like this?" She said, "Five days possibly, his heart would go out." And I'm sitting there before all of this is happening and I'm thinking, "Now, I might have to go back home, take him to a nursing home and look after him for the rest of my life like this!" I did not know how these sorts of situations were looked after and that was the vision I had - it was overwhelming. The nurses said, "Well there's no nursing home will have this. It's only a hospital situation." Well that sort of nearly answered [my question] there.

The remarkable feature of this period is that Sandra seems to have had to actively seek the information she needed to make the next and probably most important **key decision** in this scenario. She has been left to make this decision without any supporting resources: USING INFORMAL CHANNELS TO GAIN OWN INFORMATION (high) (IF) MAKING ELD WITHOUT SUPPORT (high) (IF). This information should have been covered in the discussion following the neuro-physician's delivery of their diagnosis of Grant's brain death. If the full significance of this diagnosis and its implications for Grant and Sandra had been explained then, her burden at this stage would have been ameliorated to some extent.

Then I went back out to his family and said, "What would you like to do?" They said, "You make the decision-you're next of kin." So I said, "Well, he's 'brain-dead', they're just keeping him alive and I could hear Grant saying (*tears and very choked voice here*) 'What are you waiting for? Turn it off!'" Because he hated people who couldn't walk, he was always very active and not to be able to get on his horse, he wouldn't like that. So I think he'd say, "Finish it!" I said, "Right, we'll finish it." So the priest was there, who read him the last rites, a couple of nurses were there, his sister wouldn't come in but his brothers were there. We were all standing around and they just switched it off and it was so fast, it only took two or three minutes-very fast. 'Cause I said to her (the nurse) "How long is this going to take?" and she said, "Not long at all, once they've switched it off." He was a beautiful pink colour and then he went not a light brown but a very -what's the colour- grey? That was it and we walked out.

Despite this being a terrible decision and, one that she had to make on her own, Sandra appears to have been very clear in her mind about it. Once she was convinced that Grant was brain dead, Sandra was guided by Grant's values and her discussion with the nursing staff regarding his prognosis: BEING SURE OF PATIENT'S WISHES re ELD (high) (PF). Significantly, the decision itself wasn't difficult for Sandra; the manner in which it was made was. She had to seek out information relevant to the decision and then shoulder the burden of that decision on her own. She also had to actively seek the answers that would help her in this decision at every step in this process. Like Hannah, Sandra became the relative who assumed final or sole responsibility for the decision to withdraw treatment: RESPONSIBILITY FOR ELD (High) (PF). The impact of this responsibility in the absence of support will be explored further in discussion.

Now, I'm still feeling angry with myself for not knowing everything I could about the operation – not knowing all the odds [despite all my research]. But it was Grant's choice to have the operation-to try and have a quality of life. You have to balance the pros and the cons; the dangers against the possible benefits. The main feeling though is disappointment: for the surgeon who'd done all the work and found the problem and wouldn't see Grant wake up and say, "Oh that feels better"; at missed time with Grant- not getting to find out and hear how good he felt post-op; at not finally being able to give Grant a kiss without him saying, "No, that hurts too much." Why did this have to happen to Grant- why did he have to be the one in a hundred?

Table 6.1 Key factors from Sandra's story:

Contextual Factors	
• Waiting Area	• Public
• Venue for Interaction	• Public
Personal Factors	
• Knowing or Understanding	• Low
• Worrying	• High
• Feeling Dazed	• High
• Feeling Powerless	• High
• Vulnerability	• High
• Feeling Supported	• Low
• Holding on to Hope	• High
• Visceral Shock	• High
• Loss of Hope	• High
• Emotion – Denial	• High
• Being sure of patient's wishes re ELD	• High
Interactional Process Factors	
• Waiting for news	• 4+ hours
• Being Separated	• Prolonged
• Being kept in the Loop	• Absent
• Being kept in the Dark	• High
• Giving Informed consent	• No
• Being Oriented	• Low
– to environment	• moderate
– to patient's potential appearance	• Absent
• Being emotionally supported	• Absent
• Having spiritual support offered	• Absent
• Questioning	• Absent
• Nurse as Witness	• High
• Language	• Blunt
• Medical Empathy	• Low
• Using informal channels to gain own information	• High
• Making ELD Without Support	• High
• Responsibility for ELD	• High

6.2 HANNAH:

Dad (Bill, 59 yrs) collapsed at home. The paramedics were called. There were several attempts at resuscitating him on site [...] Once the paramedics were summoned, a chain of key decisions was set in train which none of the participating health professionals would have had the power (or inclination) to derail. Decisions at these times are thought of purely from their clinical perspective, ignoring their ethical dimensions. Yet the vast majority of these decisions do have an ethical dimension (Komesaroff, 1995).

Hannah recounts, They transported him very quickly to a hospital close by and of course as a result he was actively resuscitated. Once a patient like Bill arrives in the Accident and Emergency department (A&E), the clinical imperative to maintain life tends to drive decisions. Hannah recounts later that Bill was defibrillated more that 17 times in A&E. Resuscitation follows algorithms specific to the precipitating cause (see glossary and appendix VIII). If Bill had been defibrillated more than 17 times, his resuscitation would have continued for at least another 40 minutes after he reached the emergency department. Permanent neurologic damage occurs if spontaneous circulation or effective CPR is not re-established within 4 minutes (Dougherty, 2001; Safar & Kochanek, 2002). Even 'effective' CPR never replaces natural circulation and ventilation and the compromised supply of oxygenated blood to the brain predictably results in cerebral ischaemia and oedema.

The survival rate for out-of-hospital cardiac arrests is still only one to five percent (survival being defined as discharge from hospital to an acceptable quality of life) Dougherty (2001). This reflects the long delay in definitive treatment. In 90% of out-of-hospital cardiac arrests, the precipitating causes are ventricular fibrillation or pulseless ventricular tachycardia.

Without definitive treatment (defibrillation) the chances for recovery decrease by 10% for every minute so that the patient's chances are dismal after 10 minutes (O'Rourke, 2002; Fulde, 2004). Indeed, delay in recovery of spontaneous circulation (ROSC) and stable rhythm prior to presentation in the A&E were demonstrated to be so directly related to outcome that Lindholm and Campbell (1997) felt that absence of ROSC "…strongly suggested consideration for terminating resuscitation efforts" (p126).

It is theoretically possible that the staff in A&E could have given consideration to Bill's case in light of the above information (it would have been clear that Bill's long-term prognosis was extremely poor). The time taken for this ethical consideration would, however, have potentially compromised Bill's outcome further and so it is unlikely that resuscitation would have ceased once started.

Hannah continues, He was already admitted to intensive care when I received a call to say my father had had a "heart attack". Immediately, with my intensive care background, I put two and two together and I thought: "This isn't good!" Because I also knew that the hospital that he was admitted to had a coronary care unit (*i.e. if he'd been ventilated his prognosis was very poor*).

Hannah received a call about her father's admission to ICU 'after the fact'. It is rarely possible to include family members in decisions related to initiation of life-sustaining measures unless they are present at the time (or an advance directive has been clearly documented). This scenario is unique in that staff in A&E did have the opportunity to contact a relative: Hannah was known to the critical care staff. Nonetheless, she was not contacted: DECISIONAL INCLUSION (absent) (IF). There was time to do this – he was in A&E

for at least 40 minutes. Hannah had correctly surmised that her father's condition was poor and his prognosis grim: KNOWING or UNDERSTANDING (High) (PF). She could have made an informed ELD at this point. Every effort should be made to try and ascertain the ELD wishes of a patient where this is possible: HAVING PATIENT'S ELD WISHES KNOW and RESPECTED (low) (IF). Empowering input from the family at this point could ameliorate long-term suffering as this dissertation will show. The research indicates this is not happening (see literature review P.22). I will return to this issue in conclusions.

Hannah tells us: Well, when I arrived I wasn't able to see him-they were still they were inserting lines, I guess. He collapsed on the Friday, at five o'clock; […] I got to him […] about an hour and a half later. Hannah was unable to 'get to' Bill for 90 minutes. Her words reflect a strong sense of restriction and frustration: BEING SEPARATED (prolonged) (IF). Hannah received no news of her father's condition or progress in this intervening period: WAITING for NEWS (90 minutes) (IF). For a relative, separated from their loved one and anxious, absence of information is likely to heighten these anxieties: WORRYING (high) (PF). There would have been a need for staff in ICU to 'settle' Bill into the unit (check and/or change equipment and assure them selves that he was stable). At the same time they would have been aware family were waiting. There should have been a nurse delegated to update Bill's family during this period: BEING KEPT IN THE LOOP (absent) (IF). This role would fall within the scope of the liaison nurse mentioned in Sandra's story: LIAISON BETWEEN CLINICAL STAFF and FAMILY (IF) (absent). This concept will be discussed further in conclusions.

Hannah continues, They had resuscitated him to the point where he had a rhythm. […] A colleague of mine, an anaesthetist, was involved in his resuscitation and he explained to me what Dad looked like and what had happened:[…] he'd been defibrillated many, many times; they'd lost count after seventeen. [...] What I couldn't really understand or reconcile for myself with my intensive care background, was that they defibrillated him as many times as I was told, if indeed that was the case. It certainly wasn't my experience, being an intensive nurse or being involved in providing that level of care. You know, there comes a time when you say, "Okay enough's enough". So, you know, I was a bit perplexed about that. But the explanation that I was given was that, my father was fifty-nine at the time (*Hannah explained that her Dad was a relatively young-looking 59 old man*). I mean, not that age should make a difference these days anyway. […]

When Hannah did speak to someone about her father and his condition it was to one of the anaesthetists involved in Bill's resuscitation: SENIORITY OF CONTACT PERSON (consultant) (IF). The anaesthetist's detailed explanation of the resuscitation and description of its impact upon Bill seem to have prepared Hannah for her first sight of Bill: BEING ORIENTED for PATIENT'S POTENTIAL APPEARANCE (high) (IF). Notwithstanding this, Hannah had some difficulty understanding the consultant's rationale for what seemed in her experience to have been extra-ordinary attempts to resuscitate her father: AGREEMENT with DECISION (low) (PF).

One is given the impression that this exchange occurred just before Hannah went in to see her father (in the corridor or ante-room of ICU): VENUE FOR INTERACTION (Public) (CF). There was no nurse present to add support: BEING EMOTIONALLY SUPPORTED (absent) (IF).

Hannah continues, On the Saturday morning about ten o'clock I was approached by the same anaesthetist with the news that they had assessed his status […] . Basically they said that he was brain dead. As an intensive care nurse of course I knew what that meant. Well I thought I understood at the time. […] I guess what I understood at that time was: "Oh my God, it means that there's no real hope for him, but there's also the possibility that he could be a lingering vegetable"**.** I guess I was always, also very, very aware of that and that was the last thing that I wanted for Dad, and that he wouldn't have wanted that for himself.

Hannah was 'approached' by the anaesthetist the next morning. One can infer that she was by Bill's bed and that the medical officer came and spoke to her there: VENUE for INTERACTION (public) (CF). This news was delivered by the anaesthetist she knew and someone she probably trusted: SENIORITY OF MEDICAL STAFF (consultant) (CF); LEVEL OF RAPPORT WITH STAFF (high) (PF); TRUST of health care professionals (HCPs) (high) (PF).

Hannah continues, He, then was pronounced brain dead in the morning and the anaesthetist told me that they were going to reassess him again with a view to taking him off the ventilator the following day, Sunday. It was assumed [that I knew what they were talking about]. Probably, because I had taught the course locally for many years on the one hand […] I guess you're expected to know, whereas on the other hand in those situations you suddenly become, you do, you become a lay person. You know you feel like a layperson. In hindsight I could've asked too, but I didn't think to ask. You go into a mode of '…it's all surreal'. The whole thing, the whole process was almost like, "Oh my God, I don't believe this is happening". So you're not really in a position to ask questions. If anything, I think the onus is on the health carers to actually provide the information and not make any assumptions.

It is interesting that Hannah did not question this news despite her level of knowledge and experience: QUESTIONING (absent) (IF). The information about her father's cerebral damage was delivered to her by only one consultant in what seems like a very matter of fact discussion. There should at least have been a nurse around to support Hannah and discuss/ follow-up her questions later on: SPIRITUAL COMFORT RECEIVED (absent) (IF). Hannah speaks of going into 'lay person' mode as if the shock of her father's collapse and diagnosis robbed her of her normal intellectual faculties: COGNITIVE SHUTDOWN (high) (PF); FEELING DAZED (high) (PF).

The false assumption was made that Hannah would take her critical care knowledge and training with her as a relative. She consequently seems to have felt peripheral to the situation and disempowered: FEELING INCLUDED and SUPPORTED (low) (IF). This may explain Hannah's perception that she was '… not in a position not ask questions'. The medical and nursing staff would have witnessed this phenomenon with previous relatives and should have been using strategies to ensure Hannah was fully informed and completely understood the relevant the information (eg reflective questioning; encouraging questions from Hannah). I will return to these issues in conclusions.

Hannah continues, And basically, he was reassessed and he was brain dead so the plan was still to take him off the ventilator the next day and I actually said to the anaesthetist, "Well why wait, why not do it now?" My brothers obviously, had made it clear that they didn't want to be around (*brothers were on a fishing trip and had indicated they did not intend returning*) and there was no point in prolonging anything for Dad or for us. I think by that stage it was about seven o'clock in the evening, I suppose.

The initial news about Bill's 'brain death' was delivered to Hannah less than 24 hours after his collapse. He was then reassessed later that day. This move to diagnosis of brain death was too early both in light of established practice and contemporary research into ischaemic penumbra (see literature review). Again Hannah did not question this information: QUESTIONING (absent) (IF).

Could this situation have been handled differently or better? This was a key **decision-making moment** in this story. Although Hannah's brothers professed no desire to be involved, a conference or group meeting of close family who did want to be involved and all the relevant health professionals would have ensured that all the relevant decision-makers were informed, had taken part in this decision and could thus reflect upon this with some measure of comfort in the future. I will return to this in conclusions.

Then Hannah tells us, When they extubated him I didn't expect to see him struggle as much as he did; or that's my "word", I'm starting to feel a bit... (*short for words here and crying*). I don't believe I've ever seen anybody struggle so hard to breath and when I say struggle, like in my, in my own mind I'm thinking scientifically: his glottis obviously wasn't doing what it needed to do, because he was sucking it in, sucking the air in with all the might that he could conjure up. And making this most grotesque noise, you know. Gasping isn't a strong enough word; it was a horrid sucking, like a snoring, like a deep snore with each, with each breath and his whole body was, was almost lifting off the bed to pull the air in. I had never seen anybody struggle so much. This is not a brain dead man. Cardinal signs of brain death include absence of spontaneous respirations and absence of spontaneous movement (see literature review). Clearly a misdiagnosis had occurred.

Hannah continues, I was quite distressed at the sight of that and I think I said something like, "Oh no, oh my God"…and…the response, there was a female anaesthetist on that night in the unit and she was a relatively young woman. I was grateful because she moved very quickly [When Hannah's Dad started gasping on extubation]. There was a lot of hurried action, you know, like the nurses' response was hurried, the anaesthetist on call, she looked, and this is just, these are just my thoughts, I have nothing to base it on, but she looked like she was intentionally going outside policy, that either she'd taken a cue from me, I don't know and decided to deal with it her way, not, not the hospital's way. The registrar present at this event (Julie) was 'relatively young'. This would suggest that she was a junior registrar: SENIORITY OF MEDICAL OFFICER (junior registrar) (CF). Her response to the situation that was unfolding was rapid. And it seemed to be in response in the main to Hannah's distress and expression of horror- but not necessarily with Hannah's consent.

Prior to extubating him they already had IV lines in, art lines in. They had dosed him up with morphine on the basis that he would have had pain with the mess that they created in his chest. This is a bizarre intervention and questionable rationale here. Part of the protocol for the diagnosis of brain death requires that all sedatives and narcotics be weaned before the diagnosis is made (see literature review and appendix VI). If Bill had started to breathe with Morphine already in his system, one wonders how the diagnosis of brain death had been made.

Hannah continues, All I was thinking, at the time was, "Oh my God he's struggling, you know, this could go on for ever, this could go on for hours", but I didn't actually say that . And with my exclamation: "Oh my God, oh my God, Oh No!", the female doctor moved very quickly and gave him a bolus dose of morphine and gave him another one and another one and another one and I can remember very clearly feeling relief.

It seems a **key decision** was made by the medical officer here to suppress Bill's respiratory effort. One would have expected another (more senior) medical officer at the bedside or at least in the unit during withdrawal of treatment. If this was not so, there should be a formal policy to require the presence of at least two senior registrars in an intensive care unit during withdrawal of ventilation in case of complications: FORMAL POLICY R/T WITHDRAWAL OF TREATMENT (absent) (CF). I will return to this in conclusions.

Hannah continues, …and she kept giving him these bolus doses and I don't know how much she gave him. I did ask, but she, I guess she refused to answer me and it was none of my business as a relative but I felt that I had to know how much he'd been given. I could see the ampoules being cracked open, you know, one after the other. And of course eventually he did, he did calm down and at the time I have to confess I was relieved, you know and eventually of course he, he did stop breathing. Anybody would with that amount of morphine on board, she also increased the IV infusion input, you know, she turned up the flow. So that he was getting morphine IV as well as the boluses that she gave him. And…it wasn't until later, much later, much, much later that I started to think about what happened there, you know, and I still do, I still think about what happened and I wonder whether in actual fact that we made the right decision because, because he struggled so hard to breathe. I now wonder whether in actual fact he was as brain dead as what they said he was.

Hannah was well aware of the significance of her father's struggles and Julie's interventions. While she was relieved that the registrar moved to do something about Bill's struggles: 'of course' eventually he stopped breathing. Significantly, Hannah asked once only how much Morphine her father had been given, and did not repeat her challenge when she received no response as she felt it was "…none of my business as a relative": QUESTIONING (low) (IF). Hannah had every right to challenge what she saw happening but seems to have been silenced, either by the horror of the moment or perhaps because she was witnessing her father's euthanasia and did not want to speak out against it. It may have been that despite her background and knowledge, Hannah felt dazed and silenced in the moment: FEELING DAZED (high) (PF); SITUATIONAL SHOCK (High) (PF)

More significantly perhaps, someone (another health professional) should have spoken up here. This is an extraordinary situation and Julie seemed to be out of her depth. The 'usual' clinical response to a patient's struggles to breathe is to support these. This junior registrar did the opposite. It is possible Julie was frightened but it would seem that with no senior medical support or governance, Julie acted to achieve the diagnosis she had fixed in her mind for Bill: PROFESSIONAL OVERSIGHT (absent) (CF); COGNITIVE FLEXIBILITY (low) (PF).

There would have been several nurses around at the time of varying experience. None of these spoke up: PATIENT ADVOCACY (absent) (IF). It would seem that all the nurses were either silenced by their own horror or felt unable to actively oppose the doctor's actions (it is also possible that some but surely not all concurred with the decision): NURSING SILENCE (high) (IF). This suggests that working relationships in the unit were not collegial at the time of the incident. The importance of collegial working relationships within a critical care unit will be explored in the following chapter and discussed in depth in conclusions.

[At that stage] I was aware of the absences of staff, which is interesting because under those circumstances I might've expected that a nurse or somebody might have come and at least put their arm around me- to give some sort of comfort under those circumstances. Do you know what I mean? But perhaps because they knew I was a nurse and of course I was teaching at the university as well, perhaps that was another compounding factor- I don't know. I mean I do know what nurses talk about, about relatives you know, but, you do talk about them and word gets passed around and perhaps, by that stage it was already widely known that I was a nurse, an ICU nurse. I mean I taught the ICU course as well and that's how I came to be working with the anaesthetist concerned. So I guess it would've been widely known and perhaps, perhaps that's why the young woman anaesthetist took the cue.

This was obviously a frightening time and the usual response is to place an arm around the relative involved but this did not happen: EMOTIONAL SUPPORTED RECEIVED (absent) (IF); FEELING SUPPORTED (absent) (IF). This may have been both because the nurses themselves were frightened or as Hannah suggests, because of her position. Finally, the withdrawal of Bill's ventilation would have been anticipated as the prelude to his death. In anticipation of this some form of pastoral support for Hannah could have been provided. This does not appear to have occurred: HAVING SPIRITUAL SUPPORT OFFERED (absent) (IF).

You know, it happened too quickly when I think about it. I guess I have regrets about making the decision in [the time frame I did]. Perhaps if I hadn't been told that he was brain dead and that they were reassessing him in the afternoon almost the same day when you think about it, in a twenty-four hour period you know that maybe I wouldn't have made that decision. Perhaps if they'd have gone more cautiously and again that's been my experience in the past too, when I think about it as an intensive care nurse. That more time is taken with making these diagnoses, I mean he basically arrested at five o'clock in the afternoon and by the morning of the first, well by the next day he had a diagnosis of brain death and then that was reconfirmed by the afternoon and he was off the ventilator, dead. It all happened too fast-definitely too fast. (avoidable suffering related to trajectory of illness/decision-making).

And…it wasn't until later, much later, much, much later that I started to think about what happened there, you know, and I still do; I still think about what happened and I wonder whether in actual fact that we made the right decision because, because he struggled so hard to breathe. I now wonder whether in actual fact he was as brain dead as what they said he was. I've never […] given it a voice because to do that would give it primacy, even my concerns, I've never discussed them with my husband and my husband's sitting in the lounge room at the moment and I don't know whether he's listening or not, but I've been too scared to because it's been a secret concern of mine for some time.

Table 6.2 Key factors from Hannah's story:

Contextual factors	
• Venue For Interactions	• Public
• Seniority Of Contact Person	• Consultant (then) Junior Registrar
• Formal Policy R/T Withdrawal Of Treatment	• Absent
Personal Factors	
• Knowing or Understanding	• High
• Agreement with decision	• Low
• Worrying	• High
• Trust of HCPs	• High
• Level Of Rapport With Staff	• High
• Cognitive Shutdown	• High
• Feeling Dazed	• High
• Feeling Supported	• Absent
• Cognitive Flexibility (Registrar)	• Low
Interactional Process Factors	
• Decisional Inclusion	• Absent
• Having Patient's ELD wishes know and respected	• Absent
• Waiting For News	• 90 minutes
• Being Separated	• Prolonged
• Being Kept In The Loop	• Absent
• Liaison Between Clinical Staff and Family	• Absent
• Being Oriented for pt's potential appearance	• High
• Questioning	• Absent
• Professional Oversight	• Absent
• Patient Advocacy	• Absent
• Nursing Silence	• Absent
• Having spiritual support offered	• High
• Being emotionally supported	• Absent

6.3 Harry:

Harry's mother was in her early fifties. When she was 18 years old, she had had an appendicectomy which had been complicated by septicaemia and adhesions. Prior to the story that Harry related, a variety of surgical interventions had been tried over the years to reduce or eliminate the adhesions that plagued his mother's life. This history culminated in the story Harry shared with me. On this occasion, Harry's mother (Frances) had been admitted for further freeing of adhesions and the introduction of a 'revolutionary' new gel that was to reduce the production of future adhesions. In a two step process the adhesions were freed and then the gel introduced two days later (on a Friday). Over the week end, Frances required very high levels of analgesia and her condition deteriorated. Suspecting infection/ complication, she was taken back to theatre. Harry recounted that he and his father had not been overly concerned by this course of events as it mirrored Frances' progress on previous occasions.

Harry and his father (Graham) spoke to the surgeon following this third operation: Dr X (Lancelot) came out and said, 'Yes there was infection'. He said he'd flushed the abdominal cavity out with 6 – 8 litres of water or something to get rid of all the infection and he said he was pleased with the gel, that that still seemed to be in place (*It is curious that the gel stayed in place after 'flushing'. Perhaps it was a mat of some sort*).

Frances was admitted to ICU for overnight observation. Again, this was not overly concerning for Harry-it had happened following previous surgery. ***He continues***, So we went back to ICU and were waiting outside. We were waiting for quite a while before they brought us into see her. The doctor there (*intensivist*) came out and said, "She's a really sick lady."

`Harry and his Dad (Graham) waited for 'quite some time' to see Frances following her return from theatre: WAITING for NEWS (hours) (IF); BEING SEPARATED (prolonged) (IF). Before their initial visit, Harry and Graham met with the doctor from ICU 'outside' the unit: VENUE for INTERACTION` (public) (CF). This anaesthetist as Harry explains shortly was in his mid-fifties, and had '…acquired a manner and ability to explain things'. It is likely then that this fellow was a consultant: SENIORITY of CONTACT PERSON (Consultant) (IF).

The things that I can remember; that sticks out in my mind of what was said were: that she'd aspirated stomach acid into her lungs; that's the main thing. That was the initial thing that stuck in my mind because my aunty reminded me of it when I was talking of it later – but I don't remember much of what the doctor said at that time. [He told us] also that the infection had spread. I was thinking, "This is a lot more serious". The way Dr Lancelot had come out of surgery before it was just like "Yeah this has all happened before, it's all alright." Then this was all a huge shock for us to hear that she was actually a lot, lot worse than the surgeon had said.

The news that Harry and Graham received from the anaesthetist was alarmingly different from the post-operative summary they had received from the surgeon, Mr Lancelot: GETTING MIXED MESSAGES (high) (IF). Harry and his father had not been prepared for this news at all: BEING KEPT IN THE LOOP (absent) (IF). Consequently, this marked dissonance in information came as a shock to them and neither Harry nor Graham questioned this apparent sudden change in Frances' condition: SHOCK (high) (PF); FEELING DAZED (high) (PF); QUESTIONING (Absent) (IF). Notably, there was no nurse at Harry's side during this exchange: BEING EMOTIONALLY SUPPORTED(absent) (IF); SPIRITUAL SUPPORT (IF) (absent).

Harry: We did go in and see her that night - the doctor explained everything very fully. He was a very nice fellow - an anesthetist. He ended up being the doctor that Dad had the most respect for. I suppose it comes with age- he was in his mid- fifties. He had a manner, and an ability to explain things. I remember him asking what level of knowledge we had. He didn't ask me in those specific words but he did work out what we wanted to know and what detail we wanted to go into. Dad reckoned he was quite possibly up to his third year of medical degree with all the 'going's on' with Mum (*chuckle*). So he told us exactly what was going on, didn't hide anything or try to tone it down.

The Intensivist (Martin) seems to have used several effective strategies in preparing Harry and Graham for their first visit with Frances in ICU. His attempts to establish their knowledge level and requirements ensured they were receiving full but understandable information: BEING ORIENTED (to Environment and for Patient's Potential Appearance) (High) (IF). His attempts to relate to Harry and Graham honestly and freely facilitated the trusting relationship and rapport that Harry described: RAPPORT WITH STAFF (high) (PF); TRUST of HCPs (high) (PF).

Harry continues, When we walked in, I think because we were forewarned about some of what was going on, it was easier. She was fully on a ventilator and heart monitor and numerous [...] I was pretty "taken aback". I don't really remember a lot about that night so I'm trying to picture what happened later on. What I saw initially there, we also saw for the next few days. My initial reactions, sort of were probably shock – yeah shock.

Martin's description of his mother's condition and treatment 'forewarned' Harry and Graham of what was to come and Harry felt this made his first visit 'easier'. Nonetheless, Harry describes his reaction to his first sight Frances and found it hard to recall: FEELING DAZED (high) (PF).

The rest of Harry's close family arrived the next morning. Harry returned from attending to business at home overnight. He was informed that his family were 'off *getting coffee somewhere' and that his father was looking for him. Harry found his father planning to make a few phone calls – including one to work. This call was made using a public phone at the hospital entrance.* ***This was a distressing moment for Harry*****:** "… it's not right to say he doesn't show his emotions, just keeps them inside. Dad was phoning his boss and he just said, "Look, I'm going to have to talk to you later." That was difficult (*pause & sobbing here*) because that's the first time I ever saw my father break down. We were just out the front on the bench near the entry [to the hospital], our arms round each other – that's what was really hard for me. But it was really nice, a lot of people in the office just behind where we were sitting came out and said, "Are you OK?" and "There's a room where you can go to if you would like". They were really good.

`Harry and his father sat crying together at the public entrance to the hospital until office staff came and told them of an available private area nearby: WAITING AREA (public, non-specific) (CF). It would seem that the ICU did not have a dedicated private room for relatives to make phone calls and/or had not offered such a facility to Graham: PROVISION OF PHYSICAL COMFORT (absent). Consequently, there were no ICU staff around to offer spiritual comfort for Harry and Graham at what was an Epiphaneal moment for them both: the realisation that Frances was indeed very ill.`

Frances' condition remained stable but critical. The family was told that her condition, Necrotising Fasciitis was ongoing: We were told initially that if she gets through the first 72 hours her chances would increase greatly – at each point the doctor spoke to us in percentages. He explained the reasons, how they worked out the percentages. It must have been the Wednesday, that's when things started shutting down – the kidneys, the liver, and she had the damage to the lungs – so they said she had 25% chance 'cause each of those systems counted as 25%. So… (*long pause*) at which point, it was the Wednesday they put her on dialysis and they also had some sort of new machine that they put her on which was some sort of heart monitor, I think – one that they hadn't used before. Thinking back on it - I think possibly [they used the percentages] to give us an idea of what was happening with her and I think - it was a way of saying the chances are more against than for and it was possibly better for them to talk in percentages rather than saying, "it odds on she's going to die."

The intensivist (Martin) appears to have kept Frances' family up to date with her care and prognosis regularly: BEING KEPT IN THE LOOP (high) (IF). He seems to have used 'percentages' as an objective demonstration and explanation of Frances' ongoing progress and prognosis to the family. This is a strategy discussed in detail by two of the doctors interviewed for this (Henry & Paul).

Throughout the week, Frances had daily debridement of necrotic tissue carried out in ICU as she was too unstable to be taken to theatre. The family were a little heartened by Frances' slight urine output on Thursday. Then on Friday following another debridement procedure Frances had a 'heart attack' [?cardiac arrest/?extension of MI].

Harry continues, "That's when everything just started going downhill. After the surgery she'd had a heart attack. That was about midday on the Friday – so we just kept up with still being with her all the time. But we still had this thing about the times – 'if she got through the 72 hours' that was still in our minds and then you have a big set back like that heart attack.

Then it was during that day that the intensivist came out and said that she was on the highest doses of Adrenaline (*Frances was now requiring Adrenaline to support her coronary contractility & output – it is likely then, that the last 'heart attack' was an infarct or extension of an infarct)* - they were "just off the scale", that he'd ever seen – he'd never given anyone that much before. I think they were talking about down to 4% chance at that time but Dad was always – he said, "If that's all we've got to work with I still want to continue with the interventions".

At this stage in Frances' illness, Martin was honest and clear about severity of her condition and her prognosis. It would appear though that when offered the choice, Graham insisted that all measures be continued for Frances: HOLDING ON TO HOPE (high) (PF), DECISIONAL INCLUSION (high) (IF). It may be that at this stage, Graham was in denial or did not understand the information he was given. This exchange was held 'outside' ICU – possibly in the waiting room: VENUE FOR DECISION (Public) (CF).

Harry continues, It was later that afternoon when Dad and I went into see Mum and we were talking to the guy who was the doctor in the hospital on-call, the registrar. He was a younger guy who Dad didn't particularly like; possibly because he didn't explain things in the way that the intensivist did, probably because he was a bit blunter.

This registrar on call for the hospital for the evening is unlikely to have known Frances' case or her family as intimately as the Intensivist: SENIORITY OF CONTACT PERSON (registrar) (IF). Graham found this person's manner of explaining things less comfortable and his language blunter: LANGUAGE (blunt) (IF). It may be that this registrar had not yet acquired the experience of his consultant colleague. It is interesting then that Harry had the following conversation with this doctor and not the Intensivist.

That's when I brought up: if she went into cardiac arrest what would you do? He said, "Well I'm glad you brought that up." Basically he said they didn't think she'd last through the night. He said he wasn't going to aggressively try to revive her. He said because her body was in such poor shape there wasn't a lot of hope of bringing her back so … [Dad said] he understood that, he was resigned to the fact that she was probably going to die that night and he just said that: Well, he understood 'that thinking' that "they're not going to aggressively try to revive her".

Harry intimates that he had to raise the question of resuscitation, that this had not been mentioned by anyone prior to this. The registrar's reply confirms this: "I'm glad you brought that up". Given Frances' poor prognosis, this issue should have been raised, discussed and documented much earlier – when Martin started talking in terms of percentages. That Harry has not mentioned the issue until now infers that it was not raised with him.

When Harry did raise the issue and the registrar (Alex) was 'glad' to talk about it, rather than promote a discussion, he presents a unilateral decision: He will not be aggressively resuscitating Frances: DECISIONAL INCLUSION (absent) (IF). Alex does provide a rationale for this decision but appears to make no attempt to assess the feelings or wishes of the family: ATTITUDE (paternalistic) (IF). Sadly, at this point Graham seems to surrender (Harry calls it resign) saying he understood that they would not be doing any more. Graham seems to have had this change of heart in only a few hours. One wonders if it was because Harry had raised the issue of resuscitation, because Graham had heard Frances' prognosis from a different (and blunt) point of view, or if he had finally integrated all the information himself.

Harry continues, It was actually 3 o'clock on the Saturday morning that she died. In a sense it was almost a relief [when she died] because we'd just gone up and down from the shock and then hope that she was getting better and then I think once [she'd had the heart attack] on the Friday morning we had probably almost resigned ourselves that this was going to happen. The nurses were absolutely fantastic – they were very comforting right the way through. So we went out to the lounge room and just sat down and – we'd called the local catholic priest and so he'd come in. Then we just said a prayer and basically walked back to the motel – I remember it was a beautiful night.

Harry's narrative ends on a very flat note. There is no sense of support or comfort from staff (no cups of tea or hugs or words of farewell). Frances' family went back to their motel to cope with their grief on their own: BEING LEFT ALONE AT THE END (high) (IF); FEELING SUPPORTED (low) (PF).

Harry does not mention the nurses until the final paragraph in this narrative. It seems they provided fantastic comfort throughout his experience and yet their presence was not remarkable during the exchanges Harry recounts. This silence suggests they were there for Frances and provided comfort when the family came to the bedside. Harry or someone in the family called the priest to come and be present at the time of Frances' death – not a member of the nursing staff. The office staff had to direct Harry and his father to a private place for their grieving. The nurses in this narrative were remarkable in their silence and absence: NURSING VISIBILITY (Absent) (IF).

Table 6.3 Key factors from Harry's story:

Contextual Factors	
Waiting Area	Public
Seniority of Contact Person	Consultant then Registrar
Venue for Interaction	Public
Venue for Decision	Public
Personal Factors	
Trust of HCPs	High
Rapport with Staff	High
Holding on to Hope	High

Interactional Process Factors	
• Waiting for news	• Hours
• Being Separated	• Prolonged
• Getting Mixed Messages	• High
• Shock	• High
• Spiritual Comfort Received	• Absent
• Being emotionally supported	• Absent
• Being Oriented	• High
• Feeling Dazed	• High
• Provision of Physical Comfort	• Absent
• Being Kept in the Loop	• High
• Decisional Inclusion	• Low
• Being Left Alone at the End	• High
• Feeling Supported	• Low
• Nursing Visibility	• Absent
2nd Contact Person (Registrar):	
• Language	• Blunt
• Attitude	• Paternalistic
• Decisional inclusion	• Absent

6.4 STEPHANIE:

Prior to this event, Stephanie had recently moved interstate with her partner. Her father (Henry) had been in and out of hospital as a result of his heart failure, alcohol induced diabetes and hepatic encephalopathy. On this occasion, when discharge approached, the medical staff suggested he go into care. Stephanie describes intra-family disputes over her mother's ability to manage Henry at home. Stephanie's sisters were of the strong opinion that their father should not go into a nursing home. Despite the fact that her father was unable to mobilise without assistance, Henry was discharged home on a Sunday and Stephanie's mother (Eleanor) collapsed on the following Monday while trying to assist him.

Dad called the Ambulance and she was transferred to the emergency department of a metropolitan level three facility […] We [Mum, Dad & I] had spoken about it [quality of life and care at the end of life]. We had often discussed this and Mum and

Dad had both agreed over many years that neither one of them wanted to be maintained on life-support if there was no way that they were ever going to make a full recovery - if they weren't going to be active and able to do for themselves.

Stephanie espoused strong 'not for resuscitation' preferences for herself and the conviction that her parents shared these views and values. In the event of a perceived threat to his wife's life, though, Henry made a **key decision** to summon help. Stephanie describes a father who was usually confused and incapable of independent movement, yet he managed to summon help when his wife 'collapsed'. This action suggests a strong desire for the preservation of his wife's life: INTRA-FAMILY AGREEMENT R/T ELD WISHES (low) (CF).

On arrival at the emergency department, it was thought initially thought that Stephanie's mother (Eleanor) had had a CVA (cerebro-vascular accident). This was ruled out and it was found that her efforts to lift Henry had exacerbated her longstanding heart failure secondary to mitral incompetence. She also had chronic diabetes, and renal failure.

Theoretically, the moment of Eleanor's arrival in the emergency department was the point when the next **key decision** might have been made. Pick-up, initial efforts at resuscitation and transport to the A&E are likely to have taken longer than five minutes. If Eleanor's collapse involved any element of hypoxia then her prognosis was severely compromised (see glossary and discussion in Hannah's story).

Stephanie does not mention Henry's engagement in the ensuing scenario at all so perhaps he didn't accompany Eleanor to A&E. The doctors and nurses in A&E would not have had access to Eleanor's previous history, including her ELD wishes. As she arrived by ambulance the inference would have been made that she and her family wanted her life preserved, if possible. In the absence of a documented advance directive or verbal evidence to the contrary, the staff in the emergency department would have been 'obliged' to continue the life-sustaining measures once started.

Stephanie continues, The nurse from A&E called and said, "Your mum is really sick and this is what the registrars intend to do. I don't know that we can do much to prevent it". And that is all the, you know - intubation, ventilation, putting in central lines and bloody tubes and leads and things all over the place. It would seem though that there had been some opportunity for early discussion of this decision in A&E. The nurse in A&E (Susan) alerted Stephanie to her mother's admission, prognosis and the choices that had been made regarding her treatment. It should be remarked here that the dialogue between Susan and Stephanie is most unusual in its quality of interaction. This was probably a result of Stephanie's previous membership of the staff at the hospital in which this event occurred: QUALITY of INTERACTION (high) (IF); RAPPORT WITH STAFF (high) (PF).

The inference in this conversation was that Susan felt ambivalent resuscitation for Eleanor at that stage. If Susan had time for a phone call, she could have taken the opportunity to challenge the medical officer/s and attempt to prompt a change in his or her decision. Alternatively, rather than expressing a perception of powerlessness, Susan could have used this call to elicit Stephanie's views and wishes with respect to end-of-life care for her mother. Given the opportunity, Stephanie tells us shortly that she would have asked that resuscitation efforts for her mother have ceased: HAVING PATIENTS ELD WISHES KNOWN AND RESPECTED (low) (IF).

Instead Stephanie did not seem to think this was in her ambit, If it were within my power I would not have allowed them to do anything in the emergency department. It would have been preferable for them to make her comfortable and let her go instead of all the "gunho" rubbish that the medical side of the world do. They all act like little Gods, little life savers, you know. I mean at the end of the day - she was ready to go - her heart was failing her. Had they not done all these life-prolonging things that they do in emergency then she would have gone to God if they'd left her alone. And that would have been preferable to me rather than the 10 or 11 days that she endured pain as a result of being 'tubed (*intubated*) etc. It was very uncomfortable for her.

Stephanie was angered by and not in agreement with the initiation of treatment for her mother: EMOTION – anger (high) (PF); AGREEMENT WITH DECISION (Low) (CF). She perceived herself as powerless to contend with the treatment choices made for her mother: FEELING POWERLESS (High) (PF) She seemed to accept Susan's assessment of the situation: without challenge: QUESTIONING (low) (IF).. One might ask why Stephanie did not speak up herself when contacted by Susan and say – 'stop'. As Eleanor's daughter and recent principle care giver she could have done so. It is likely that the stress of the moment and Stephanie's personal connection to the situation clouded her thinking: FEELING DAZED (high) (PF). It is not unusual for this to happen to the stressed individual (Wright, 1993).

Stephanie seems to conceptualise medicine in this context as an adversary; she uses the term "…the medical side of the world", suggesting the strength of her anger: EMOTIONS-anguish, antagonism (high) (PF). It is interesting that this attitude seems to some extent to have been shared by the nurse from the emergency department who contacted Stephanie to notify her of Eleanor's admission.

Eleanor remained in ICU for a week. Her condition improved to the point where ventilatory support was removed briefly. However, her condition deteriorated and the possibility of re-intubation was raised. During this period, Stephanie's sisters had been challenging their mother's decision-making:

Stephanie explains, My sisters would make a decision - mother was not able to - and the staff would ring and say, "This is what's afoot." It had been put to Mum that she really did require 'tubing again (*re-intubation*) and she just shook her head and said, "No". My sisters were down there insisting that she be 'tubed and the medical staff was in something of a dilemma because one of my sisters can be very, very forceful and she was tending to lord it over Mum a bit. So, the medical staff rang again and said, "Look this is what your Mum is indicating; you are the oldest sibling - what do you want?" I said: (*tears, & catch in voice*) "Whatever Mum wants". Stephanie seemed to have benefited from a unique relationship with the staff in the intensive care unit during her mother's illness. As mentioned earlier, this level and quality of interaction is unusual and probably related to Stephanie's earlier position on staff. This relationship seems to have had reciprocal benefits for the staff in the matter of decision-making. There was significant intra-family disagreement about End of Life care for Eleanor. Stephanie had described her sisters' personalities and the challenges they had mounted with respect to their parents' care. These arguments would have been stressful for both Eleanor and the staff: INTRA-FAMILY AGREEMENT R/T ELD WISHES (low) (IF). If Eleanor was lucid and able to refuse intubation as Stephanie describes, then her wishes should have taken precedence here and this seems to have been the staff's aim in calling Stephanie: RESPECTING PATIENT'S WISHES (high) (IF). Stephanie's decisional input appears to have been beneficial for all concerned. Stephanie seems to have felt included in the decision-making she describes: DECISIONAL INPUT (high) (IF). The nursing and medical staff seem to have benefited as her third voice or arbitration in the decisions has lightened some of the load they have been suffering. Asking Stephanie to taking on this role would however have the potential to increase her personal responsibility with respect to decision-making here. She does not remark upon it, however: RESPONSIBILITY FOR DECISIONS (high) (PF).

Stephanie continues, Mary**,** the Charge Nurse who was looking after Mum called me and said, "Look, I'd like to start your Mum on morphine, do you know what that means? I said, "Yes. I do" She said, "You understand?" I said, "Yes" She said "You're OK with it?" I said, "Yes". She said "Will your sisters be, or not?" and I said "Be that as it may." Because by that stage Dad was back in hospital and they (her sisters) had switched their attention once again from Mum to Dad. Anyway that was it - morphine as you'll understand was the beginning of the peaceful end for Mum and that was great. Mum went to God and I was very happy about that - I was quite happy for her (*tears*).

This dialogue and its outcome are extraordinary and illustrative of attitudes around the concept of the Doctrine of Double Effect (see literature review p 47). Mary and Stephanie had established a verbal contract without either of them stating their specific aims. They were, in effect, negotiating what Stephanie called, "…the beginning of the peaceful end…" for Eleanor-her euthanasia. Stephanie was content with the manner of her mother's death: VALUE-comfortable death. In this scenario, Stephanie seems to have been very much engaged in the decision-making process for her mother: SHARED DECISION-MAKING (high) (IF). Although Stephanie was originally distressed by the initiation of life-support for her mother, it seems that her inclusion in decisions towards the end of Eleanor's care facilitated Stephanie's satisfaction with the manner of her mother's death: NEGOTIATING COMFORTABLE DEATH (high) (IF); SATISFACTION with MANNER of RELATIVE'S DEATH (high) (PF). Of course, as has been mentioned previously, this level of engagement and interaction was extraordinary by virtue of Stephanie's relationship with staff at that facility.

Table 6.4 Key factors from Stephanie's story:

Contextual Factors	
• Intra-family agreement R/T ELD Wishes	• Low
Personal Factors	
• Agreement with Decisions	• Low
• Feeling Powerless	• High
• Feeling dazed	• High
• Emotions	
-Anger	• High
-Anguish	• High
-Antagonism	• High
• Responsibility for Decisions	• High
• Value	
- comfortable death	• High
• Rapport with Staff	• High
• Satisfaction With Manner of Relative's Death	• High
Interactional Process Factors	
• Having patient's ELD Wishes Known and respected	• Low
• Quality of Interaction	• High
• Intra-Family Agreement R/T ELD's	• Low
• Respecting patient's wishes	• High
• Decisional Input	• High
• Negotiating comfortable death	• Yes
• Shared decision-making	• High

6.5 LLOYD:

Lloyd's partner, Judith had a large hepatic mass which had developed over the last 6-7 months. At the time of this narrative, she was having a second biopsy of a mass described as 'massive'. Although this was found to be benign, Judith was requiring repeated abdominal paracenteses (drainage of fluid) – Lloyd was told 6-7 litres at a time. This large loss of fluid and the impact of the large mass on liver function had the potential to cause a sudden deterioration in Judith's physiological status and she was transferred to critical care for 2-3 days for observation. When her condition stabilised, Judith was returned to the medical ward. She was receiving significant amounts of analgesia via infusion pump. Judith had been back in the medical ward for 3-4 days.

Lloyd continues, Suddenly her haemoglobin levels dropped quite markedly. *Bang* - they'd gone immediately into action. It's quite surprising how quickly people can get things to happen really. But any way, they'd organised with the critical care unit ... (*at this stage of the interview there was a sudden profound silence on the other end of the phone, long enough to prompt me to enquire if Lloyd was still there).* I'm back – they'd organised with the critical care unit to take her on up there, *(long shuddering sigh)* ah... There is a point when there are some things that you just can't help, you tend to ah, pray a bit. They're not exactly pleasant memories. […] they started that process off and you stand there with your jaw on the floor. Really the only reason that I was aware that Judith was going to be placed in ICU was the simple fact someone came and said "Look we've got a problem" - and then she's off, she's there! I didn't know why or what was going on until later that evening.

Judith's drop in haemoglobin was the result of a bleed from ruptured oesophageal varices (see glossary) which would have been a secondary but foreseeable result of Judith's hepatic mass. This is a medical emergency. Treatment of bleeding oesophageal varices requires that the patient be intubated and ventilated, hence Judith's transfer to ICU. Lloyd was later informed of the reason for Judith's swift transfer to ICU but at this stage in his story, he was not provided with an explanation and not involved/included as the decision to move her to intensive care was made: DECISIONAL INCLUSION (absent) (IF); BEING KEPT IN THE LOOP (low) (IF). It might be argued that, given the circumstances, there was no time to include a relative, but the impression one gets is that Lloyd was overwhelmed as his partner swept past him to ICU: SITUATIONAL SHOCK (high)(PF); FEELING POWERLESS (high) (PF). It seems, with their primary focus upon Judith's urgent needs, staff (both nursing and medical) had neglected Lloyd's integral relationship to Judith: FEELING SUPPORTED (absent) (PF). In this moment of crisis, in the absence of a clear explanation and preparation, Lloyd clearly suffered. Just recounting this experience silenced him momentarily: FEELING DAZED (high) (PF).

Lloyd tells us, Any way as they wheeled her off up there, the nursing staff - there were a couple of nursing staff there and they just took one look at me and came over, had a few words and one in particular was off on her break and she grabbed me by the collar and said, "I'm buying you a coffee". And she just got me out of there and sat me down. She was a nurse with transplant experience, she more or less just sat me down and brought me back to earth, calmed me down quite a bit. Something I was very grateful for and still am.

Lloyd implies that he was visibly shocked at the events unfolding before him. It would appear that in the absence of a formal policy to provide support and comfort for a relative affected by an urgent transfer he was left standing and gaping as Judith left the medical ward: RELEVANT, CLEAR POLICY R/T CLINICAL SITUATION (ABSENT) (CF). It is fortunate then that a nurse was serendipitously present to informally offer Lloyd the support he needed and clearly appreciated. That this comforting exchange seems to have happened in the context of the nurses' tea break suggests that there was no dedicated quiet room where such interactions could have occurred in private and comfort: for INTERACTION (public) (CF); PROVISION FOR PHYSICAL COMFORT (absent) (IF).

Could this situation have been handled better? The medical staff would have been aware of this possible complication of Judith's condition. They would probably have been monitoring Judith's haemoglobin regularly – hence the detection of the 'sudden' drop. Aware of the possibility of a move to ICU, medical and/or nursing staff could have spoken to Judith and Lloyd during the preceding days to alert them to this. Lloyd, it appears, was left behind as Judith was "…wheeled off up there". His needs for information and support were neglected. This avoidable suffering could have been ameliorated if there had been a formal policy in place detailing strategies that would support the needs of the relative involved (point/person of contact, waiting area etc): RELEVANT, CLEAR POLICY R/T CLINICAL SITUATION (ABSENT) (CF).. I will deal with this issue in more depth in conclusions.

Lloyd continues, I didn't know why or what was going on until I saw her later that evening. That was when it *was* (Lloyd's emphasis) possible to see her - that was that evening - we would have gone probably from the middle of the day to that evening until I could see her. The first I knew about the internal bleeding would have been just before I saw her that evening, whereupon the registrar from the (*medical*) ward she was taken from told me what was going on and the fact that she had these veins at the bottom of her oesophagus that had ruptured, burst or done something. They'd taken about 2 litres of blood from her stomach and they put several units back into her again and her condition was not real good but stable.

Lloyd estimates that he waited from the middle of the day until the evening before he could see Judith: WAITING for NEWS (many hours) (IF); BEING SEPARATED (prolonged) (IF). Lloyd had no specific news/ information about the reason for Judith's transfer until his conversation with medical registrar from the transferring ward: SENIORITY OF CONTACT PERSON (registrar) (IF). This is a long time to wait without news or 'updates' on the condition of a loved one, and is likely to raise anyone's anxiety: BEING KEPT IN THE LOOP (absent) (IF); WORRYING (high) (PF). It would seem that this particular unit did not have a specific policy related to maintenance of contact with relatives of patients. The provision of a dedicated liaison nurse to a) establish a rapport with Lloyd and b) provide the necessary regular updates would have would have addressed Lloyd's needs here. I will return to this in conclusions.

The medical registrar spoke to Lloyd 'just before he went in to see Judith'. One can assume then that the venue for this conversation was the anteroom to ICU or the corridor outside the swinging doors to ICU: VENUE for INTERACTION (public) (CF). One can infer, too, that Lloyd had been waiting all this time in this or other public areas: WAITING AREA (Public, non-specific) (CF).

Next step was I was allowed to see her and the nurse who was actually looking after her met me in the corridor briefly. She had a reasonable sort of smile on her face introduced her self to me: "Don't look so glum you'd be amazed what we can do in here" and I was.

This meeting too occurred in the corridor leading to the unit: VENUE for INTERACTION (public) (CF). The aim of such meetings is usually to prepare relatives for the ICU environment and technology attached to loved ones. Lloyd recalls a nurse with a cheerful face and strongly encouraging words whose aim seemed to be improving or increasing Lloyd's level of hope after the news he had heard from the medical registrar: FEELING SUPPORTED (moderate) (IF). Lloyd does not recall explanation but it is very likely that he was stressed at the time: FEELING DAZED (high) (PF).

Yeah, so that probably helped me a little bit rather than to front up into a room full of different people in all sorts of attitudes with all sorts of gear hanging off of them. […] and I will say they [ICUs] are a very off -putting place to walk into, there's no doubt about that - busy, noisy. There's some very sick people scattered around a very big room, just one big open plan, there's all sorts of equipment making all sorts of noises. You sort of waltz across and here's someone (*Judith*) looking absolutely dreadful with more tubes and wires and God only knows what sticking out of them and in a very distressed state themselves - you know, not totally lucid - but knowing that you're there - panicky - not panicky - but I knew that she was in a lot of trouble.

Lloyd found Anna's reassuring words gave "a little bit" of help when he entered ICU: BEING ORIENTED for ICU ENVIRONMENT (moderate) (IF); PERCEPTION OF SUPPORT (moderate) (PF). His description of himself, his first impressions of ICU and of Judith within this context tend to belie this impression though. Lloyd sounds confused as he describes himself (panicky/ not panicky) upon first seeing Judith in ICU, enmeshed in the technology of her various treatments. Lloyd gives the impression of being overwhelmed both by the environment and the full realisation of Judith's situation. He talks of himself in the second person, as if he is gazing on and distancing himself from a traumatic event: SHOCK (high) (PF); FEELING DAZED (high) (PF).

Lloyd does not mention any staff around him offering support or explanation of the immediate environment and Judith's care which is curious in light of his description of his initial 'orientation' : PROVISION OF SPIRITUAL COMFORT (absent) (IF); BEING KEPT IN THE LOOP (absent) (IF). It is very likely that Judith's care at this stage would have required very close observation and frequent attendance to technical tasks which would have fully occupied the nurse's attention. Cognisant of this possibility, Anna or the charge nurse could have organised for a pastoral care officer to be present when Lloyd first visited Judith to offer the support he needed. I will return to this issue in conclusions.

I wasn't [involved/ included] in decision-making at that point and not really at any point. They just more or less did what they had to do. […] Really there was nothing I could make a decision on - it was just a case of being aware of the situation as it was going on - depending upon how successful these people were and what they were attempting to do. They know who you are and they treat you with a great deal of respect and kindness, but information-wise you can still be in the dark a little bit unless you ask a few questions of the right people at the right time. It's very hard to know what to ask - because you're uneducated really as to what people are doing. After that it was just a case of being there and letting her know that I was there.

Lloyd described himself again as peripheral to Judith and her care: the health professionals caring for Judith were polite to him and acknowledged his presence, but did not include him in the care process: SENSE OF INCLUSION (low) (PF); FEELING POWERLESS (high) (PF). On the other hand, Lloyd seemed to think this was an acceptable situation given his knowledge level: RELEVANT KNOWLEDGE BASE (low) (CF). Although he realised that he needed to ask questions and yet needed knowledge to ask those questions, Lloyd appears to have made the **key decision** to not be proactive and seek that knowledge: PROACTIVITY (low) (IF); QUESTIONING (low/ absent) (IF).

The position Lloyd adopted here may to some extent have been a product of his awe of the environment, the medical profession and/ or his fear for Judith: AWE OF MEDICAL PROFESSION (high) (PF); FEELING DAZED (high)(PF). In an almost reciprocal relationship, a paucity of relevant and timely information also contributed to Lloyd's hesitancy to question-as he himself acknowledged: BEING KEPT IN THE LOOP (low) (IF). In the absence of strategies to a) gauge Lloyd's understanding of his partner's progress and care and then, b) address his knowledge needs, he suffered a sense of isolation: BEING ON YOUR OWN (high) (IF). I will return to this in conclusions.

Later, on the evening of Judith's transfer back to ICU or during the following morning (Lloyd was hazy about time frames) the possibility of liver transplant was raised. Lloyd describes a three-way phone conversation including himself, the consultant surgeon and the ICU registrar with who he had most contact:

"We had a bit of three way conversation via the phone whereupon the intensive care doctor stood beside me and handed me the phone and I talked to the other fellow and he said "I believe Judith has had a couple of better days" - he was the only one who did - the intensive care doctor beside me was just about ripping his hair out! You could see him mentally thinking, "Whoa back pal! - You're throwing too many decorations on this one" He sort of said you've got this problem still there and you've got all these other problems - her kidneys still weren't working all that well- who knows what else? That man was obviously very concerned about her ability to survive that next 24 - 48 hours. Here I had one man telling me things should be OK and the other man who's doing the job going, "Oh I don't know about that". He didn't want to tell me that nor did he express that in words to me but his body language was good enough - you didn't have to be a psychologist or a rocket scientist to work out what was going on. But at the same time the man (*intensive* *care registrar*) was quite supportive and reassuring - he was the only one I really spoke to about what was happening - what was going on.

In this exchange there seems to have been an effort to include Lloyd, but as he discerned, the main thrust of the discussion was obtaining consent for transplant rather than inclusion of Lloyd in the decision. The venue for this discussion appears to have been the unit's office: VENUE for DECISION (public) (CF); and the medium a telephone receiver passed between the participants in the conversation. This arrangement would not have allowed for face-to-face contact for all three parties, nor would it have been conducive to active listening, questioning or reflective feedback: QUALITY OF INTERACTION (very poor) (IF).

Lloyd had discerned very different messages regarding Judith's condition and prognosis from the surgeon and the anaesthetist during this interaction: GETTING MIXED MESSAGES (high) (IF). Nonetheless, he did not question either of their viewpoints: QUESTIONING (absent) (IF).

Actually, the day that they decided they were just baby-sitting her, [*Judith was extubated after 24 hours and awaiting transfer to the medical ward*] a whole clutch of them including the main man came down and politely and pleasantly said, "Transplant's in because there's no other action we can take". They were making sure that I was aware that transplant was in at that stage; that I understood that was the only way we could go forward at this stage. I said, "We've talked, there won't be any problem getting Judith to consent to that particular process - she knows that's it".

Once again, it would seem that a decision was presented to Lloyd and Judith as virtually non-negotiable. This aspect of this interaction is concerning as Lloyd infers that Judith was aware by this stage and able to participate in her own decision-making: SHARED DECISION-MAKING (absent) (IF); RESPECTING PATIENT'S WISHES (absent) (IF). There is an air of paternalism here as Lloyd is taken aside to be presented with persuasive information and the asked to decide on Judith's behalf. This is a decision with profound implications for Judith. Both Judith and Lloyd should have been presented with ALL relevant information. While her wishes should have remained paramount, a decision could have been made in discussion with the health professionals Lloyd mentions previously. Without these elements, this decision does not meet the requirements of freely-given, fully-informed consent: GIVING INFORMED CONSENT (absent). It would seem though that despite the apparent dearth of information during the last few days, Lloyd, and possibly Judith, understood the gravity of the situation. One gets the impression that Judith too had 'handed over' decisions about her care to the medical care: '…there won't be any problem getting Judith to consent…' SURRENDER OF DECISION-MAKING (high) (IF).

Finally Lloyd raised an issue that was significant for him, Probably the only other thing that really gets you on edge apart from the fact that the joint is noisy all the time is the fact that people gather at the end of the bed. Yeah, good this case is very medically interesting, someone's going to write a nice paper when it's all finished one way or the other - but when you get groups of 5 or 6 doctors and lord know who else, sometimes you don't know who these people are, having great discussions at the end of the bed in a very impersonal way: "we're the only people in this room - blow the rest of you". I wouldn't call that emotionally good for anyone - anyone with the patient or the patient themselves. It makes you angry at times it really does, because they're distressing the person that's on the bed and you can see that distress. They're not happy about themselves being talked about or them talking about the persons on the other side or anything else. I know it definitely angered Judith, she told me it did - very much so. She was very upset about the whole idea of that - not the idea of being referred to as a piece of meat or anything like that - but the noisy discussions that go on all hours of the day and night.

These discussions about the patient (in this case probably Judith and/ or the patient just seen before Judith) were held in the open ward: VENUE for INTERACTIONS (public) (CF). This is a practice designed to facilitate discussion and teaching related to cases, particularly interesting ones, as Lloyd alludes. It does not contribute to a peaceful ambiance in the unit. The practice clearly caused Judith some distress and increased Lloyd's anxiety. The provision of a dedicated room or area for the discussion of ward rounds would ameliorate this problem. I will return to this issue in conclusions.

Coda:

I spoke to Lloyd one month after this interview. Judith had been transferred from the medical ward back to ICU for treatment of bleeding oesophageal varicies twice (she was in ICU when I called). She had been 'moved up' on the transplant list because of her deteriorated health but her outlook was not good.

Table 6.5 Key factors from Lloyd's story:

Contextual factors	
Waiting Area	Public
Relevant, Clear Policy R/T Clinical Situation	Absent
Impact of technological Environment	High
Venue	Public
Personal Factors	
Situational Shock	High
Feeling Dazed	High
Awe of Medical Profession	High
Feeling Powerless	High
Relevant Knowledge Base	Low
Sense of Inclusion	Low
Perception of Support	Low - moderate
Interactional Process Factors	
Waiting for news	Many Hours
Decisional Inclusion	Absent
Spiritual Comfort Received	Absent
Formal Strategy for Provision Of Crisis Support	Absent
Provision of Physical Comfort	Absent
Being Separated	Prolonged
Being oriented to Unit	High
Being kept in the Loop	Low
Questioning	Moderate
Proactivity	Low- moderate
Seniority Of Contact Person	Registrar
Quality of Interaction	Very Poor
Clarity of Information	Confused
Inclusion of family in decisions	Absent
Giving Informed consent	Absent
Surrender of Decision-making	High

6.6 RUTH:

Ruth's mother-in-law Margaret, 42, collapsed at home on a Friday evening. Her 15 year old daughter (Anne) had been at and had summoned the ambulance. Margaret was intubated and transferred to the level three facility in town. Margaret was ventilated over the weekend as investigations were carried out to discover the cause of her collapse. C/T scanning revealed cerebral bleeding and oedema. Margaret did not regain consciousness.

Ruth continues, She was on all these different drugs, you know, Adrenaline, Dopamine, Dobutamine and so many different things that I can't remember them all. And that kept going; at no time did they cease anything. She didn't have dialysis or any thing like that. Then she had two physicians review her to see if there was any response (*checking for cranial nerve reflexes*). That was done Friday; and Saturday and Sunday and there was nothing. Then Monday came and Dr … (intensivist) came in and talked to Nigel (*Ruth's husband*) and me and Archie, Marg's partner. He's a man who's never made a decision in his life. She was always the decision-maker and the planner in the family. […] So Archie looked to Nigel and me to make that sort of decision. So come Monday morning we had a family meeting. There were the anaesthetic doctors – some were physicians. We had the C/T experts there. She had seven brothers and sisters and their partners and us, and my mother was there to give support for Anne being 15, you know, just not knowing what was going on. And Marg's Mum and Dad were there. There would have been about twenty-five people in that room.

Ruth implies that this family conference was convened to facilitate decision-making: DECISIONAL INCLUSION (high) (IF). This strategy would have ensured that all family members received the same information at the same time and that questions could be addressed together, hopefully reducing the likelihood of confusion or mixed messages. On the other hand, Ruth indicates that there was a large group of people in the room. It is possible that some questions might not have been answered. Given the large number of people involved in this discussion, it is very likely that a separate room was found to facilitate privacy and physical comfort (chairs for everyone to sit on etc): VENUE for ELD MAKING (Private) (CF). Ruth indicates later that family members waited outside the unit while others visited Margaret in turn, so a dedicated area for family members of ICU patients was clearly not available: (Public, non-specific) (CF). It is worth noting that Ruth does not mention any nurses in her list of participants in this decision-making conference NURSING SILENCE (high) (IF). The nurses in the next chapter of this dissertation lament their exclusion from decision-making. It is possible that they were present but just not 'visible' to Ruth. I will return to this issue shortly.

Ruth continues, So we had the meeting with the 'voices', the knowledge and they said this is what's happening, "There's no response". The medical professionals 'facilitating' this family conference, as Ruth tells us, were intensivists, physicians and C/T 'experts': SENIORITY OF CONTACT PERSONS (consultants) (CF). It is interesting that Ruth refers to these people in the third person and with reverence as 'the voices' and the 'knowledge'. It is as if she holds this particular group of professionals up on a pedestal: AWE OF MEDICAL PROFESSION (high) (PF).

Everyone was there and they went through everything from admission – this is what we've done, this is what we've found, this is what [your Mum's] responses are and this is the outlook. I remember they said: "Every part of Marg that you know is gone – every part of her you know is gone! (*Ruth's emphasis*)"– any questions from the family? [They said] We can continue like this indefinitely. Her systems will gradually stop working and we'll have to put in counter measures to like "...pick the kidneys up" was what I remember. She's had no spontaneous breathing. She's had no spontaneous or voluntary movements since Friday night. They said, "that one arm movement (*had 'dropped'/ ?moved arm when being moved from trolley to bed*) was probably just a reflex or a bump during movement from the trolley to the bed". They couldn't definitely say it was voluntary movement until they saw more. Any questions? Her brothers asked, "Are there any other tests, or could you have operated?" That was a big one. Because I was thinking if it's a blood clot -could you have stopped it happening? But with the location - we found out later with the location of the aneurysm – you couldn't have clipped it. So there were a couple of those sorts of questions. *Post mortem examination revealed the source of the bleed to be a ruptured Berry Aneurysm.*

The explanation that Ruth reported seemed thorough and clear: DEPTH OF INFORMATION (thorough) (IF). Ruth gives the impression that the medical officers explained Margaret's clinical situation and care with appropriately pitched terminology: COMPLEXITY OF INFORMATION (low) (IF). One gets the impression that the family was left in little doubt about Margaret's prognosis although this was explained gently: BEING KEPT IN THE DARK (absent) (IF). The family conference included opportunities for clarification through questions: QUALITY OF INFORMATION (high); QUALITY OF INTERACTION (High) (IF); OPPORTUNITY FOR CLARIFICATION (high) (IF). The phrase used "Every part of Marg that you know is gone" seems a very clear means of explaining the concept of 'brain death' to a lay relative. This is the best example of dealing with ELD-making encountered during my data-gathering. I shall return to this issue in conclusions.

Ruth continues, So that was Monday morning and the decision was made really. We couldn't see her suffer like that for another two or three weeks or whatever-it was finished. It just had to finish. But the decision was made based on the information given to us and I felt it was honest and it was substantially backed up by other doctors. It wasn't just one person's opinion – we had several people's opinions and it was people with different levels of skill –some were the anaesthetic doctors – some were physicians. We had the C/T experts – the radiology experts up there reviewing the scans [...]. So, as hard as the decision was it really wasn't our decision – it was made for us.

Margaret's family relatively swiftly reached a decision together to withdrawn treatment. Ruth indicates that she, and by inference the family, felt that this decision was based on sound information from a variety of knowledgeable sources: BEING KEPT IN THE LOOP (high) (IF); SHARING IN THE DECISION-MAKING (high) (IF). Ruth infers that quality of life issues also guided/ supported the family's decision: VALUE-quality of life (high) (PF), AGREEMENT WITH DECISION (high) (PF).

Ruth continues, So that morning after the family meeting we went away – they'd taken Marg's father away and sedated him – he has a heart condition and he wasn't coping. So we couldn't do anything at that stage, we had to wait for him to wake up. The decision was made: "Yes, we need to turn off this machine." And then it was up to Archie, her partner, for a time, you know, when will we do this? He decided: "We'll do it 5 o'clock this afternoon." That was just terrible because the three of us as a family: Nigel, Anne and I needed to do it then! We needed closure, because we didn't want her to suffer another 6 hours. Yeah we just didn't want to prolong it. But then I thought he was her partner and he needs to be here so we said 5 o'clock, which was good because everyone had that day to say goodbye.

It is interesting that the family was included in such decision making minutiae as timing of withdrawal. The inclusion of the family at this level of the decision would probably have conferred an increased sense of control at a very difficult stage in this experience. Ruth's reflections on the merits and problems associated with waiting for treatment withdrawal reflects this: SENSE OF CONTROL (high) (PF).

Ruth tells us, That was good, every one had time to say good-bye because the staff was really flexible. All the brothers and all the sisters got a chance to spend some time with Marg. Father R… (pastoral care) stayed with them while with Father T... stayed outside with the family. It was a really long day, cause everyone was watching the clock, you know, "…only an hour to go". And then we said a little prayer, they just turned the machines off and they extubated her and everybody sort of left then. Family members all had a chance to sit with Margaret and say their goodbyes: OPPORTUNITY FOR CLOSURE (High) (IF). Throughout the day there was a pastoral care worker or minister to support the family members both at the bedside and outside the ICU: HAVING SPIRITUAL SUPPORT OFFERED (High) (IF). Ruth says that the rest of the family waited 'outside' the unit while brothers and sisters sat with Margaret. This infers that a private or dedicated room was not available or provided for the family during this period: WAITING AREA (public, non-specific) (CF); PROVISION OF PHYSICAL COMFORT (absent).

Ruth finishes her story, I stayed and sat with Cheryl who is her sister, because her heart was still beating – and you still think she's gong to breath! We just sat there until her heart stopped beating. Cheryl wasn't going to leave her, I said, "Come on Cheryl it's finished." And she said "No, her heart's still beating.' So we waited, and waited – (*sigh*) and what really struck me […] at that point, she was cold so quickly and the colour just drained. As soon as the machines were turned off the colour just drained- she was blue- as if she had been gone since Friday- just the way her colour drained so quickly. Cardiac death may not occur until minutes after oxygen supply is withdrawn as the heart has its own inherent pacemaker which will keep going until overcome by metabolic acidosis (Romanini & Daly, 1994). In the absence of a policy requiring bedside monitoring to be ceased when a patient's treatment is withdrawn, Cheryl suffered unnecessarily waiting for Margaret's technological death: RELEVANT, CLEAR POLICY R/T CLINICAL

SITUATION (ABSENT) (CF). I will return to this issue in conclusions.

Finally, as in Harry's story, Ruth is silent with respect to the nurses in this narrative. She mentions them by inference in the closing stage of this story when referring to the 'flexibility' of the staff, but there is no mention of their presence or support during the family conference or during the withdrawal of treatment for Margaret: NURSING VISIBILITY (absent) (IF). This is an issue I will return to in conclusions.

Table 6.6 Key factors from Ruth's story:

Contextual Factors	
• Seniority of Contact Person	• Consultants
• Waiting Area	• Public
• Venue for ELD-making	• Private
• Relevant, Clear Policy R/T Clinical Situation	• Absent
Personal Factors	
• Awe of Medical Profession	• High
• Sense of Control	• High
• Agreement with Decision	• High
• Value- Quality of Life	• High
Interactional Process Factors	
• Decisional inclusion	• High
• Nursing Silence	• High
• Nursing Visibility	• Absent
• Depth of Information	• Thorough
• Complexity of Information	• Low
• Opportunity for Clarification	• High
• Quality of Information	• High
• Quality of Interaction (high)	• High
• Being Kept in the Dark	• Low
• Being Kept in the Loop	• High
• Sharing in Decision-Making	• High
• Opportunity for Closure	• High
• Provision Of Spiritual Comfort	• High
• Provision Of Physical Comfort	• Absent

6.7 DISCUSSION:

In this chapter the narratives of six relatives have been examined as they have 'talked' about their experiences around the end-life decisions made for their loved ones, their participation or otherwise in these decisions, and their perceptions of those with whom they have interacted in these decisions. During analysis, key decision-making moments were identified in each relative's story, and then the interactions occurring around these moments were examined. During this process, key factors within and/ or impacting on the interactions have been identified. The stories the family members related came from a variety of critical care contexts, yet there were many commonalties in their experiences and thus factors common to each story. Conversely, some factors were unique to the individual unit and relative's experience.

These factors have been gathered and grouped together in their various categories: Contextual Factors, Personal Factors and Interaction Process factors. In the process of further understanding the process from the relatives' perspectives, these factors have been re-examined, ordered and sorted as outlined in methodology.

This stage of analysis is summarised in the two tables below: 1) sorting of factors and 2) the organised process:

Table 6.7 Key factors from Relative's Stories:

Contextual factors
• `Seniority Of Contact Person` • `Formal Strategy for Provision Of Crisis Support` • `Formal Policy R/T Withdrawal Of Treatment` • `Intra-family agreement R/T ELD Wishes` • `Venue for Interactions` • `Venue for Decisions` • `Waiting Area`
Personal Factors
• `Worrying`

- Shock
- Feeling dazed
- Awe of medical profession
- Feeling powerless
- Knowing or Understanding
- Feeling Supported
    - Being Alone
- Holding on to Hope
    - Loss of Hope
- Being sure of patient's wishes re ELD
- Trust of HCPs
- Level of Rapport with Staff
- Emotions
    - Anger
    - Anguish
    - Antagonism
    - Denial

Interactional Process Factors

- Waiting for news
- Being Separated
- **Being kept in the Loop**
    - Using informal channels to gain information
    - Quality of Interaction
    - Clarity of Information
    - Getting Mixed messages
- Liaison Between Clinical Staff And Family
- Being kept in the Dark
- Spiritual Comfort Received
- **Being emotionally supported**
    - Nurse as witness
    - Nursing Silence
    - Nursing Visibility
    - Being left alone at the end
- **Being oriented**
    - to Unit
    - to patient's potential appearance
- Questioning/ Proactivity
- **Making the Decision**
    - Sharing in decisions
    - Decisional Inclusion
    - Inclusion of family in decisions
    - Surrender of Decision-making
    - Making ELD Without Support
    - Responsibility for ELD
    - Agreement with decision
    - Giving Informed consent

Table 6.8 Process of End-of-Life Decision-making: Relatives' perspectives

Key factors: Relatives	Suffering reduced when:
Contextual factors	
• Seniority Of Contact Person	• Consultant
• Waiting Area	• Private, dedicated
• Venue for Interactions	• Private
• Formal Strategy for Provision Of Crisis Support	• Documented & Clear
• Clear relevant policies R/T clinical situation	• Documented & Clear
• Intra-family agreement R/T ELD Wishes	• High
Personal Factors	
• Worrying	• Low
• Shock	• Low
• Feeling dazed	• Low
• Feeling powerless	• Low
• Knowing or Understanding	• High
• Feeling Supported	• High
• Holding on to Hope	• Supported but realistic
• Being sure of patient's wishes re ELD	• High
• Trust of HCPs	• High
• Level of Rapport with Staff	• High
• Emotions	
– Anger	- Low
– Anguish	- Low
– Antagonism	- Low
– Denial	- Low
Interactional PROCESS Factors	
➢ **WAITNG**	
- Waiting for news	- Brief
- Being Separated	- Brief
➢ **BEING ORIENTED**	
- to Unit	- High
- to patient's potential appearance	- High
➢ **BEING KEPT IN THE LOOP**	
- Liaison Between Clinical Staff and Family	- High
- Venue for Interactions	- Private

➢ **BEING SUPPORTED**	
• Spiritual Comfort Received	• High
• Ability to meet own basic needs – Privacy – Physical comfort – Communication needs	• High
➢ **MAKING THE DECISION**	
• Venue for Decision-making	• Private
• Offered inclusion in decision-making	• High
• Shared decision-making	• High
• Agreement with ELD	• High
• Being supported in ELD making	• High

The stories these participants told involved a variety of precipitating illnesses and case scenarios. They occurred in differing critical care venues with a wide range of resources. Nonetheless, the commonalities in each and the parallels between stories allow one to draw conclusions about the process of end-of-life decision-making from the perspectives of the family members.

Each of these stories related in some way to end-of-life decisions. All but one of these (Lloyd) related a story which culminated in the withdrawal of treatment for their loved one. As analysis has shown there were interim steps prior to withdrawal of treatment at which potentially vital end-of-life decisions (key decisions) were made. Significantly in all but two of these stories (Ruth and Harry) inclusion of the relatives in such decisions was not sought or encouraged. At the same time, the relatives themselves were not active in seeking such participation. They did not ask questions, seek clarification, or apart from Sandra, seek further information themselves (not that this last step should have been necessary).

Lloyd threw light on the possible reason for the reluctance of relatives to be proactive in questioning and decision-making in critical care. Most of the relatives in critical care are already in awe of the environment and of their relative's need for high-tech care and support. In the absence of adequate levels of knowledge, like Lloyd, they don't know that a question need be asked. This knowledge deficit is exacerbated in the absence of assessment of knowledge levels, explanation, and provision of contemporaneous updates by the staff caring for their loved ones. The best example of how this might be done well was given in Harry's story. Although his mother's case was a sad one, the family was kept well informed and included by the intensivist.

A common aspect of these stories is the time relatives spent waiting to see their loved ones. Most were separated from their critically ill family member for hours without some news of their condition or progress. The period of waiting and separation in many cases cannot be reduced as vital complex care or time in theatre requires separation. The absence of news could be addressed though. Contemporaneous updates could have been provided personally by a dedicated staff member (a liaison nurse) on a regular basis, preferably face to face. This nurse could be a dedicated staff member, perhaps CNS level, who could establish close ties with the relatives throughout their contact with the critical care unit. I will develop this recommendation further in conclusions.

Further to the matter of waiting-relatives spoke of waiting for phone calls while having a cup of coffee at the hospital's canteen or they spoke of talking to health professionals 'outside' ICU. These data infer that many of the units in these stories did not have dedicated private areas/ rooms where relatives could wait and rest in comfort or where private conversations with health professionals might be held. Such structures need to be included in the construction of new ICU's and adapted in some way into current ICU's. I will pursue this recommendation further in conclusions.

Finally, most of the relatives in this story at some stage said how 'marvellous' or 'wonderful' the nurses were – usually when summing up. They did not, however, refer to specific supportive or comforting measures provided by the nurses in their stories. Instead the nurses were noticeable in their absence. Hannah for example indicated how she would have liked a comforting arm around her shoulder when her father was fighting for breath. Sandra noted the witnessing rather than comforting presence of the nurse in her story. The nurse in Stephanie's story did actively seek to include Stephanie in the decision-making for her mother, but there was no indication of spiritual comfort or support for Stephanie or her sisters during their struggles.

The relatives in these stories seemed to have remembered and related these interactions clearly and yet the nurses in this chapter seem as wraiths, hardly mentioned. This may be because the relatives saw the doctors as figuring more in the end-of-life decisions for their loved ones. Yet there were times in these stories when individuals were distressed and dazed by the situation around them.

Nurses need to be supportive and sheltering of the relatives involved in such situations. Relatives need to be relieved as much as possible of extraneous stresses (i.e. provision of physical comfort) so that they may deal 'best' with the crisis at hand. When faced by the emotional & spiritual challenges of ICU & their critically ill relatives – they need support & facilitation of that support. They require clear and adequate information so that they a) actually know a decision is impending and, b) are prepared/informed to participate in that decision. Nurses need to supply this information and/ or make sure this supply is facilitated). If and when a relative is distressed/ shocked/ suffering & can't question for some reason, the nurse needs to be there for them and advocate/ support/ encourage questioning. ALL of this is NURSING SUPPORT and without it avoidable suffering occurs for the relatives of the critically ill patient.

CHAPTER SEVEN- ANALYSIS OF NURSES' STORIES

7.1 PETA:

The one that sticks best in my mind was a gentleman who at the time was my own age. I would have been about 34, I suppose, and he'd had a sub-arachnoid haemorrhage. His daughter found him collapsed on the bathroom floor and called the ambulance. They took him into the nearest hospital. They 'tubed (*intubated*) him , brought him into us, and he was basically brain dead when he arrived, but had had some muscle relaxants so we couldn't do anything until those had worn off. He had two daughters (6 and 9), the same age as my daughters. And his wife had died six months previously of bowel cancer. So the day that he came in the children weren't brought in. His mother and his wife's mother and several of his siblings were there and they came in and were basically told that, we were just waiting for these muscle relaxants to wear off (*before diagnosis of brain death could be made and treatment withdrawn*). He'd had CT scans and there was nothing we could do (*inferring that the cerebral damage from his sub-arachnoid haemorrhage was huge*). They [medical staff and family] discussed organ donation and decided, no, they (*family*) didn't wish to go through with that. And so (*pause*) - I was on the late shift that day, and on early shift I was given the same patient – this man.

Peta gives the impression from the outset that she considered John to be very ill and that his prognosis was very poor indeed: CLINICAL SEVERITY (extreme) (CF); PROGNOSIS (very poor) (CF). As John was drug paralysed, the diagnosis of brain death could have been an assumption only. The problematic aspects of the diagnosis of brain death have been raised and discussed previously in this dissertation (see literature review). It should have taken at least 24 hours – preferably 36 hours (and two physicians) before the diagnosis of brain death was made. It is possible that John's C/T scan indicated such gross damage from his sub-arachnoid haemorrhage that an assumption had made been about the probable findings of clinical testing for brain death and John's prognosis. This would explain the decision to discuss the possibility of organ donation with John's family at such an early stage.

Peta indicates in her prelude to this story that she identified closely with John and his children because of his age, the age of his children and the similarity with herself and her family: IDENTIFICATION WITH PATIENT (high) (PF). Most critical care nurses tend to perceive that they develop close relationships with the families of the patients they care for as they spend hours at the bedside together. It is this aspect of their 'nursing' in critical care that nurses finding both rewarding and draining (Burr,2001; Pearson, Robertson-Malt, Walsh& Fitzgerald, 2001; Holde, Harrison & Johnson, 2002). It is not surprising then that Peta empathised closely with the plight of this patient and his young children and that this affected her experiences related to his care EMPATHY FOR PATIENT AND CHILDREN (high) (PF).

Peta continues, At about ten in the [following] morning they [John's parents] brought the children in. They were six and nine at the time. No one had prepared them for what they were going to see; no one had, and no one was telling them that their father was about to die, and this sort of stuff.

Peta's empathy did not seem to extend to John's parents. Her language here is depersonalising and harsh as she describes the arrival of John's children, referring to the grandparents (John's parents) in the third person only. This may be due to the judgement she seems to have formed about their handling of this situation (see below). At the same time, her words underline an absence in policies in this unit with respect to support for families at these times – especially families where a patient has dependent children. Several times Peta emphasises the fact that *'No-one'* was there to specifically prepare John's children for the critical care environment and its potentially frightening atmosphere or for the strong possibility of their father's death. From Peta's narrative one can infer that the family's visit the next day would have been anticipated. Theoretically it should have been possible to arrange for support services in the form of a social worker and/ or hospital chaplain to be available at the time of the family's arrival to facilitate the family and grief counselling that morning: FAMILY COUNSELLING (low) (IF); GRIEF COUNSELLING (low) (IF). This is an appointment that a nurse should have made and that could have been built into policy.

In the absence of specific policies, the responsibility for explanations regarding the ICU environment and the 'appearance of the patient' usually devolves to the nurse in charge of the shift, or the nurse in charge of the patient, in this case to Peta: POLICY R/T PREPARATION OF 'NEW' RELATIVES (Absent) (CF).

Peta continues, And so I met them at the door and told them exactly what they were going to see before they came in; described the tubes, the wires, the machines, all those other things, but I said, "Apart from that he just looks like he's asleep, you know? There's no need to be frightened, everything looks, I know it all looks awful, but he, just looks like he's asleep. So don't worry about the machines and things, just look at him". Peta's 'orientation' of the children to the potential environment and picture of their father was gentle in its approach and appropriately directed for their level of understanding: PREPARATION FOR ICU ENVIRONMENT (high) (IF). Peta does not seem to have included the grandparents in this preparatory orientation though. One gets the sense of intense focus on the children as she tries to prepare them for what is to come: to the exclusion of the grandparents: INCLUSION OF ALL FAMILY IN INTERACTIONS (low) (IF).

And so they came in and all the rest of it and, I mean everyone was in tears, myself included. And (*pause & deep breath*) when they were about to leave, the grandparents who were with these kids said, "Okay, well we'll go now". Peta's open display of empathy for John's situation and for his family would probably have been perceived as supportive. Families of patients in critical care report displays of grief from the staff as supporting and comforting (Burr, 1997). It is possible that Peta's own tears synergistically gave the family support/ permission to express their own grief openly: EXPRESSION OF EMPATHY (high) (IF); PERMISSION TO GRIEVE OPENLY (High) (IF).

Peta adds, And I was unable to say to them, you won't see him again, because the family had said, oh well, we're not telling them. They purposely didn't tell the children because they didn't want to traumatise them. But from my point of view, it's more traumatising not telling them. And, I mean I've had no contact with the family of these children since, so I can't say whether what was done was the right thing or the wrong thing. But it just didn't sit well with me that, in that situation; these kids were left in the dark.

This decision by the grandparents to delay telling John's children about his impending death is the **key decision** of this scenario-Peta seemed particularly affected by it. Peta had no clear evidence that telling John's children his medical prognosis would have any effect in reducing their future suffering. She would have had only fleeting contact with this family. Nonetheless, in this brief time, she had passed judgement on the grandparents' ability to decide in their grandchildren's' best interests: RESPECT FOR FAMILY UNIT (low) (CF).

And nobody said to these children, "This is the last time you'll ever see your father". And (*pause & sigh*) I said to them, "You better give him a kiss, eh?" So they did that, and then they left. Here again, Peta focuses on the children to the exclusion of the grandparents. The implication of her suggestion is that this gesture may somehow ameliorate the suffering for the children as they recall this as a kiss goodbye and perhaps avoid the suffering of regret. The inference to the grandparents of this suggestion (though made to the children), seems to be: "At least they will have ***something*** to remember" ATTITUDE – rude (IF). Could Peta have dealt with this situation more effectively? She should not have spoken to the children directly but instead spoken with the grandparents and explored the possibility that they tell the children of John's prognosis. She would have to be careful here that her approach did not overstep the role of boundaries of parental responsibilities that the grandparent had assumed. Peta's approach should have been was suggestive and advisory only. She could have contacted a social worker and enlisted their assistance in discussing this issue with the grandparents. Issues such as honesty and healthy grieving might have been raised.

Peta continues, Now I had a lot of trouble dealing with this from their [children's] point of view. […] I had problems with that. I also had problems with my colleagues who were, some were somewhat supportive, but in the main they were trying to cheer me up by telling me jokes and it was, you know, inappropriate in that situation. Staff working with Peta recognised either the difficulty of the situation she was facing or the problems Peta was having dealing with its related challenges. It is interesting that the staff told jokes in an effort to reduce Peta's stress or suffering. Making light of a situation, joking about it, usually reflects some element of difficulty or stress on the part of the person/s expressing the jocularity (Wright, 1993). It is likely then that all the staff in the unit was to some degree affected by the sad situation evolving in this narrative: IMPACT OF NURSING CULTURE (High) (CF); COLLEGIAL SUPPORT (Low) (IF) TRAGIC CIRCUMSTANCES of PATIENT HISTORY (high) (CF).

Peta continues, And they did the brain-dead test at half past two and said to me, okay, you can turn that ventilator off. And I just looked at them and said, "No. You can turn it off, I'm going home". And they just looked at me. And I said, "I've had enough, I can't cope, I'm going". So, you know, that would probably be the most traumatic experience I have had in an end of life situation. The final **key decision** in John's care: treatment withdrawal followed 'the brain death test' that afternoon. This was a decision with which Peta would appear to concur, but one into which she has had no input – she is told what to do – there is no sense of collaboration in the decision described: "OK you can turn the ventilator off ": DECISIONAL INPUT (absent) (IF). Peta gives the impression that she was expected to carry out what would normally be a medical task: SENSE of PERSONAL RESPONSIBILITY (high) (PF).

Peta's response, indeed outburst, here is indicative of the stress she has been under for the two previous shifts. Her exchange here is immature in terms of "you do it, no you do it". It is also abrasive and confrontational, almost inviting of a similar response (***like a pugilist***). This interaction seems to be inclusive of all staff in the immediate vicinity as she takes her leave of the patient and the situation: ATTITUDE- Hostile and Aggressive (IF); COMPLIANCE WITH 'ORDER' (low) (IF).

Peta knows however, that in the long-term, such an outpouring of emotion will be not be conducive to future smooth interactions/ decision-making. The time frame Peta describes (testing at 2.30 pm) means that this exchange would have occurred close to the end of her shift. It is unlikely then that Peta would have been rebuked for leaving a shift early. She is however, likely to have incurred condemnation from her peers as one who could not cope with the pressures of ICU. It would seem that the level of emotional suffering Peta was experiencing at the end of this episode was strong enough to outweigh what would have been her usual or 'normal' understandings of professional practice: PERSONAL SUFFERING (extreme) (PF).

Aside from the joking, Peta gives the impression that she was not offered any support, during her care for John; indeed she perceived that she was asked/ ordered to turn off his ventilator. The response of staff to Peta's outburst above was to "just look" at her. While there may have been an element of shock at Peta's refusal to follow what was essentially an 'order', this should have prompted realisation of her need for support at the closing stages of this incident: STAFF DEBRIEFING (absent) (IF); COLLEGIAL SUPPORT (low) (IF). Issues of peer support and the amelioration of related suffering will be discussed more fully in conclusions.

Table 7.1 Key factors in Peta's story:

Contextual Factors	
Clinical Severity	Extreme
Perceived Prognosis	Very Poor
Policy R/T Orientation of 'New' Relatives	Absent
Tragic Circumstances of Patient History	High
Impact of Nursing Culture	High
Interactional Process Factors	
Family Counselling	Absent
Grief Counselling	Absent
Preparation for ICU Environment	High
Inclusion of All Family in Interactions	Low
Expression of Empathy	High
Permission to Grieve Openly	High
Respect for Family Unit	Low
Quality of interaction with staff	Poor
Attitudes	- Rude - Hostile & Aggressive
Compliance with 'order'	Low
Decisional Input	Absent
Collegial Support	Low
Staff Debriefing	Absent

7.2 CAMILLE:

The event Camille recounted involved a woman (June) in her early eighties who had been admitted to coronary care following a myocardial infarct. She had been treated with streptokinase but had had three ventricular fibrillation arrests on the first evening of her admission. She had responded quickly to resuscitation and had suffered no discernable cerebral damage as a result of these first three 'arrests'. On the second day of her admission, June suffered three more arrests, the third of which required 'lengthy' resuscitation and left her semi-responsive only. She had had no *urine output for 12 hours despite Lasix and Dopamine infusions. She was displaying a variety of cardiac dysrhythmias despite a Lignocaine infusion. On the evening of the second day, a documented order for 'full resuscitation in the event of an arrest' remained current in June's chart. June's niece (Madeleine) was at her bedside most of the time and had been involved in discussions with the medical staff. According to Camille, the niece* "…felt they were going too far. She felt that her aunt had come to the end of her time and it was time to let her go at least with some dignity".

Camille continues, Then, that [third] evening the staff had heard her say to this niece, "Will you please stay with me, I'm dying and I don't want to be on my own but don't let them do any more to me". […] These were actually the only words she spoke during her admission - she didn't speak at all until after about her fifth arrest and that was apparently to make sure that the niece wasn't going anywhere and then she became deeply unconscious not long after that. Now the niece made very sure that the medical staff was aware of what her aunt said and it had been overheard by one of the nursing staff so they were well aware of how the lady felt prior to losing consciousness. She was well aware that she was dying and happy to do so if she could be left alone to do it. The registrar who had been looking after her had written quite detailed notes and that she felt that there was no further need for resuscitation in view of this patient's hypotension, anuria, age and mental state - and the niece had agreed with that.

This is the first important **key decision** in this scenario and has a bearing on all those that follow. Camille describes a shared decision between this patient's niece (Madeleine), and a Registrar. This patient's condition was very poor and she had suffered a number of arrests already: CLARITY OF CLINICAL SITUATION (clear) (CF). This decision would not have been a pressing one in this situation: the registrar had time to 'discuss' June's clinical condition with her niece and document detailed notes. The documentation of "no further need for resuscitation" orders clarifies how the nurses should respond if and when June's condition deteriorates further: DECISIONAL CLARITY (high) (PF).

Once the 'not for resuscitation' decision had been reached and documented, however, the nurse in charge of coronary care could have an initiated June's transfer to a medical ward and taken steps to prompt a decision to withdraw June's inotropic support but this did not happen June was still there the following night: CONGRUENCE BETWEEN NFR DECISION and CARE PROVIDED (Low) (CF). It may well be that the absence of a policy related to this situation meant that the staff in the unit had not either considered June's transfer or were ambivalent about this situation. The issue of 'not for resuscitation' orders, DNR's and advance directives is causing increasing debate in the contemporary literature (see literature review): SPECIFICITY of POLICY RELATED to CLINICAL SITUATION/DNRS (low) (CF).

A move to the medical ward may have provided June and her niece with a quiet, private room, away from the noise of critical care. More importantly perhaps, June's continued presence in coronary care and maintenance on inotropes could be seen as contradictory with her documented 'not for resuscitation' order: CONGRUENCE BETWEEN DNR AND CONTINUING 'HIGH-LEVEL' TREATMENT (low) (CF). The perception is held by many such health professionals that the patient's presence in a critical care environment implies the use of maximal efforts to preserve life should these be needed. In June's case this perception would have been enhanced by her maintenance on inotropic support: CONGRUENCE OF TREATMENT OBJECTIVES (low) (CF).

Camille continues, The fourth night […] she had died not long before I came on. The evening staff had been told she was not for resuscitation but they had rung the doctor because she was deteriorating rapidly in that she was becoming bradycardic. She still had the dopamine and everything going and they wanted to clarify that order. He said "Oh yes, you must resuscitate her." [This was] a registrar who worked in the unit and who was more than "au fait" with what happened in the unit and also knew her history because this patient had been in the unit for four days while he'd been working there looking after other patients. This next **key decision** made by the nursing staff during the evening of the fourth day to call the registrar is crucial. There would appear to be no need to question or clarify this order but for the conflict between the order, June's continued inotropic support and her continued presence in coronary care. The nurse making this phone call must be ambivalent about following the 'not for resuscitation' order: NURSING AMBIVALENCE (High) (PF). She may have been fearful of the repercussions upon herself of following an NFR. In phoning the registrar, the nurse in question was probably expecting confirmation of the 'not for further resuscitation efforts' rather that the response she received: NURSING FEAR (high) (PF); CONFLICTED ORDERS (high) (CF).

The registrar who was contacted (Howard) also seems to have been affected by the apparently conflicting treatment approaches for June. Camille tells us that he had been 'aware' of June's case as he had been busy in the unit with other patients during the three previous days of her admission. This does not mean that he was involved in any decision-making related to June's care though and when confronted now by "not for resuscitation" orders for a patient in coronary care on inotropic support, Howard may understandably also have experienced some fear related to the possible impact of an incorrect decision on his part here. This would have been particularly so if he was a 'junior' registrar: MEDICAL FEAR (high) (PF). If a new medical registrar is to take over responsibility for a set of patients for a 'shift', then the plan of care for those patients should be discussed and handed over in detail to ensure clarity and consensus around critical decisions like this DNR decision for June. It would seem that this had not happened here, hence Howard's ambivalence: MEDICAL AMBIVALENCE (High) (PF). Camille assumed that the registrar would have 'absorbed' the relevant information about June while he was working in the unit with other patients over the past three days. It is unrealistic to expect Howard to take in all developments in decision-making for all the patients in a unit. In the absence of clear information about June's plan of care, the registrar's default position was to commence resuscitation should June need it: INTRA-PROFESSIONAL COMMUNICATION/ MEDICAL (Poor) (IF); MEDICAL CONSENSUS (Low) (IF); CONTINUITY OF CARE (low) (CF).

At the same time, hand over of relevant information regarding resuscitation decisions for patients needs to pass between nurses from shift to shift. This did not happen in this case: INTRA-PROFESSIONAL COMMUNICATION/ NURSING (poor) (IF). In essence, the absence of a specific policy regarding documentation and handover of patient's resuscitation status lead to nursing ambivalence lead and the problematic phone call of this narrative. I will discuss this issue further I conclusions.

Theoretically, the nurses on the evening shift could have left the 'not for resuscitation' order unchallenged and June would have died during that shift (***her bradycardia was suggestive of imminent death***). The nursing staff could have informed the registrar of her death and the not for resuscitation orders which they had followed in the same phone call. This strategy would perhaps have seemed devious to the registrar (some medical officers might perceive such an action by a nurses to be undermining their authority). It could however have relieved him of any responsibility in the decision as well as obviating the suffering that followed the phone call. Not resuscitating June would have required high moral agency from the nurses on duty that evening and varied levels of internal conflict depending upon their 'ambivalence' with the order. The issue of "not for resuscitation orders" in the critical care environment is one that tends to polarise opinions. It is my experience that there is likely to have been discussion related to this order, possibly even argument between the nurses in the unit preceding the phone call.

Camille tells us, He (*Howard*) came up just as she went asystolic (*had gone from bradycardia to asystole- June had just died*) and he worked on her for forty minutes.

The niece was really very distressed because to her the decision had already been made and confirmed when the aunt said what she did. She was aware that her aunt was dying and was quite accepting of it - especially in light of what her aunt had said the day before.

Madeleine had expressed and documented her wishes on her aunt's behalf only to see them violated: RESPECT FOR PATIENT'S WISHES R/T ELD (low) (IF). This 'change' of decision had rendered her 'very distressed': RELATIVE'S ANGUISH (high) (PF). Camille clearly empathised with Madeleine's distress and this was source of her own anger: EMPATHY FOR FAMILY (high) (PF).

You feel like you should be able to physically stop them and say, "Hey what about giving this person some dignity" or, "Hasn't everything that can be done been done?

- People do die in coronary care". He was one of the ones who were always very difficult in situations like this […]. `In the aftermath of these events, Camille's foremost emotions appear to be anger and frustration: EMOTIONS-anger, frustration (high) (PF).` Everyone [in ICU had the same reaction to [the decision] - everyone found it very hard to believe that he (the doctor) had done what he had. [Everyone felt] disgust, anger in some ways that he could just blatantly carry on like that without any regard for the patient's wishes or well being. […] And the well-being of the relative and the fact that he blatantly ignored what was being said by the girls who were on, all of whom were very experienced R.N.s. The doctor concerned knew they were experienced and that their judgement was as a rule very sound. `Interestingly, 'everyone' was disgusted, angered at the doctor Camille seems to have no insight into nursing or procedural problems that may have contributed to this scenario's end.`

Table 7.2 Key factors in Camille's story:

Contextual Factors	
• Clarity of Clinical Situation	• Clear
• Incongruity between NFR Decision and care provided	• High
• Specificity of policy related to clinical situation/DNRs	• Low
• Congruence Between DNR And Continuing 'High-Level' Treatment	• Low
• Congruence of treatment objectives	• Low
• Conflicted Orders	• High
• Continuity of care	• Low
Personal Factors	
• Nursing Ambivalence	• High
• Medical Ambivalence	• High
• Nursing Fear	• High
• Medical Fear	• High
• Decisional Clarity (Camille)	• High
Interactional Process Factors	
• Interactional Engagement (Doctor to family)	• High
• Intra-professional Communication/ Medical	• Poor
• Intra-professional communication/ Nursing	• Poor
• Medical consensus	• Low

7.3 JILL:

Jill was working in a ten bed cardio-thoracic ICU when a patient (George) was admitted following coronary artery bypass grafting. George, in his early sixties, was a reformed smoker, had no other risk factors for atherosclerotic disease but had presented with a 'big' infarct. This was George's first infarct. According to Jill, angiography on admission had revealed single vessel disease and the decision had been made to take George to theatre the next day to bypass the diseased vessel. George was a doctor. His sons and a large number of his close relatives were also doctors.

Jill suggested, In the first place, in coronary care most other people would not have been considered for early coronary artery grafts. "I think that the decision [was made] because he was a doctor and with his family I think they thought - we'll jump the queue and get this all over and done with. I think that probably was the cause of his demise because his surgery actually could have been enough to cause him to re-infarct". George's angiography revealed single vessel disease. He therefore two patent coronary arteries and this placed him in a low risk category. At this stage in the narrative,

George's condition is stable and his PERCEIVED PROGNOSIS reasonably good (CF). There were no clinical grounds to take him to theatre: NURSING KNOWLEDGE (high) (PF); RELEVANT EXPERIENCE (high (PF): LEVEL OF AGREEMENT WITH DECISION (low) (CF).

The decision made in coronary care to intervene early with bypass grafts is a **key decision-making moment** destined to have a critical impact on this man's outcome. This decision was unusual for the following reasons:

1. This patient's myocardial infarct was very recent and areas of his heart would have been inflamed and weakened.

2. General anaesthesia places the cardio-pulmonary system under stress, increases the workload of the heart, potentially reducing oxygen supply to all other areas including the myocardium itself. At the same time, the anaesthetic agents themselves tend to have a suppressant affect on cardiac contractility, thereby increasing the potential ischemic impact on the myocardium and the rest of the body.
3. At the time of Jill's experience, bypass grafting of coronary arteries required that the patient's chest be surgically opened and normal blood flow through the heart temporarily 'bypassed'. The time to implement and then reverse this process means that this patient would have been anaesthetised for many hours.

Thus normal practice is to delay surgery for approximately six weeks until the myocardium has 'healed'. In fact this decision at this stage placed George in danger (Romanini& Daly, 1994; Kidd & Wagner, 1997; Urden, Stacey & Lough, 2001).

One wonders why the physicians and surgeons involved in George's care chose such a divergent and risky plan of care for their patient. Jill's earlier description of the family and the dynamics in coronary care gives the impression that she felt that the decision to intervene early came from a fraternal affiliation between the treating doctors and George and his family of doctors. This apparent desire to 'look after their own' seems to have clouded the doctors' judgement in relation to evidence-based practice. Despite her reservations, Jill does not appear to have made any contribution to this decision, either by invitation, or in an effort to change the decision when she learnt of it: DECISIONAL INPUT (low) (IF); DISCUSSING CONCERNS (Absent) (IF). Indeed, there is a silence throughout this narrative from the nurses involved. Neither Jill nor any of her colleagues appear to have been overtly interacting with the doctors making the key decisions throughout this story: INTER-PROFESSIONAL ENGAGEMENT (poor) (IF).

What could have been done instead? Jill or the nurse in charge for the shift could have acted to try to change the doctors' decision. It is my experience that many critical care nurses tend to enter into these types of discussions with veiled hostility. In order to avoid conflict, this would need to be done in a non-accusatory and sensitive manner. One gets the impression from the outset though of antagonism towards the doctors (and George's family as decision-makers). Jill does not mention any significant conversations between herself, other nursing staff and the medical staff regarding these decisions: NURSING SILENCE (high) (IF). It is my experience though that the medical staff would have been well aware of the nursing staff's attitude/ standpoint. The nurses' body language, clipped conversation, particularly when discussing George's care, 'work to rules' rather than helpful 'extra' would all have made it quite plain they were unhappy about George's treatment: ATTITUDE - silent and hostile) (IF); COLLEGIAL SUPPORT (low) (IF); COLLEGIAL RESPECT (low) (PF); QUALITY OF INTERACTION (poor) (IF).

Jill continues the narrative: In theatre he was stable; he only had two grafts. He came back to the unit post-op and didn't wake up (*regain consciousness post-operatively*). He didn't react to voice, pain, any sort of stimuli at all (*strongly indicative of extensive cerebral damage*). We presumed he'd had a [cerebral] bleed (*this is a rare but recognised complication of thoracic surgery, particularly in* *patients with atherosclerotic disease*). He was scanned and this was confirmed. Jill's description of George's absence of reaction to any form of stimuli suggests severe cerebral injury-probably brain death as a result of the bleed revealed on C/T scan. At this point in George's progress a decision to withdraw treatment should have been considered. Continuance of treatment, however, implies that some medical decision has been made i.e. to persist with treatment despite poor clinical signs. Apparently though, Jill was not aware of discussion related to this decision. Neither has there been any input from the nursing staff: DISCUSSING CONCERNS (Absent) (IF), COLLEGIAL COLLABORATION (low) (IF).

He then re-infarcted; basically wall-to-wall Q-waves on his E.C.G. (*indicative of a full thickness infarct involving both ventricles, which means very little viable myocardium remains; cardiogenic shock and death are virtually inevitable)* and with that he went into cardio-genic shock (*mortality rate in excess of 80%, Fulde 2004*). He ended up with a 'balloon' (*left-ventricular assistance*), the usual central lines, arterial lines, and he still had his chest drains in; he was only about day two - and he just kept deteriorating. It got to the stage where he was on 100% oxygen with the highest PEEP (*positive end expiratory pressure*) we could give with blood gases that to me weren't compatible with anything that was living (*this patient was having maximal ventilatory support without any therapeutic result*). We had just about pure inotrope through his central line (*in an effort to stimulate cardiac strength and output, see glossary*). We were running Adrenaline and Isoprenaline via the burette in absolutely ridiculous proportions and we in fact had to get in Isoprenaline and Adrenaline in because we depleted the hospital's supplies (*Jill is describing maximal chemical support for this man's failing heart*). This had happened very quickly, within two days. I mean he was anuric, his mean B.P. was 25 mm Hg (*George had no effective cardiac output, therefore his kidneys could not be perfused enough to produce* *urine*). Jill describes George and his condition in the bleakest of terms: CLINICAL SEVERITY (extreme) (CF); PROGNOSIS (Very poor) (CF).

Jill continues, I think the thing that upset everyone the most was that none of our medical staff would take the initiative to talk to his relatives who were all predominantly medically educated and basically say, "Hey we're ventilating a corpse here". I think they really realised that they were at fault for not getting in earlier and saying to the family, "Look your husband, father, uncle or what ever is not doing well and we need to look at being realistic and ceasing all these huge amounts of drugs".

Jill expressed frustration that none of the doctors took the initiative to talk to the family about George's clinical situation and prognosis. At the same time, there is a vast silence here from the nurses in two areas. Firstly, they themselves are not proactive in prompting a decision to withdraw treatment: NURSING SILENCE (high) (IF); DISCUSSING CONCERNS (Absent) (IF). Secondly, they apparently make no efforts to provide George's family with information or any form of support themselves: SUPPORT FOR PATIENT'S RELATIVES (absent) (IF); INTERACTIONAL ENGAGEMENT WITH FAMILY (absent) (IF).

Theoretically, during the progress of George's treatment and rapid deterioration in the cardio-thoracic unit, there were at least two points when the nursing staff involved with his care might have chosen to ask the doctors to consider withdrawal of extraordinary measures for George. When his C/T scan confirmed that a cerebral haemorrhage was indeed the cause for George's continued unconsciousness, the treating physicians & intensivists should have reviewed their treatment plan for George. Assessment of George's cerebral status for 'brain death' should have been performed. If this was confirmed, withdrawal of treatment should have occurred at this stage. The implications of such a decision at this stage will be discussed shortly. Jill also tells us that the hospital's entire stocks of Isoprenaline & Adrenaline were depleted and still more were brought in. This event, marking the unusually high consumption of a group of drugs, would normally have given the treating medical staff strong reason to consider the merits of their current line of treatment.

It is clear that the treating doctors' emotions were affecting their judgement here. They appear to be having trouble ceasing a course of action they had initiated but that had gone badly wrong. Using either or both of the above events as triggers, the senior nurse on the shift could have spoken to the one of the physicians or intensivists to suggest that treatment withdrawal was an appropriate decision: CHALLENGE TO TROUBLING MEDICAL DECISION (No) (IF). The proactive and yet empathetically mindful initiation of such discussions could have ameliorated some of the suffering for George's family related to his prolonged death. It could also have ameliorated some of the suffering for George's doctors related to the burden of decision-making. The options for professional and collegial dialogue between nurses and doctors at key moments of end-of-life decision-making will be explored more fully in discussions and conclusions.

Jill tells us, The family wouldn't accept that he was going to die, even though they could see his colour. They would come in and talk to him - all that sort of stuff. They were very much in denial. Our staff wasn't game to talk about it - they were treading on eggshells - for fear of being overheard - there were medical staff in and out all the time. Jill uses terms that convey furtiveness and reluctance to raise the decisional and treatment issues that she and her nursing colleagues were concerned about. She describes a tense and fearful atmosphere within the unit-a highly dysfunctional workplace. Team members should be conferring and collaborating rather than "walking on eggshells": INTER-PROFESSIONAL INTERACTION (absent); COLLEGIAL COLLABORATION (absent); ATTITUDE (submissive and hostile) (IF).

What strategy might have resolved this situation? The charge nurse in this unit could have enlisted independent/ detached assistance from the nurse manager of the area. This more senior colleague could have reviewed the details of the case and then approached the consultant to discuss her concerns and broach the subject of treatment withdrawal. If necessary she too could enlist senior medical help, perhaps the medical director of the hospital. The importance of levels of seniority in interactions as well as the strategic enlistment of an independent mediator in dilemmas around end-of-life decision-making will be discussed further in conclusions.

Jill continues, I think they thought we were being very critical of them which was a definite "No, No," - doctors don't get criticised by nurses. […]. They knew they'd done wrong and the fact that we (the nursing staff) had made the move in the end to get something done only made it worse". Despite claims in the contemporary literature that nurses and doctors are collaborating and cooperating more effectively as professionals, in practice there remains the perception that nursing criticism of medical treatment choices is not appropriate and will meet with responses ranging from anger to retribution (Sundin-Huard & Fahy, 1999). It is in anticipation of this response that nurses tend to frame requests to doctors in terms that they know will meet with the outcome they seek or not speak at all (Wicks, 1999) In this case: ANTICIPATION OF MEDICAL BACKLASH (high) (PF); NURSING FEAR (high) (PF); PERCEIVED VICTIMHOOD (high) (PF).

There is also a silence here with respect to interactions with George's family. Jill's suggestion that the family was isolated in their grief demonstrates an aspect of alienation in suffering here. Jill and her colleagues could see that that the family were suffering as George's condition deteriorated. While they might not be accepting of his imminent death, the family would have seen this was a possibility and would have been grieving, feeling guilty and probably angry. Jill and her colleagues should have taken measures to ease their suffering. Instead of tip-toeing around this group of people, the nurses could have been doing a number of things. They could have been:

- initiating conversations with the family,
- facilitating dialogue with the treating doctors
- ensuring the family's physical comfort (a private quiet room to sit and sleep with facilities for tea/coffee, organising meals)
- ensuring spiritual comfort (contact relevant pastoral carer or minister/ other family members if necessary)

INFORMATION SHARING (low) (IF);FACILITATION OF INTERACTIONS WITH PHYSICIANS (absent) (IF); PROVISION OF PHYSICAL COMFORT (absent) (IF); PROVISION OF SPIRITUAL COMFORT (absent) (IF); INTERACTIONAL ENGAGEMENT (nurse-family)(absent) (IF).

As fellow health professionals, Jill and her colleagues could have empathised with Georges's family and offered a support. Instead, they kept them at arm's length, distancing themselves from the suffering others and possibly their own guilt in contributing to the suffering for the family. This 'alienation' of the sufferer described by Younger (1995) (see literature review page 62)can be seen manifested in the critical care environment in the form of the relative left sitting at the side of bed on their own or in the waiting room outside the unit for hours at a time: FAMILY ISOLATION (high)(IF).

Jill continues, Anyway I was on night duty on day two; it was a busy night - the usual 'first nighters' (*patients back from theatre day one*) were dropping their BP s all over the place and the usual sort of carry on. I had just made up all these extra lines (I.V. infusions) ready to change them over [for George] because they were going full pelt. It took me two hours until I actually stood back and looked at what I was doing and thought "This is ridiculous!"

Why was this **key decision** made now? George had been deteriorating rapidly over the last two days with no response to maximal therapy. There have been huge silences throughout this narrative with respect to discussion about George's care and related decision-making. There has been no apparent discussion about end-of-life decisions between nurses and doctors, nor nurses and family, nor doctors and family. The most appropriate time to consider treatment withdrawal had been when George's C/T scan had shown that a cerebral haemorrhage was the cause of his continued unconsciousness. Delay of this decision resulted in extended emotional and spiritual distress for George's family, emotional turmoil for the treating doctors and dysfunction within the unit: TIMELINESS OF CHALLENGE (too late) (IF). Jill's challenge at this juncture though, seems to have been prompted just as much by frustration with the techno-rational components of George's care as by a perception that George was suffering as a result of their impact upon him: EMOTIONS-frustration (high) (PF).

Jill tells us, So I went and dragged […] the junior registrar out of bed. I said basically, "Look this man is dead," and he said "Oh, turn off the ventilator" and I said "No you turn it off". He wasn't very happy about that but I said basically," If you're not happy to turn it off, I'm not turning it off but I am not putting up any more of these drugs etc." So he did, he finally turned it off and I said "will you be calling the family?" and with bad grace he did.

Jill's approach to the registrar (Andrew) here is immature and aggressive. Her language is blunt, conveying a sense of accusation: "You haven't done the right thing here-now I am going to tell you what that should be!" There is little sense of conciliation, invitation to discussion or respect for Andrew in this exchange: ATTITUDE (aggressive and hostile) (IF); LANGUAGE (blunt) (IF); COLLEGIAL RESPECT (low) (PF). Jill's behaviour in this exchange may be explained to some extent by her anger and frustration at what she perceived to be inappropriate treatment for George but up until this point none of the nursing staff including herself have done anything to challenge this.

While Jill's challenge of George's treatment and the decisions made to date was not timely, its timing would have been crucial here. On the night shift, Jill would have been the most senior nurse from the unit talking to one of the more junior doctors at a time when he was not closely supported by senior staff. At the same time, Jill had woken Andrew from his sleep and he would have been tired, potentially angry and perhaps a little slow to return to full alertness upon waking. Jill's relative seniority would potentially have enhanced her chances of achieving her aims: LEVEL OF NURSING SENIORITY (high) (CF); LEVEL OF MEDICAL SENIORITY (low) (CF); TIMING (crucial) (CF). The timing of this decision and others discussed in this chapter is of vital important to the outcome of the decisions made. This is an issue I will take up and discuss further in discussion and conclusions.

We have no sense from Jill's account of Andrew's intonation in this exchange. He could have uttered the sentence: "Oh, turn off the ventilator." without any especial emphasis, suggesting resignation and concurrence with Jill's appraisal of the situation: ATTITUDE: submissive. His response could just as easily have been phrased like this: "Oh (***pause***) YOU turn the ventilator off! ATTITUDE: conciliatory and defended. The subtext of this exchange being "Oh, ***I agree with you, but*** YOU ***can be the one to*** turn the ventilator off. This decision will result in the actual withdrawal of life-sustaining treatment although there is very little of George that is alive any more. Withdrawal of treatment from George would have involved turning off his ventilator and infusions, a decision and action involving a high degree of responsibility. George's seemingly rapid acquiescence to Jill's challenge indicates that he concurred with her appraisal of George's condition. The almost juvenile nature of the "You do it; No you do it" exchange related to actual withdrawal of treatment though, stems from a mutual perception of increased responsibility and a reluctance to be seen as the final arbiter in a decision to withdraw treatment: SENSE of PERSONAL RESPONSIBILITY/ Nursing (high) (PF); SENSE of PERSONAL RESPONSIBILITY/ medical (high) (PF).

As this decision was made at night, Andrew's perception of his responsibility in relation to this decision was likely to have been very high. Andrew is unlikely to have had senior medical support in the hospital at night. In the absence of a specific policy, responsibility for decision-making defaulted to Andrew. His alternatives here were: a) calling a senior colleague (and possibly appearing indecisive); or b) making this decision /taking this action himself and anticipating the consultant's wrath in the morning if his (Andrew's) decision was not supported: SENSE of PERSONAL RESPONSIBILITY (high) (PF; SPECIFICITY OF POLICY R/T LINE OF AUTHORITY IN MAJOR CLINICAL DECISION-MAKING (end-of-life decisions) (Absent) (CF), CERTAINTY OF SENIOR MEDICAL SUPPORT IN CLINICAL DECISION-MAKING (low) (PF); MEDICAL FEAR (high) (PF). Jill's interaction with Andrew should have been more supportive in anticipation and recognition of Andrew's particular challenges: Collegial Empathy (low) (IF). Jill and Andrew could have managed the interaction with George's family as a team. Jill could have offered to share his discussion with the family and to then secure a private room for George in a medical ward INTER-PROFESSIONAL ENGAGEMENT (poor) (IF); COLLEGIAL SUPPORT (low) (IF); PROVISION OF PHYSICAL COMFORT (absent) (IF); PROVISION OF SPIRITUAL COMFORT (absent).

In the absence of specific policies outlining lines of responsibility and support related to end-of-life decision-making, nurses and doctors seem to have floundered, suffered and inflicted suffering on others. In conclusions I will be discussing and outlining possible formats/ policies related to support for all parties involved at the time of treatment withdrawal.

Table 7.3 Factors identified in Jill's narrative:

Contextual Factors	
• Clinical Severity	• Extreme
• Perceived Prognosis	• Initially reasonably good → very poor
• Level of Agreement with Decision	• Low
• Timing	• Crucial
• Level of Nursing Seniority	• Low
• Level of Medical seniority	• High
• Specificity Of Policy R/T Line Of Authority In Major Clinical Decision-Making	• Absent
Personal Factors	
• Nursing Knowledge	• High
• Relevant Experience	• High
• Sense of Personal Responsibility/ Nursing	• High
• Sense of Personal Responsibility/Medical	• High
• Anticipation of Medical Backlash	• High
• Perceived Victimhood	• High
• Nursing Fear	• High
• Medical Fear	• High
• Emotions	
- Frustration	• High
• Certainty Of Senior Medical Support In Clinical Decision-Making	• Low
• Collegial Respect	• Low
Interactional Process Factors	
• Decisional Input	• Low
• Interactional Engagement	• Low
• Discussing Concerns	• Absent
• Inter-professional Engagement	• Poor → Absent
• Nursing Silence	• High
• Language	• Blunt
• Collegial Empathy	• Low
• Collegial Support	• Low
• Collegial Collaboration	• Low
• Attitude (nursing)	• Submissive & Hostile → Aggressive & Hostile

Attitude (medical)	Submissive → conciliatory & defended
Timeliness of Challenge	Too Late
Information Sharing	Absent
Facilitation of interaction with physicians	Absent
Provisions of Physical Comfort	Absent
Provision of Spiritual Comfort	Absent
Family Isolation	High

7.4 ELIZABETH:

This incident involved an 85 year old woman (Margaret). Initially admitted with sepsis, her condition deteriorated quickly to multi-systems failure. Her previous medical history included a myocardial infarct, COPD and diabetes. She also suffered terribly with arthritis. Elizabeth was unable to recall the primary source of her sepsis at interview. Margaret was admitted to intensive care commenced on antibiotics and was requiring nearly 100% oxygen therapy to maintain acceptable oxygen saturations, although she was never ventilated. Elizabeth was of the opinion that Margaret's admission to ICU was inappropriate: "I mean there was no point; the woman was going to die. The fact that she was eighty-five with a poor medical history - I don't think she should have been in I.C.U. to start with".

Elizabeth cites Margaret's age, poor previous history and very poor prognosis in her argument that Margaret was not a good candidate for ICU: PERCEIVED PROGNOSIS (very poor) (CF). None of the reasons she has cited would necessarily have excluded Margaret's admission. Decisions regarding the admission of patients to intensive care are based upon clinical judgment and are guided in Australia by the decision-making framework offered by the American College of Critical Care Medicine (ACCM) (Society of Critical Care Medicine, 1999) (see glossary). The ACCM suggests decision-making within three models: prioritisation, diagnosis and objective parameters. The last of these:

objective clinical parameters, constitute clinical data gathered using APACHE II & III scoring systems – see appendix IX. Although these tools are yet to be validated as pre-admission screening tools (Wasiak, 1999), their validity as predictors of outcome sees them used in this mode.

Age and previous quality of life contribute only 11 out of the possible 71 points on the APACHE scales. In Margaret's case, the more influential factors impacting on decisions about her admission to intensive care would have been diagnosis, acute history and her need for intensive interventions and monitoring. Elizabeth could not recall the specific site of Margaret's infection. It is possible that this was respiratory and that the admitting doctors were anticipating the need for ventilation in Margaret's care.

Elizabeth does not indicate whether she attempted to discuss/clarify the actual reason for Margaret's admission. By inference, she did not or she would have told me about such a conversation: DISCUSSING CONCERNS (Absent) (IF). This apparent silence may have been the result of reluctance on Elizabeth's part to challenge the admitting consultant's decision. The reluctance of some nurses to challenge the reasons for particular orders or decisions for fear of medical anger, or retribution may lead to silence at important junctures in patient care. This in turn leads to further misunderstanding and frustration on the part of those nurses (Wicks, 1999; Sundin-Huard & Fahy, 1999; McHaffie, 2001): NURSING SILENCE (High) (IF). This is an aspect of the role of collegial dialogue and collaboration between doctors and nurses as peers that I shall return to in depth in conclusions.

If Elizabeth believed that Margaret's admission to intensive care was inappropriate or futile, she had several courses of action open to her. Upon receiving notification that Margaret was to be admitted to ICU, and learning the details of her previous history, she could have contacted the admitting medical officer to suggest a revision of this decision. If Elizabeth was still not happy with the reasons for Margaret's admission, she could impress this upon the registrar by indicating that her concerns would be both documented and passed on to the nursing supervisor for the shift. The proposal of a more senior staff member's contribution to the discussions is more than likely to prompt revision of this decision, if appropriate. In this case it probably would not have been necessary had Elizabeth engaged in collaborative/ collegial discussion with the admitting medical officer prior to Margaret's admission. The possible strategies open to Elizabeth will be dealt with more fully in discussions and conclusions.

Elizabeth continues, She was never ventilated and basically the story is she was in the unit and her husband was told, after they'd treated her for a couple of days [she was on antibiotics and 100% oxygen], there was no improvement. The consultant who was on for the weekend told the husband that this lady's prognosis was poor; and the husband was told, "There's not much more we can do about it".

Elizabeth's description of this interaction between the consultant and Margaret's husband (Alfred) gives the impression of a unidirectional, virtual proclamation of the news about his wife's condition and the **key decision** not to try any further extraordinary measures. There is no sense of conferring or collaboration with Alfred: INTERACTIONAL ENGAGEMENT (Doctor-patient) (poor) (IF). One gets the sense that this exchange was probably held at or near the patient's bedside, at the end of a clinical ward round: VENUE (public) (IF). There is no sense of any collaboration between health professionals prior to this interaction or as this information is imparted to Alfred: SHARED DECISION-MAKING (absent) (IF). Nor is there is any indication from Elizabeth of any nurse involved in the interaction to offer comfort and support to Alfred. The nurses were passive witnesses to this exchange only: NURSE AS (PASSIVE) WITNESS (IF).

Could this situation have been managed differently; more satisfactorily? If the nursing staff had no idea that the consultant was planning to talk to Alfred about his wife's condition and further treatment then prior planning would have been impossible. They would have been nearby, would have noted the beginning of a conversation between Albert and the consultant and could have moved in to offer comfort and follow-up explanation and support. If Elizabeth and her colleagues had been notified that the consultant planned to talk to Alfred about Margaret's prognosis and his plans for future care, they should have taken that opportunity to clarify precisely what the consultant's plans were: DECISIONAL CLARIFICATION (absent) (IF). Most importantly, they should have taken this opportunity to organise a supportive, private environment in which the doctor, Alfred and a nurse or nurses could talk. They should also have organised spiritual support for Albert in the form of pastoral care and/ or another relative to sit with him: PROVISION OF PHYSICAL COMFORT (absent) (IF); PROVISION OF SPIRITUAL SUPPORT (absent); FACILITATION of SUPPORTIVE ENVIRONMENT (absent) (IF).

Margaret was maintained on 100% oxygen therapy and antibiotics for four days (though no new measures were added).

Elizabeth continues, None of the nursing staff talked to the consultant [about this decision]. In this unit you can't say too much - sure we talk amongst ourselves and to the residents and registrars and say things like, "Why is all this stuff kept going when there's obviously no hope, no chance of survival for this woman, why prolong the agony?" But when you've got a director of the unit who is dead set against terminal weans and anything like that, how can you expect the other consultants to say that's it? (*Elizabeth provided anecdotal evidence and inferred that the consultant's attitude to withdrawal of treatment and practice was the result of past personal tragedy*).

Elizabeth's description of the ambience in this critical care unit is disturbing. There has been a nursing silence throughout this narrative with respect to challenging or and seeking clarification for medical decisions: NURSING SILENCE (high) (IF). Most of this silence seems to be directed toward the consultant (Alan). Elizabeth infers that Alan's end-of-life decision-making abilities might in some way be affected by past experiences. This may indeed be so, but her information is only hearsay. While the nursing staff and medical registrars had discussed their concerns about Margaret's treatment, this collegial dialogue did not extend to Alan. It is very likely that he was made aware of this exclusion by the attitude of the nurses in the unit: ATTITUDE-Silent and Hostile (IF).

Alan has effectively been isolated by all the other health professionals involved in this case: MEDICAL ISOLATION (High) (IF); COLLEGIAL SUPPORT (nurse-doctor) (low) (IF).

It is possible that an awareness of this isolation would have increased the burden associated with decision-making in this instance for Alan. Elizabeth or one of her more senior colleagues could have addressed their own concerns with Alan about the continuance of Margaret's treatment by taking the consultant aside to seek his rationales for his decisions. A conversation carried out in a private area in non-judgemental tones would have allowed Alan to share some of his reasoning together with the burden of decision-making. Such a conversation is rare in the current context of intra-professional relationships and would require educational intervention. Full development of these strategies will be covered in conclusions shortly.

Margaret continued on this treatment regime for four days. During this time, Elizabeth had observed Alfred's distress at the bedside or as he left the unit in tears on occasions. As nurse in charge of the shift, she had been in the position to go out to offer him comfort: You know the feeling: "I'd love to do something more for you but there's just nothing more I can do/ we can do as nurses".

Could Elizabeth have done more for Alfred 'as a nurse'? If she observed Alfred to be so distressed that he left the unit in tears, she could have phoned and asked the consultant to come and explain the situation to Alfred himself: FACILITATION of DISCUSSION WITH PHYSICIAN (absent) (IF). An explanation of Alfred's level of distress would probably have prompted agreement from Alan to this request and may have prompted a decision to withdraw treatment. Elizabeth could also have offered to provide a private room for Alfred if this had not already been done (with tea and coffee facilities): PROVISION of PHYSICAL COMFORT (absent) (IF). As she would have been engaged in duties within the unit, Elizabeth could also have organised pastoral care and/ or friends to sit with Alfred: PROVISION of SPIRITUAL COMFORT (absent) (IF).

Elizabeth believed, We know or I knew myself that treatment should be stopped but I can't go and say that directly to the husband. It would have been undermining the doctor's authority. It's just not the done thing. In the context of this decision-making episode, Elizabeth gives the impression that she knew there was a rule to be obeyed which constrained her interacting freely with Alfred (one does not undermine the doctor in front of the relatives): FEAR OF MEDICAL BACKLASH (high) (PF). Who establishes what is the 'done thing' here? Elizabeth seems to be referring to some higher authority whose 'rules' she has taken on board as part of her nursing socialization. In the doctors' narratives, the Medical Establishment filled this void. In the professional lives of nurses, these rules, beliefs and norms tend to be moulded by the 'nursing culture': SUBMISSION TO NURSING CULTURE (high) (HF).

Elizabeth continues, [The husband] spoke to a lot of the nursing staff who were reinforcing that there was nothing more that could be done for her so he was prepared in that way but instead of getting it over with when it was obvious she was going to die, he was forced to wait fours days And so of course he started to build up hope, you know, 'She's lasted this long. Maybe she'll be all right'. It shouldn't have gone on that long. And then the husband, after three days of waiting for her to die started saying things like, "What if we did a transplant or dialysis?" Things like that and this lady's blood pressure was low - it would never have coped - not even with dialysis. And the patient "wasn't there" - she was just moaning - she couldn't acknowledge that anyone was there - not even her husband.

The nursing staff in the unit did interact with Alfred to some extent (though at Alfred's instigation). The content of these interactions according to Elizabeth was directed towards reinforcing a similar point of view to hers: that Margaret's prognosis was very poor and that continuance of current treatment or introduction of further interventions was unlikely to be successful: AMPLIFICATION OF POOR PATIENT PROGNOSIS (high) (IF); REINFORCEMENT OF RELEVANT INFORMATION (high) (IF). Elizabeth gives the impression that she felt these interactions were supportive and helpful for Alfred as they amounted to 'reality checks' and prepared him for the inevitability of Margaret's death: PREPARATION FOR RELATIVE'S DEATH (high) (IF). Nonetheless, after three days, Alfred still built up a sense of hope. The development of this 'false hope' – hope unfounded in clinical data or unsupported by the explanations relatives are receiving (when received) is a phenomenon that frequently seems to develop for relatives witnessing the prolonged death of a loved one. The importance of clear information in explaining the balance between hope and reality in end-of-life decision-making is one of the more delicate issues of this dissertation. I will return to this again in discussion.

She basically stayed on everything until about ten o'clock the night before she died when the husband said, "I want everything stopped. I understand from talking to the nursing staff that the only reason she is alive is because of all this stuff". [He meant] the drugs, the oxygen, the dopamine- and so he asked the consultant to stop everything and she died at 10 o'clock the next morning.

As a result of his conversations with the nursing staff, Alfred was able to infer that the withdrawal of treatment from Margaret would end her life and his vigil. Although it might not have been their stated aim, it seems that the nurses in the unit had employed covert tactics here to achieve the outcome they thought was most favourable. This is an indirect or covert strategy for effecting decisions that I have seen used in critical care in situations similar to this one. Its use is reflective of the perceived power differentials and dynamics within the unit or decision-making situation: QUALITY of INTERACTION: (limited) (IF); USE of COVERT TACTICS (high) (IF). The issue of power differentials and the impacts this has upon interactions between health care professionals will be discussed again in depth in conclusions.

Table 7.4 Key factors in Elizabeth's story:

Contextual Factors • Perceived Prognosis	• Very Poor
Interactional Process Factors • Discussing Concerns • Interactional Engagement (Doctor-patient) • Venue • Nursing Silence • Attitude • Shared decision-making • Nurse As (Passive) Witness • Provision of Physical Comfort • Provision of Spiritual Comfort • Facilitation of supportive environment • Facilitation of Discussion with Physician • Decisional Clarification • Amplification of Poor Patient Prognosis • Reinforcement of Relevant Information • Collegial support(nurse-doctor) • Medical Isolation • Preparation for relative's death • Use of Covert Tactics • Quality of Interaction	• Absent • Poor • Public • High • Silent & Hostile • Absent • High • Absent • Absent • Absent • Absent • Absent • High • High • Low • High • High • High • Limited
Historico-Political Factors • Submission to Nursing Culture	• High

7.5 BERNADETTE:

The case Bernadette recounted involved a 35 year old Aboriginal woman (Elsa). Elsa had a history of atherosclerotic disease, starting in her twenties, including several cerebro-vascular attacks and one previous myocardial infarct. On this admission, Elsa had had an extensive infarct. On arrival in the unit she had a central line inserted so that pressures within the right side of her heart could be monitored and so that inotropic drugs could be given to improve her blood pressure. At the time her cardiac rhythm was most unstable – deteriorating frequently into complete heart block.

Bernadette had described Elsa's infarct as 'global'. This description refers to ischemic damage involving virtually the entire left ventricle of the heart. As a result of this damage, Elsa had had at least three 'arrests' prior to her admission and her cardiac rhythm repeatedly deteriorated into complete heart block. This dysrhythmia is diagnostic of damage to the septum of the heart (Conover, 2003). All these signs would have suggested to the treating health professionals that all three of Elsa's coronary arteries were severely compromised (Urden, Stacey& Lough, 2001): CLINICAL SEVERITY (Extreme) (CF).

The usual course of treatment for a myocardial infarct, lysis of the clots probably causing the ischaemic damage to Elsa's heart, was not an option here. She had already had CPR once before arriving in hospital and use of lysing agents is contra-indicated due to the bleeding and bruising that is associated with CPR (Fulde, 2004). Without lysis, Elsa's myocardial infarct would not have been curtailed and may even have increased in size. The likelihood of Elsa surviving this level of injury to her heart was minimal: PROGNOSIS (very poor/ hopeless) (CF).

Nonetheless, a **key decision** was made to admit Elsa to coronary care.

If Bernadette had been sceptical of Elsa's chances of survival and the suitability of her admission to coronary care, could she have done anything to act upon these concerns? Notification from the emergency department of Elsa's imminent admission would have included information about her past history and the history of the acute episode leading to this admission. Bernadette could have contacted the consultant and suggested that admission to coronary care wouldn't be appropriate in light Elsa's poor past history. Given Elsa's age (35 yrs) and Indigenous background, however, this is not a suggestion that the consultant would be likely to have countenanced. It is my experience that no matter how little the admitting criteria for critical care rely upon age (see glossary and appendix vii), health care professionals tend to perceive youth as an extra reason to consider initiating life support measures, or maintaining them for a little longer: PATIENT'S AGE (35 yrs) (CF).

At the same time, Elsa's cultural background would have been a further consideration here. The decision 'not to do anything' for Elsa or the perception that the medical staff had withdrawn treatment 'early' could have been seen as racially discriminatory by her family and some of the consultant's colleagues (nursing and medical). Recognition and consideration of these cultural values within society and their potential impact upon his career, would have affected the consultant's decision-making in this case, increasing his inclination to initiate life-saving and then continue extraordinary measures: SIGNIFICANCE of PATIENT'S CULTURAL BACKGROUND (high) (CF). Bernadette could have taken her concerns to the nursing supervisor in the hope that support from a senior nursing colleague might prompt reconsideration of this decision. Strategies for prompting reconsideration of treatment decisions in critical care will be dealt with in depth in conclusions. In any event, Elsa's admission to coronary care went ahead: DISCUSSING CONCERNS (Absent) (IF).

Elsa was admitted to coronary care and Bernadette continues, They got the C.V. line in and started Dobutamine (an inotrope – see glossary). We'd been given a range to run it *(The physician's orders for the Dobutamine would have included a dosage range, optimum BP and an upper limit for heart rate. The aim would have been to try and increase Elsa's BP without raising her heart rate past a certain point as the cardiac demand for oxygen then defeats the purpose of the infusion (Romanini& Daly, 1994)).* As time progressed, I kept increasing the dobutamine to keep her blood pressure up. Her pressures had been low - 60/40 from the start and it was becoming almost impossible to keep her pressures any higher than this […]. There just was no myocardium left to support cardiac output. It wasn't accomplishing anything. […] Really this was a heart that was dying no matter what we did. Elsa's condition and prognosis were very poor. Given Elsa's lack of response to the Inotropes, Bernadette should have requested early clarification of Elsa's status with respect to resuscitation. Indeed this is something that should have been established and documented upon Elsa's admission to Coronary care. Elsa's BP on admission: 60/40 mm Hg is suggestive of cardiogenic shock (see glossary) and she was most unlikely to have responded to resuscitation attempts. In the absence of documented "not for resuscitation" orders however, the health professionals caring for Elsa would have been obliged to attempt this: PRESENCE OF "NOT FOR RESUSCITATION" DIRECTIVE (No) (CF).

She was an Aboriginal woman with a large family - they had all been visiting her in relays. They were already into the mourning process and it was fairly obvious that this patient wasn't going to survive the night and the family had a lot of grieving to do; their good-byes to say basically […]. A lot of cultures value the family's presence during that process-during the dying time, which was what prompted me to make the phone call initially.

Bernadette infers that it was consideration of this 'extra dimension' to Elsa's family's suffering (their potentially unmet cultural requirements) that prompted her decision to make the following call to the medical registrar with her concerns about the efficacy of Elsa's treatment: SIGNIFICANCE of PATIENT'S CULTURAL BACKGROUND (high) (CF).

At the same time, in her recall of these events, Bernadette tells us that the family was "…already in the mourning process". Although Elsa's prognosis was very poor, Bernadette has made an assumption here. The family were likely to be confused and very fearful, but unless the doctor or Bernadette had spoken to them and said "Your mother/sister/daughter/wife is dying…" it is unlikely that this family had begun to mourn already. Bernadette does not mention a conversation of this significance at all; by inference it had not happened at this stage. Indeed, throughout this narrative there is no mention of discussion between nurses and Elsa's family or between the doctors and Elsa's family of her condition or prognosis: INTERACTIONAL ENGAGEMENT WITH FAMILY (absent) (IF); FACILITATION of DISCUSSION WITH PHYSICIAN/S (absent). Although it is clear that Elsa must have had a large family (they were visiting 'in relays'), there is no mention of efforts by Bernadette or her colleague to provide a larger quite room for them to wait: PROVISION of PHYSICAL COMFORT for RELATIVES FAMILY (absent).

Bernadette was also aware of the 'special' cultural needs' of Elsa and her family and yet there is not particular mention of provision for these needs with respect to the family: PROVISION of SPIRITUAL COMFORT (absent). Quite rightly, the comment could be made that Bernadette was far too busy with Elsa to be concerned with the issues raised in the analysis above. In the absence of 'physical' support and policies though, these responsibilities would have devolved to Bernadette or her colleague: POLICY R/T ADEQUATE STAFFING in TIME of CRITICAL EVENT/S (absent) (CF). The issue of specific policies related to support for staff upon the admission of a critically ill patient will be raised later in conclusions.

Bernadette 'phoned the registrar, So at about eight o'clock, I rang up the registrar […] and said, "You're going to have to make a decision - are you going to turn the dobutamine off and let this family have their time with the patient - which is important - or are you going to persist with this line of treatment?" So I was basically saying, "You're going to have to make a decision - are you going to let this lady go peacefully with her family there - which is important to them - or are you going to invade her body with all the things that you do?"

The tone of this interaction and the language used by Bernadette are strong, indeed harsh. She is abrasive and aggressive here suggesting the level of anger and stress this episode caused her. The language she uses also gives a clear indication of her opinion of the line of treatment being used for Elsa at the time: "…are you going to invade her body with all the things that you do?" The use of 'You' in these exchanges is accusatory and likely to arouse a defensive and retaliatory response: ATTITUDE: Hostile, abusive, aggressive (IF); EMOTION- anger (PF).

And he said, "Well to be quite honest, I think we'll be jumping on her chest by midnight". Just then ... she arrested again. [She went into a] complete block and her resps became really stertorous. A general arrest was called; […] the consultant physician decided it was time to insert a pacemaker. The dobutamine wasn't doing any good so he thought a pace- maker might do the trick! (*Resuscitation efforts continued for approximately three hours*).

This would seem to have been another **key decision-point** where timing was everything. It seems possible that with a little more discussion and conciliation, a decision to withdraw treatment might have been reached. Had Bernadette called the registrar a little earlier, she could have discussed her concerns and obtained a 'not for resuscitation order' for Elsa: TIMELINESS OF CHALLENGE (Too Late) (IF). This opportunity did not arise however and just as in Camille's story, Elsa arrested as Bernadette was on the phone.

Elsa 'went into' a slow complete heart block and a general was called. Bernadette described a resuscitation scenario which lasted three and a half hours during which the consultant tried to insert a pacing wire to stimulate Elsa's left ventricle (without success. At one stage the coronary care unit contained sixteen extra staff as unsuccessful efforts were made to resuscitate Elsa.

Bernadette continues, It was possibly 10 P.M. by the time they let her be. I wanted to say don't you think enough's enough, but we just kept going. The physician eventually decided on his own [to stop]. I tried [to have more input to the decision-making]. At that point I don't think there was a great deal for me to contribute because things had gone beyond the extreme and it was then just a decision to stop medical treatment (*Bernadette became curled up in an almost foetal position, talking softer and softer as she described the later moments of Elsa's resuscitation*).

There is a silence here with respect to communication between nurses and doctors or between junior doctors and the consultant with respect to the decision to stop resuscitation INTER & INTRA-PROFESSIONAL COMMUNICATION (low) (IF). Bernadette tells us that the consultant decided unilaterally to cease resuscitation attempts SHARED DECISION-MAKING (absent) (IF). There appears to have been no input from any of the other health professionals in the unit into this decision. Nor does there seem to have been any earlier exchanges suggesting that it was time to stop – that they had done all that could be done: TIMELY RESUSCITATION WITHDRAWAL (absent) (IF). Indeed Bernadette says that she wanted to say something or tried to say something but felt constrained here. It is interesting that Bernadette felt empowered to speak up earlier in an effort to prompt a withdrawal of Elsa's treatment but felt constrained now in the face of her even more certain death: NURSING SILENCE (high) (IF).

There seems to be two factors contributing to the silencing of Bernadette's voice here. It is as if Bernadette felt constrained by the power differential operating between herself and the physician directing this resuscitation scenario. In this situation, the doctor she would have to have challenged was a consultant: MEDICAL SENIORITY (Consultant) (CF). Bernadette, on the other hand, was a relatively junior registered nurse (at the time had been in the unit for six months; had not completed her critical care course) NURSING SENIORITY (Junior Registered Nurse) (CF). She states that she felt the decision to cease resuscitation was purely a medical one and her language around this issue is very strong, suggesting that this decision was therefore out of her ambit once resuscitation had begun. This would suggest that Bernadette thinks in terms of medical responsibility versus nursing responsibility and that once the resuscitation process had commenced: "gone past the extreme" then responsibility was out of her hands even though she had "…told you so".

Three and a half hours is far too long to persist with resuscitation efforts – particularly for a patient who was in cardiogenic shock to begin with. None of the health professionals on the scene at this resuscitation seems to have felt 'strong' enough or in a position to suggest to the consultant that the process had gone on long enough: none of the registrars and none of the nurses present at the time: CHALLENGE TO CONTINUING RESUSCITATION (absent) (IF). Who then should take on this role at such a time? Bernadette does not mention the presence of a nurse manager in the unit during this arrest. It is my experience that the nurse manager usually arrives on the scene when a general arrest is called to supervise the logistics of the situation. This person should have spoken to the consultant or failing that, called in the chief medical officer of the hospital to talk with the consultant and deal with this situation. Strategies to address confusion and communication problems leading to inappropriately lengthy resuscitation efforts will be discussed in conclusions.

Table 7.5 Key factors in Bernadette's story:

Contextual Factors	
• Clinical Severity	• Extreme
• Perceived Prognosis	• Very poor/hopeless
• Presence of "Not for Resuscitation Directive"	• No
• Policy R/T Adequate Staffing In Time Of Critical Event/S	• Absent
• Patient's Age	• 35 years
• Significance of Cultural Background	• High
• Medical Seniority	• Consultant
• Nursing Seniority	• Junior RN
Personal Factors	
• Emotions -Anger	• High
Interactional Process Factors	
• Discussing Concerns	• Absent
• Interactional engagement with patient's family	• No
• Facilitation of Interaction with Physicians	• Absent
• Provision of Physical Comfort	• Absent
• Provision of Spiritual Comfort	• Absent
• Timeliness of Challenge	• Too Late
• Attitudes	- Hostile - Abusive - Aggressive
• Inter& Intra-professional-communication	• Low
• Shared decision-making	• Absent
• Timely Resuscitation Withdrawal	• Absent
• Nursing Silence	• High
• Challenge to Continuing Resuscitation	• Absent

7.6 GEORGIA:

This decision-making scenario involved a 70 year old gentleman (Richard) who was admitted to ICU following major abdominal surgery. Richard had not been tolerating physiotherapy and had not been breathing effectively post op and so he had been electively ventilated.

A potential complication of abdominal surgery and epidural anaesthesia is atelectasis (collapsed lung) and pneumonia. With sedation and ventilation it is possible to conduct more regular and thorough physiotherapy and to inflate a patient's lungs a little more to facilitate optimal gas exchange (Romanini & Daly, 1994; Kidd & Wagner, 2001). At this stage of Richard's admission to intensive care, it would probably have been anticipated that short-term ventilation would prevent the development of pneumonia and reduce the overall length of his stay in hospital. Richard's CONDITION at this stage was moderately severe and his PROGNOSIS was reasonably good (CF).

Georgia continues, Then he just got very sick. He ended up needing Dopamine, Dobutamine, and Adrenaline to keep him alive. [He was] very sensitive to the adrenaline (*tending to develop cardiac dysrrthmias*). He eventually needed 100% oxygen on the ventilator. He was well sedated so I don't know how conscious he was of what was going on around him. He never really woke up [even in] the last days when they decided to stop his morphine (*suggesting hypoxic cerebral damage)* […] there was no improvement, even with the dialysis he continued to deteriorate. He was needing more and more Adrenaline to keep his blood pressure up, more oxygen, more PEEP (*Positive-end expiratory pressure: a ventilation mode to optimise gas exchange in the alveoli*). [This all took] about a week. […] I think once he started having the V. Tach with the Adrenaline things were starting to look pretty grim then (*he was having so much Adrenaline to support his cardiac output that it was irritating his myocardium and producing the Ventricular tachycardia.*). Despite prophylactic admission to intensive care, a combination of respiratory and cardiac failure combined/ cascaded into multi-systems failure which did not respond to maximal treatment: CLINICAL SEVERITY (extreme) (CF); PROGNOSIS (very poor) (CF).

Georgia continues, It then became evident that the doctors had been chatting and had agreed that there was not much more that we could do for this man. So they had a talk to the wife and told her this and she virtually said, "Well - yes I know that you've done everything that you can".

There is a 'dramatic' silence with respect to collaboration between nursing and medical staff over this **key decision** re Richard's treatment and its effectiveness. Georgia gives us the impression that the medical officers' decision filtered down to the nurses rather than being the result of discussion and collaboration. From the tone of Georgia's description of the event, no inter-professional initiative was taken by either the nurses or the doctors to include their colleagues in this discussion: INTER-PROFESSIONAL ENGAGEMENT (low) (IF); DISCUSSING CONCERNS (absent) (IF); NURSING SILENCE (high) (IF). Georgia or one of her colleagues could have initiated such a discussion at any stage during the previous week of Richard's decline. Moments that would most ideally have offered themselves would have been just after 'unit rounds', so that discussions were not held over the patient's bed. Georgia gives the impression that a nurse or nurses were present at the exchange between the doctors and Richard's wife (Claire) (she was able to paraphrase her words). There is no indication though of a nurse offering Support for Claire during this exchange: PROVISION of SPIRITUAL COMFORT (absent) (IF)

Georgia continues, But this is another one of those situations in which the doctors say, "We're not going to do anything more for this man". And they speak to the relative; tell them this and then it turns into a long drawn out saga. The wife was really good, she accepted the fact that he was going to die; it was just going to be within the next few days. Or SHE thought it was going to be within the next few days. I think it's unfair mainly for his wife. I mean even though she was a fairly strong woman and had accepted the fact that he was going to die, she was always there talking to him, talking to us, touching him - a loving wife. […] - why not let that be goodbye instead of - fair enough - you'd expect a day or two, but not a week and a half later because of the fact that he was just being kept alive by our interventions *(The medical staff 'weaned' Richard's support measures rather than withdrawing them all at once. His management over the next week included titration of his inotropes to his blood pressure, weaning of his oxygen to 70%, and continued treatment of his cardiac dysrhythmias – this included an alternate antidysrhythmic.*).

It seems Georgia had formed the impression that Claire was accepting of the doctors' decision to do no more for her husband as she paraphrased Claire's words: "Well - yes I know that you've done everything that you can".

Claire's behaviour seemed important to Georgia. She refers to Claire's response to news about Richard's condition and the ongoing situation almost as if she was a well-behaved child: she was "good" or "strong" and "accepting". In the context of Georgia's description of events, she seems to be implying that 'good' and 'strong' meant behaving well and accepting that Richard was dying. Contrastingly, bad behaviour would have involved protesting and insisting that everything that could be done should be done. The behaviours that Georgia is extolling above are those of a relative who is not 'causing trouble', not increasing the workload or suffering for the nurses involved in the care of the particular patient. Claire was also concurring with

Georgia's evaluation of Richard's condition and prognosis. To have challenged Georgia's evaluation of the situation and asked for greater efforts on Richard's behalf would have added to Georgia's 'load' in terms of potential suffering and work. Georgia also perceived Claire to be a 'loving wife'. She describes a wife who sat by the bed, touching her husband and talking to the nurses. These are all of behaviours that would probably have increased any empathic tendencies Georgia already had towards Claire and the rest of Richard's family: EMPATHY FOR PATIENT-FAMILY UNIT (high) (PF). Surprisingly though, there is no indication from Georgia's narrative of her having made provision for physical or spiritual comfort for Claire or any family who might have accompanied her. Her concerns for Claire emphasise her plight as she sits beside Richard for days on end, though she does talk to the nurses: PROVISION OF PHYSICAL COMFORT (absent) (IF); PROVISION OF SPIRITUAL COMFORT (absent) (IF).

Georgia continues, After about a week I actually spoke to the top guy and said "Why are we keeping going with all this treatment and the wife's expecting him to die? […] Why are you putting up Amiodarone (*the alternate antidysrhythmic*) when you've told the wife there's nothing more you can do? Why is he still on 70% oxygen?" and he said "Oh, well maybe there is hope - maybe there is that one bit of hope that he might pull through".

Until this stage in her story, there has been no interaction between Georgia or any of the other nurses on the unit and the medical staff with respect to decision-making for Richard: TIMELINESS OF CHALLENGE (delayed) (IF). Although Georgia's address is cordial, the barrage of questions about Richard's treatment, couched as they are in negative connotations, gives them an accusatory tone. Georgia gives the impression of one trying to understand but with the sting of aggression in her questions: ATTITUDE-polite, hostile and aggressive (IF). Such an approach is more than likely to result in a defensive backlash from the receiver in such an interaction. In this case though, the consultant (Frank) seems brusque and dismissive. He does not seem angry, yet he does not seem inclined to discuss his rationales at length: CONSULTANT ATTITUDE- brusque and dismissive (IF).

Frank's response was very brief and unsatisfactory. It may have been that this was a curt response to Georgia's barrage of questions. It is also possible that Frank has a similar philosophy to several of the doctors in this dissertation with respect to treatment withdrawal (see Henry and Paul). Some intensivists espouse weaning of life-supporting measures as a means of allowing relatives to accommodate the notion of their loved one's impending death. Earlier and more collegial/ collaborative discussion of her concerns with the consultant would have elicited his rationales in Richard's treatment, established congruency of aims and ameliorated the frustration Georgia appears to have suffered over the past week: COLLEGIAL RESPECT (low) (PF); COLLEGIAL COLLABORATION (absent) (IF); CONGRUENCE OF AIMS (low) (CF); EMOTIONS- frustration (high) (PF).

This is the doctor saying this. I mean if there is one bit of hope "Why aren't you still fully going on with the treatment of this patient?" I think it was in his mind that well maybe if we just keeping going a bit, this patient might come round, although it's darn well obvious to the nursing staff - and residents and registrars that there' no hope for this patient. I think it was just a way of him saying well I'm not going to be the one who makes the decision to put him on 21% oxygen, and stop the drugs. Sometimes I just want to punch them in the head or something or say something like, "You're the doctor - you're having trouble with this patient's life - do something! Help them to live or let them die" It can't be half- hearted – it's got to be one thing or the other. I'm all for doing the best you can and giving the patient a good chance - but if they're not getting better or if they're deteriorating then - accept the fact - you can't live for ever.

Georgia's perception of this situation is unambiguous. Her scale of end of life care seems to have two distinct poles: maximal treatment or complete withdrawal: "…if there is that one bit of hope – Why aren't you going fully on with the treatment…": NURSING VALUE- Polar view of Treatment withdrawal (Full on/Full off) (PF) (high). Frank on the other hand seems to perceive end of life care on a continuum from maximal support, through hopeful titrated (step-wise) withdrawal to complete withdrawal: MEDICAL VALUE- Continuum view of treatment withdrawal) (PF) (high).

As previously mentioned, it may well be that Frank was reducing life-support slowly to allow Richard's wife to come to terms with his death. Georgia, however, seems to have formed the impression that Frank had difficulty assuming the responsibility for final decisions in the withdrawal of treatment. This may also have been true. Doctors in this dissertation spoke of experiences in their past history which influenced their current decision-making (see Gordon's story). The issue of the burden of responsibility in decision making and strategies to address this perception, particularly for members of the medical profession will be addressed in depth in conclusions.

Having formed this impression however, Georgia could have spoken to Frank, offering to talk over and share in the decision-making without seeming condescending. This aspect of professional, collegial dialogue between peers will be explored further shortly in discussion.

Table 7.6 Key factors in Georgia's story:

Contextual Factors	
• Perceived Prognosis(initially)	• Reasonably good
deteriorated to	• Very poor
• Clinical Severity (initially)	• Moderate
deteriorated to	• Extreme
• Congruence of Aims	• Low
Personal Factors	
• Emotions -frustration	• High
• Empathy for Patient-Family Unit	• High
• Collegial Respect	• Low
• Nursing Value (Polar view of treatment withdrawal)	• High
• Medical Value (Continuum view of treatment withdrawal)	• High
Interactional Process Factors	
• Inter-Professional Engagement	• Low
• Discussing Concerns	• Absent
• Nursing Silence	• High
• Provision of Physical Comfort	• Absent
• Provision of Spiritual Comfort	• Absent
• Timeliness of Challenge	• Delayed
• Nursing Attitudes	- Polite→ Hostile, - Aggressive
• Consultant Attitudes	- Brusque - Dismissive
• Collegial Collaboration	• Absent

7.7 DISCUSSION:

This chapter has examined the stories and experiences of six nurses in a variety of critical care units. In analysis of these stories, the key decision-making moments were identified, discussed and many key factors identified. Although the nurses contributing to this project came from a variety of clinical areas and had a wide variety in levels of experience, many of the factors are common to each story, some are unique.

These have been arranged in the model below in an effort to summarise the 'interactive' process of ELD-making as portrayed by the nurses this study. For clarity's sake, all the factors identified in analysis of the nurses' narratives are listed in their identifying categories: Contextual Factors, Personal Factors, Interactional process factors and Historico-political factors at the end of this discussion.

Initial key decisions in many cases, in particular, decisions to admit, were mandated by the clinical imperative and the 'training' of health professionals in these narratives (the arrival of Elsa in coronary care after her 'arrests'; John's admission to intensive care following his collapse at home which proved to be the result of an aneurysm). In these situations, as we have seen in the families' chapter, once the initial decision to resuscitate is made, a cascade of key decisions is set off. The end of this trajectory may be recovery, but more often is the sequelae of ELD-making described in these chapters.

Table 7.7 Nurses: Minimising Suffering

Nurses' Factors	**Suffering Minimised if:**
Contextual Factors	
• Clinical Severity	• High
• Perceived Prognosis	• Poor
• Decisional Urgency	• Low
• Medical Decision to withdraw/withhold treatment	• Discussed & documented
• Presence of Documented DNRs	• Yes
• Incongruence between DNRs and continued 'High-Level' treatment	• Low
Personal Factors	
• Nurse's Knowledge	• High
• Relevant Experience	• High
• Level of Nursing Seniority	• High
• Values Congruence with ELD	• High
• Sense of Personal Responsibility	• Low
• Empathy for patient and/or family	• Moderate
• Nurses' Fear	• Low
Interactional Process Factors	
• Intra-professional Communication	• High
• Inter-professional Communication	• High
• Expressed negativity	• Low

• Decisional Input • Level of Collegial Support • Discussing concerns • Timeliness of Questioning • Level of Family Hostessing	• High • High • High • Timely • High

Decisions to admit may also have been covered by policy and protocol (George's admission to coronary care for monitoring and care of his infarct; Richard's admission for prophylactic ventilation and physiotherapy). In some instances, frustration with the decision to admit the relevant patient to critical care was in itself a source of anger and distress for the nurse (Bernadette, Elizabeth, Georgia). These nurses could have chosen to have some decisional input at this stage of their experiences by contacting the relevant medical officer and discussing these concerns. These discussions, if they are to be successful, need to be non-judgemental, and recognise the emotional load and decisional responsibility that their medical colleagues may be carrying at the time. For example, Elizabeth learnt of Margaret's impending admission to intensive care, and she felt it was inappropriate; she had several courses of action open to her. Upon receiving notification that Margaret was to be admitted to ICU, and learning the details of her previous history (85 yrs old, diabetes, COPD, renal failure) she could have contacted the admitting medical officer to suggest a revision of this decision. Questions that might have prompted the revision or clarification of the decision to admit to ICU could have included: "I have just received notification that Mrs… is coming to ICU and I have the details of her medical history. I am concerned that ICU might not be the best place for her. Is there some reason that you particularly want to admit her here?" If this enquiry angered the registrar and he/she was not able to provide a valid rationale for Margaret's admission, then Elizabeth might have had needed to impress the registrar with her perception of the importance of the issue: "I am concerned that admitting Mrs… to ICU is not an appropriate use of resources and not fair to either her or her husband. I will be contacting the nursing manager to discuss this issue and documenting this conversation". 'Enlisting the assistance' of more senior colleagues might seem like a threat but should ensure a change of decision if warranted.

Once the patient has been admitted to the critical care unit, the clinical imperative and timing are crucially important in their impact upon the patient and all the decision-makers. There has been a silence from the nurses in these stories with respect to challenging key decisions. Nurses may have been distressed by decisions, their timing or sequelae, but they have chosen either not to ask for clarification at all or to delay their challenge for several days, and so their own distress is aggravated by the perceived suffering of relatives. In effect – timely challenge of decisions in an effort to clarify rationales or prompt a change in the decision that distressed would seemingly have ameliorated much of the distress the nurses experienced in these narratives. For those nurses who did seek to clarify **key decisions,** their timing of these challenges was such that they were only able to effect a little relief from the suffering they experienced or perceived (Jill, Georgia), or worse-in some situations it was exacerbated (Camille, Bernadette).

It has been noted that policies and protocols have governed the initiation of some of the decisions in these stories. At the same time though, analysis has illustrated the impact of the absence of clearly documented protocols and procedures related to or as adjuncts to the decision-making process. This absence had impact upon all decisions-makers. For example in Camille's narrative, there was a documented DNR for the patient of concern, but no evidence of handover from doctor to doctor, or indeed nurses to nurse of this decision and its parameters. A policy mandating the clear handover of this sort of information between shifts and between all levels of staff would have eliminated the ambivalence the nurses and doctors in Camille's story experienced. Such a practice would also enhance continuity of care. A discussion and full development of suggestions for this policy will follow in conclusions.

Similarly, once the DNR decision had been reached and documented, consideration should be given to discharging the patient to a medical ward (away from the critical care environment). This practice would give the patient and family privacy and further decrease any ambivalence staff might have regarding a DNR order. This consideration should be encompassed in a policy although I am aware it is a contentious issue with many contemporary Intensivists who would argue that there is place for continuing intensive care despite the presence of a DNR (Saul, July 2004). I will discuss this in more depth in conclusions.

During these narratives there were a number of instances in which the nursing staff did not adequately support the relatives they were working with or in which challenging roles devolved to them by default as a result of gaps in policy frameworks. Peta for example orientated John's children to the ICU environment well in the absence of a clear framework for that role. Georgia and Elizabeth though did not provide physical, emotional or spiritual support for relatives despite their concerns for the suffering of those families. This may have been a result of their own stress compounded by the absence of policies that supported them with the extra workload these patients would have represented. I will be discussing these issues further and recommending strategies to address these problems in conclusions.

In many of these narratives, a level of personal responsibility and accompanying fear constrained approaches to medical officers to challenge decisions that were troubling the nurses in these stories. Similarly, it appeared that a level of medical fear also constrained junior medical officer's confidence in making major clinical decisions (the DNR decision in Camille's story; withdrawal of treatment for George in Jill's narrative). At the same time, none of the nurses in these stories used their senior colleagues as supports to challenge the decisions that troubled them. Clear documentation of (and orientation regarding) lines of authority/ and thus support (both nursing and medical) would give guidance for the health professionals in critical care at key decision-making junctures and ameliorate some of their suffering related to responsibility. The details related to these strategies will be discussed in conclusions.

Finally, none of the nurses in these narratives mentions any form of debriefing following their experiences. Camille does talk of 'gossip' about the issues around her story in hospital for days after the event which in itself is reflective of the absence of a formal debriefing structure. Many of the nurses who spoke to me exhibited long-retained grief and emotions related to their stories – they cried, shouted, curled up like babies as they talked. There is clearly a need for formal debriefing structures for the nurses involved in end-of-life decision-making in the critical care environment. I will pursue this in conclusions.

Table 7.8 Table of Key factors: Nurses' Narratives

Contextual Factors	• Clinical Severity • Perceived Prognosis • Clarity of Clinical Situation • Tragic circumstances of patient's history • Policy R/T Orientation of 'New' relatives • Policy R/T Adequate Staffing in Time of Critical Event/S • Specificity of policy R/T DNR orders • Presence of Documented DNRs • Specificity R/T lines of Authority in Major Clinical Decision-making • Level of agreement with decisions • Congruence between DNRs and continued 'High-Level' treatment • Gap between decision and care provided • Level of Nursing Seniority • Level of Medical Seniority • Congruence of treatment aims/ objectives • Conflicted Orders • Continuity of Care • Patient's Age • Significance of Patient's Cultural Background • Impact of Nursing Culture • Timing
Personal Factors	• Nursing Knowledge • Relevant Experience • Identification with Patient • Empathy for Patient and

	Children - Empathy for patient-Family Unit - Decisional Clarity - Nursing Ambivalence - Medical Ambivalence - Personal Responsibility (nursing & medical) - Certainty of Senior Medical Support In Decision-Making - Nursing Fear - Anticipation of Backlash - Perceived Victimhood - Medical Fear - Emotions -Anger -Frustration - Collegial Respect - Nursing Values - Polar view of Treatment withdrawal - Medical Values -Continuum view of treatment withdrawal
Interactional Process Factors	- Intra-professional Communication - Inter-professional Communication - Nursing Silence - Medical Isolation - Medical Consensus - Decisional Input - Shared decision-making - Compliance with 'orders' - Attitudes - Language - Collegial Support - Collegial Collaboration - Staff Debriefing - Discussing concerns - Timeliness of Challenges - Discussing Concerns - Timely Resuscitation Withdrawal - Family Counselling

	• Grief Counselling • Preparation for ICU Environment • Inclusion of All Family in Interactions • Expression of Empathy • Permission to Grieve Openly • Respect for Family Unit • Facilitation of Interaction with Physician/s • Provision of Physical Comfort • Provision of Spiritual Comfort • Family Isolation • Use of Covert Tactics
Historico-Political Factors	• Submission to Nursing Culture

Footnote:

The analysis of the nurses' narratives has been a 'struggle' for me. As a critical care nurse, I have identified very closely with many of the stories and consequently suffered through them. I have tended to analyse for suffering experiences on first, second and even third pass through these stories, instead of examining the interactions for structural barriers or constraints to effective decision-making processes that might ameliorate avoidable suffering. As one reads these stories it is easy to recognise the nurses' vicarious suffering as they 'feel' for the families and patients they dealt with. It has been challenging though to 'stand back' and recognise the presence or absence of strategies used in dealing with this suffering

CHAPTER EIGHT - ANALYSIS OF DOCTORS' STORIES

8.1 GAVIN

Gavin is now a specialist obstetrician working in metropolitan New South Wales. He contacted me as a result of my overtures to the doctors' reform society. The story he told me in relation to his experiences with end-of-life decision-making came from a time when he was in the position of registrar working in a large metropolitan teaching hospital. Gavin would have been little more than three years into his post-graduate experience, in a position with increasing responsibility.

I was working […] in a big teaching hospital as the obstetric registrar and I got called to a miscarriage (*the hospital Gavin speaks of is equipped with a neonatal Intensive care unit*). It was supposed to be nineteen weeks' gestation. And I mean the baby was on the way out when I got there. The babe was 19 weeks - probably more like about 23 or so and it took a couple of breaths and died. By definition, up until 20 weeks' gestation a foetus is not considered viable (Brown& O'Toole, 1992; Baginski, 2004). If the information received before he arrived was accurate then, at 19 weeks' gestation, Gavin had been called to a miscarriage or spontaneous abortion of a non-viable foetus which legally need not have been admitted to the delivery suite. Alternatively, at 23 weeks' gestation, with maximal support and in the best of hospitals, this foetus may have been viable. Even so, the possibility of short-term complications such as hyaline membrane disease and organ dysfunction are high as are the possibility of physical and intellectual retardation in the long-term (Boyle, 2002;Baginski, 2004): (CF) CLINICAL SEVERITY (extreme) ; (CF)PERCEIVED PROGNOSIS (very poor). Gavin tells us that the babe was delivering as he arrived, this was a precipitate clinical event which virtually over-ran Gavin: (CF)DECISIONAL URGENCY (high).

When I was called down I think there was this assumption that the infant was 19 weeks. […] I would have had a look at her notes later, I don't recall, but I think she would have had an ultrasound at some stage to confirm. I guess they [obstetric team] were a month out. And of course, I'd just run up there and gotten in there. I hadn't talked to the Mother or anything to find out what she wanted. I mean, I had no idea about she wanted. The paucity of clinical and contextual information received related to this case prior to arrival increased Gavin's difficulties here. The gestational age of foetuses which may be underestimated by one month due to the mother's confusion of the dates of her last menstrual period, can usually be clarified with ultrasonography (Frazer & Cooper, 2003). Gavin was not able to access this information until after the event: (CF) CLARITY OF CLINICAL SITUATION (Very obscure). I didn't do anything to call the paediatric people. I did talk to her [the mother] a little bit afterwards. It was all right afterwards, but there hadn't been an opportunity to do that before the birth. Obviously she was pretty upset about what had happened. But she didn't seem to have any unusual kind of issues about things.

Gavin tells us he felt there was no time to talk to the mother and establish her wishes at this juncture: INTERACTIONAL ENGAGEMENT (IF) (low). Acknowledging that Gavin was pressed for time here, this was a decision that should have included the mother if she was aware at the time. Gavin could have talked to her through the delivery and explained his actions, the choices available to her and their possible repercussions. Ideally the presence of the father could have facilitated this process, but Gavin does not mention his presence at all in this narrative. This is an issue that Gavin seemed concerned about as he talked to the mother following the birth. His concern though seems related to repercussions for him after the fact-the mother's having 'issues' to raise-perhaps about Gavin's decision or actions:

COMMITMENT TO FULLY INFORMED CONSENT (low) (PF). Theoretically, he could have taken a the opportunity to talk to the nurse briefly prior to or during the delivery and ascertain her knowledge of the mother's wishes. We hear nothing, however, from Gavin of interaction with the nurse/ midwife to gather clinical and contextual data quickly as he assesses his options: INTERACTIONAL ENGAGEMENT (low) (IF).

Gavin made the **key decision** not to do anything for a 'babe' which was very, very premature. There may have been a policy covering this clinical eventuality in the institution in which Gavin was working. He does not refer to it or indicate he was working within it at the time of this event: CLARITY or SPECIFICITY of POLICY (none) (CF). Gavin made this decision without consulting with the mother or any nursing, obstetric or paediatric colleagues and does not refer to any policies or protocols-he makes this decision on his own: PERSONAL RESPONSIBILITY (high) (PF). Following delivery: the babe 'took one breath and died'. Gavin did not actively facilitate its death, but neither did he take steps to intervene: ACTIVE AGENCY (moderate) (IF). At that stage, I think the world record for the youngest surviving baby was about 24 weeks. I felt a bit of a dilemma about should I be rushing around? Should the paediatric people be rushing in here with their trolleys and stuff or not? It probably wouldn't have done too much good but I guess I felt a bit uncomfortable with the sort of things that go on with the very, very premature babies anyway. […]. I get a bit worried about the degree of technology and intervention that gets brought to bear. I mean almost invariably, in fact invariably at that age they die anyway, and there is something a bit funny about the world where all the kiddies in the third world are dying for lack of very simple interventions; then people play... play with their toys. Well in some cases. I mean obviously there's a role for that in some cases. When they're really very, very premature, well, I hadn't noticed it being helpful. I mean for this kiddie, even if it was born now... Gavin was able to make the key decision not to offer this babe life saving initiatives with apparent ease: he expressed no hesitation or qualms about this aspect of his involvement in this case: INTERNAL CONFLICT (low) (PF). Gavin said he had a bit of a dilemma in relation to this decision but this does not seem to be related to the actual withholding of extraordinary measures. His reflection on his observations of the efficacy of the use of extra-ordinary measures for extremely premature infants suggest that this aspect of this decision was not difficult: VALUES-Quality of Life (high) (PF), and Utilitarian conservation of resources (high) (PF).

I mean I had a dilemma over whether I was overstepping my authority in making the decision not to do anything […] the midwife there basically thanked me for my role and said, "that was good". […] but it was a responsibility. The more challenging aspect of Gavin's key decision lay in the degree of independence this decision would require and the extent to which he would be operating outside the system. Gavin was an Obstetrics Registrar, into his third year of post-graduate studies and experience. He would have attained some measure of seniority within the hierarchy of the health care facility but would still be working in a junior capacity to the consultants and senior registrars on staff. In virtually all aspects of his practice within the hospital he would normally have been expected to refer and defer to his superiors. In this decision, Gavin has been independent and has also flouted one of the mores of the 'establishment' – 'sanctity of life': CONCORDANCE WITH RULES OF MEDICAL ESTABLISHMENT (low) (PF). Such independence of action in a hierarchical society requires strength of character and commitment to one's values. It does not comes without internal struggle and anticipation of personal or professional consequences: INTERNAL CONFLICT (PF) (high); EMOTION – fear (low) (PF).

In this narrative, though, we hear no word of input or support from Gavin's medical peers or seniors prior to or after the clinical event: INTERACTIONAL ENGAGEMENT (low) (IF). He is able to tell us about the support he draws from brief discussion with the mother and feedback from the midwife present but he mentions no feedback, or any form of debriefing after what was a traumatic event from his medical colleagues: COMMITMENT to COLLEGIAL RECIPROCITY (low) (PF). This may well be behind the suffering that caused Gavin to recall this event so easily years later. Debriefing in the company of peers following a crisis allows the individual to reconcile their internal conflict and fears about their actions and vent their emotions (Wright,1993). This did not happen for Gavin. Until this point in the narrative there is very little that might have been done to ameliorate the suffering Gavin experienced or, more importantly, has continued to experience. In light of Gavin's experience, the presence of a supporting peer may have reduced his perception of responsibility and given both medical officers a debriefing partner, thus ameliorating avoidable suffering for Gavin and his hypothetical partner. I will explore the issue of collegial support amongst peers more fully in conclusions.

Table 8.1 Key factors in Gavin's story:

Contextual Factors	
Clinical Severity	Extreme
Perceived Prognosis	Very poor
Decisional Urgency	High
Clarity of Clinical Situation	Very obscure
Clarity or Specificity of Policy	None

Personal Factors	
• Personal Responsibility	• High
• Concordance with Values of medical establishment	• Low
• Internal Conflict	• High
• Value	
-Quality of Life	• High
-Utilitarian use of resources	• Low
• Emotion – fear	• High
• Commitment to Collegial Reciprocity	• Low
• Commitment to 'Fully' Informed Consent	• Low
• **Interactional Process Factors**	
• Interactional Engagement	• Low
• Active Agency	• Moderate

8.2 MAX

An elderly man, 77 years old, came here on Wednesday from a private hospital. [He had previously been] admitted for two days and inadequately resuscitated by any stretch of the imagination. [His history included an underlying bone malignancy] (*this would have weakened this man's bones and compromised his general immune response*) and he'd originally fallen over and broken his rib. He had a collapsed consolidation of his right lung (*he had not been able to fully expand his chest due to pain form his fractured rib and had developed pneumonia*), was subsequently was admitted by his GP for "pain in the abdomen" (sic). He had a C/T, which showed a ruptured spleen and fibrosis (*The fractured rib had probably penetrated his spleen causing it to bleed. It had been undetected so long that fibrosis – early healing has begun*). Thereafter he didn't have anything done for another eight hours. Finally he had an anesthetic [and surgical repair of his spleen]. He had a post-haemoglobin of five, a pre-haemoglobin of fifteen - wasn't transfused. The first medical notes were [recorded] six hours later in the high dependency unit. He remained anuric for the next 24 hours (*essentially no urine output indicating acute renal failure*). I get phoned at nine o'clock on Wednesday, "…will I take him to (*accept his admission to*) intensive care?"

Although the pre-hospital management that Max describes for this man (Frederick) occurs prior to the key decision-making moments of his narrative, it is instructive to consider the decisions that were or were not made in the private hospital and their possible causes.

- As soon as his ruptured spleen was discovered on C/T Frederick should have be taken to theatre for a splenectomy and to halt the related bleeding. The eight hour delay may have been due to any number of causes from concerns about his ability to tolerate general anesthesia to delays in obtaining consent.
- His post-operative haemoglobin of 5mg/dL should have been corrected as promptly as possible (normal for men is 13-18mg/dL (O'Toole, 1992)).
- Anuria should have been treated with fluids as soon as it had been noted for three hours consecutively.

The decisions by the medical staff in the private hospital to leave Frederick's haemoglobin uncorrected and to do nothing about his anuria are suggestive of purposive inaction on their part at that stage. It would seem that a 'non-decision' to allow Frederick to die had been taken and then something altered this. Perhaps a relative had changed their mind about the course of management for Frederick. Alternatively, a different doctor may have taken over Frederick's management and viewed his prognosis from a different perspective.

This was the first **key decision-making moment** from Max's point of view. Frederick had an underlying malignancy, was severely anaemic, had been anuric for over 24 hours so was now in acute renal failure. He originally had fractured ribs and a collapsed consolidation of one lung.

Frederick had had major surgery and was not healthy to begin with. He was in multi-systems failure. This information was available to Max before he accepted the patient for transfer: CLARITY of CLINICAL SITUATION (clear) (CF).

Max does not mention any policies which guided his decision-making at this point. There may have been policies linked to resources (staffing/ beds with ventilators in intensive care etc.) and how this would impact upon the acceptance of inter-hospital transfers. Max does not refer to such guidelines: CLARITY or SPECIFICITY of POLICY for SITUATION (none) (CF). At the same time, there are broad guidelines for admission intensive care that Max should have been considering when making this decision.

Decisions regarding the admission of patients to intensive care are based upon clinical judgment and are guided in Australia by the decision-making framework offered by the American College of Critical Care Medicine (ACCM) (Society of Critical Care Medicine, 1999) (see glossary). The ACCM suggests decision-making within three models:

- **prioritization**: which patients would benefit most from admission;
- **diagnosis**: those diagnoses that in the clinical judgment of the specialist indicate the need for intensive interventions, monitoring and nursing care; and
- **objective parameters**: clinical data gathered in the acute situation which can be used to gauge clinical severity and need for intensive intervention. These clinical data are gathered and graded using the APACHE II & III scoring systems – see appendix IX.

> Although these tools are yet to be validated as pre-admission screening tools (Wasiak, 1999), their validity as predictors of outcome sees them used in this mode.

Age and previous quality of life contribute only 11 out of the possible 71 points on the APACHE scale, but this elderly gentleman (Fredrick)'s acute history suggested that his prognosis was very poor and that he was most unlikely to benefit from further extraordinary interventions: PERCEIVED PROGNOSIS (very poor) (CF). In theory, Max could have discussed these points with the doctors requesting to transfer Fredrick to ICU. He could have made the point that his transfer would only further stress this patient and his family. He could have refused to accept Fredrick's admission. There would have been no urgency to have this discussion and reach this conclusion; Max gives no indication in his narrative that Fredrick had suddenly deteriorated: DECISIONAL URGENCY (Low) (CF).

Max made this decision on his own-it should be remembered though that he was the director of this particular Accident and Emergency department: PERSONAL RESPONSIBILITY (high) (PF). In this instance, Max essentially just let this transfer happen: ACTIVE AGENCY (low) (IF). Acceding to the request for a transfer was the easier path here, whereas trying to prevent or refusing to accept Fredrick's transfer would have been more difficult for Max, requiring higher personal agency. This would have involved a fairly lengthy dialogue and some diplomacy from Max.

Max accepted Fredrick's admission to 'his' facility, [I was feeling] really pissed off about this because I was going to have to monitor the dying process of somebody who could easily have been adequately resuscitated. Everyone dies, let's be honest about that: either don't give him an operation and say he's going to die because he's got an underlying bone malignancy, or at least give him the best shot! This idea of: "Oh, we'll cop out at the end and let someone else pick up the pieces" I find offensive. "I was going to have to monitor the dying process of somebody who could easily have been adequately resuscitated. And I find it more offensive that the nurses here know that, [this patient could have been adequately resuscitated – this need not have happened] but they're the ones picking up the pieces as well as [supporting] the family […]

The bottom line, though, is if a registrar did work like that, you'd shoot him! And yet […] people are paying for the privilege. And their parting comment was, 'you know he's got the full private cover, so you know, you'll be able to charge for this'. To which one of my few brave comments was; I was proud of this: 'I think he can die for free don't you?'

Max's language reveals that he is passionate about this topic. The strident tone of his voice and his body language (***sitting hunched forward like boxer on the edge of the chair***) supported this, displaying the anger he was still feeling: EMOTION-anger (strong) (PF). Max's anger appears to have several causes. He implies that Frederick's earlier care at the private hospital was inadequate; that with earlier surgery, adequate hydration and transfusion of red blood cells, Frederick should have lived. Max tells us that he was angry that he and his staff would have to monitor the dying process for this patient. By inference he already knew it was too late to save Frederick and therefore futile to accept his transfer to ICU. Nonetheless, the primary catalyst of Max's fury here seems to relate to the quality of care delivered to Frederick prior to his transfer.

Max clearly values the delivery of high quality care for his patients and high standards of practice in the delivery of that care: VALUES- Professionalism in Practice, Quality Care (high) (PF). Max's analogy with the repercussions for a registrar who performed in a similar manner indicates that he was outraged with Frederick's care and condition as a result. It may be that Max's interactions with the medical team transferring Frederick conveyed this opinion. This could explain the throwaway line by the departing team, "…you'll be able to charge for this". Max's less that conciliatory riposte is indicative of the level of his feeling; what would appear to be professional outrage at his colleagues' behaviour in the matter of this patient's care: QUALITY OF INTERACTION (low) (IF); PROFESSIONAL RESPECT (low) (IF); EMOTION – contempt (high) (PF).

Finally, Max's anger in this situation extended to the impact this patient's transfer would have upon 'his' staff:
VALUE-Collegial appreciation (moderate)(PF). Max's concern for and empathy with the nursing staff is admirable here, but it is interesting that as Max recounts this episode and related issues, he does not tell us about an interactions with nurses: INTERACTIONAL ENGAGEMENT (low) (IF).

So he came across here, having a blood pressure of 70 (*this man was in severe shock*); he had O^2 sats. of 80 (*indicative of respiratory failure*) ; he looked like a cadaver. So he got intubated, ventilated, an adrenalin infusion, a lasix infusion. I elected not to dialyze him and he died 36 hours later. As Max describes this patient's clinical condition on arrival, we come to his next **key decision-making** moment in this story. Max has enough clinical information on hand to determine this man's condition and prognosis: Clarity of Clinical situation (clear) (CF). He describes a patient in the end stages of multi-systems failure. Frederick's vital signs are those of a patient near death and his prior history does not promise recovery: CLINICAL SEVERITY (Extreme) (CF); PERCEIVED PROGNOSIS (Very Poor) (CF). At this stage this patient's condition will not benefit from heroic measures – as Max says, he will be monitoring the dying process: DECISIONAL URGENCY (low) (CF). Here again, Max does not talk in terms of any policy which guided or supported his decision-making: SPECIFIC POLICY FOR SITUATION (None) (CF). There is no mention from Max at this stage of consultation with other staff, either nursing or medical about the decisions he makes here, nor does he talk about assessing the relatives' wishes before he makes any decisions: Interactional engagement (absent) (IF). The responsibility is very much his as he uses the personal pronoun often: "I" elected not to dialyze and, did "I" make the right decisions? : PERSONAL RESPONSIBILITY (high) (PF). Rather than being actively engaged in a decision either way Max implements supportive measures only which he knew were not going to save Frederick's life: Active Agency (low) (IF). Max could have chosen not to implement any extra-ordinary measures for Frederick. Having evaluated this man's condition as severe and prognosis as hopeless, Max could have spoken to Frederick's relatives, outlining this information and suggesting that the best course of treatment and care for Frederick would be to transfer him to a medical ward, to keep him pain free and let him die in peace with his family around.

Was an hour of adrenalin enough, that's where I draw the line. Have I killed him? Probably. Has he reason to die? Sure. Have I hastened it? Sure. Could I have I dialyzed him? Yes. Is not dialyzing the right answer? I don't know. I chose not to. But I don't know if it was the right answer. If it was my grandfather I wouldn't do anything. I mean if it was my grandfather I wouldn't have ventilated. If it were my wife, I wouldn't have ventilated. So by not dialyzing a 77 year old who has been anuric for 36 hours, who has got respiratory failure, well he's dead by any stretch of the imagination. Dialyzing him to me is just making him more miserable. I'm not going to put a Vascath in as well as everything else for someone who's ready for the high jump. `Max's language is harsh here as he describes Fredrick's condition and prognosis, yet it indicates that he had little difficulty making the decisions he did about this man's treatment : INTERNAL CONFLICT (low) (PF). Reflecting upon this incident one week later Max seemed more distressed about Fredrick's earlier care that the decisions he had made. Hi body language at this stage of this interview was laid back and relaxed and although his language is harsh, comparisons with care he would expect for his family infers that Quality of life is an important factor in his considerations in end-of-life decision-making: VALUE- Quality of life/ reduction of suffering (high) (PF).`

But, I've still got to make my peace with my maker eventually. No one talks to us about it, ever. We get zero debriefing. I get angry that there's absolutely no support for my staff or me. It's got to be meaningful. I'd like another specialist. That's what I want, someone who understands, someone I can talk to. `Max speaks of the importance of feedback and debriefing to himself and his staff and of the impact of its absence in his department. He has twice spoken of the value he places on his own staff and yet at all times, it is of 'his' decisions rather than teamwork within the department – shared decision-making that we hear. Although he feels the need, Max's commitment to reciprocity with his colleagues is low : COMMITMENT to COLLEGIAL RECIPROCITY (low) (IF); SHARED DECISION-MAKING (nil) (IF).` As to what you tell relatives? I still firmly believe that it's my role to withdraw treatment. It's not the family's decision. Because at the end of the day, I'm the one that's paid to make the decisions. I don't believe they should have to make it. (PF) PERSONAL RESPONSIBILITY (high) And it becomes apparent that you're not just making it for the family, you're making it for your staff. […] It's very much easier to say to someone [you know], this is a non-survivable head; here is why, that's why we're doing it [withholding/withdrawing treatment] If you don't know the nurse, or on this particular day one of the nurses in question [has] a student here, it would be a very difficult thing to do. Working in an ethically and clinically complex and problematic environment, Max feels safer with staff around him whose knowledge and more importantly, values he has already gauged: VALUES-Trust (high) (PF); Taking Decisional Responsibility (high) (PF). I don't know their values, I don't know what she's taught, I don't know. It's a gray area; it's a legal minefield, as to how much of it's withdrawal of treatment and how much of it is euthanasia. It's a very, very gray area. And that's what you pay specialists for, unfortunately. Every one of them gets tired and burnt out.

Table 8.2 Key Factors from Max's Story

Contextual Factors	
• Clinical severity	• Extreme
• Decisional urgency	• Low
• Perceived prognosis	• Very poor
• Personal responsibility	• High
• Clarity of clinical situation	• Clear
• Clarity or specificity of policy	• None
Personal Factors	
• Personal responsibility	• High
• Internal conflict	• Low
• Value	
- professionalism in practice	• High
- quality care	• High
- collegial appreciation	• High
- quality of life	• Moderate
- trust	• High
- taking decisional responsibility	• High

• Emotion - Anger - Contempt • Commitment to collegial reciprocity	• High • High • Low
Interactional Process Factors • Active agency • Interactional engagement • Quality of Interaction • Professional respect • Shared decision-making	• Low • Low -absent • Low • Low • Nil

8.3 GORDON

[I was caring for a] young fellow who had driven a friend's car home and ended up head down in a ditch [full of water]. He had water intoxication and possible hypoxia. His C/T scan showed diffuse brain swelling. Our policy then for those cases was two days of ventilation and rest, then wake [them] up. If they showed signs then of coning etc. we would put them back to sleep [with sedatives, muscle relaxants & ventilation] for five days *{Gordon is referring to the use of methods to try and reduce raised intracranial pressure (Schubert et al., 2001; Hankey, 2002)}* Diffuse cerebral oedema is likely to cause raised intracranial pressure with all its sequelae (see glossary: CLINICAL SEVERITY (severe) (*CF*). Until the period of ischaemic penumbra has passed (36 hours) (see literature review p.80) and cerebral oedema has settled, accurate assessment of the extent of cerebral damage will be not be possible: CLARITY OF CLINICAL SITUATION (moderately obscure) (CF); PERCEIVED PROGNOSIS (indeterminate) (CF). Gordon expressed no reservations about his decision to treat this young man along the lines described at this early point: CLARITY and SPECIFICITY of POLICY for SITUATION (clear)(CF).

Gordon's decision to follow policy here is the initial **key decision-making moment** in this narrative. This patient would have arrived in the unit intubated and stabilised. Gordon is not pressed at this time to consider or discuss end-of-life issues with family members or colleagues DECISIONAL URGENCY (low) (CF); INTERACTIONAL ENGAGEMENT (low) (IF). At this stage, personal factor PERSONAL RESPONSIBILITY (low) (PF); ACTIVE AGENCY (low) (IF): Gordon is acting within and is 'protected' by the guidelines of a precise policy. He could 'comfortably' allow the young man's progress within policy to decide the final outcome here.

During those five days the boy's father came to me and said, he didn't allow animals on his farm to suffer. He didn't intimate anything but you knew what he was asking. This challenge from Luke's father represents the next **key decision-making moment** here. Gordon is now approached by the boy's father but Gordon implies that they didn't have a 'sit-down' conversation about Luke's condition and outlook at this stage: INTERACTIONAL ENGAGEMENT with father (low) (IF). Although Luke's father is by implication asking that extraordinary measures be withdrawn, Gordon could 'comfortably' argue that the clinical picture is not clear enough to make such a decision. At this stage, Gordon is still acting within the guidelines of the policy: DECISIONAL URGENCY (low) (CF). I also had a lot of difficulty knowing I could have ended it but felt obliged to carry on. You have to actually say to yourself: "For what?" I mean if you've got this young fellow who you believe is not going to have any meaningful existence; why don't you switch it off? People can always come along and say to his parents, his mother, brother: "Somebody learns something from his vegetative existence - so therefore his life has meaning." As Gordon implies, he has formed the opinion at this stage that Luke's prognosis is very poor. He intimates that this young man's prospective quality of life is not one that he himself values and yet he offers the arguments and rationalisations for maintenance of extraordinary life-supporting measures that professional experience has taught him will be raised should he suggest otherwise: VALUES-Quality of life Vs a vegetative existence (low) (PF).

"So there's a big debate there and I feel that contrary to my own thoughts and possible wishes if I was in that person's place, I feel obliged by teaching, history or whatever is expected of me to "do the right thing". It's almost as if you're following orders even if you don't like the orders. Where are the orders come from? The orders come not from the medical fraternity but the medical establishment -you have to do it. Gordon's differentiation between the medical fraternity (the brotherhood) and the medical establishment (the patriarchs) is an instructive dichotomy. It is almost as if nameless, faceless senior doctors exist somewhere and exercise power over Gordon. But Gordon is an ICU specialist. If he is not free to make moral ELD's then who is? CONCORDANCE WITH RULES OF MEDICAL ESTABLISHMENT (Low) (PF), INTERNAL CONFLICT (high) (PF).

The prognosis for someone in Luke's age group with a severe head injury as indicated by diffuse cerebral oedema is around 21-50% (Marshall et al, 1998; Murray et al, 1999; Hukklehoven, 2003; Gomersall, 2004), with 40-60% possibility of returning to anything like a semblance of quality of life in terms of independence and communication (Marshal et al, 1998; Murray et al. 1999; Hukklehoven, 2003) As the head intensivist for this ICU, it is theoretically possible for Gordon to choose not to use extraordinary measures for Luke in light of his very poor prognosis. It is my experience, though, that if Gordon had chosen this path, he would have faced outrage and censure from his colleagues even though the majority of them would have privately agreed with his values and reasons. It is an interesting paradox in the health professions that our education and socialisation trains us to value life at any cost in the professional sphere even though this is not something we would wish for ourselves or our families. This is an issue I will pursue in discussions.

At the end of the five days I think I did actually say that I was hoping the guy would just cone and die but he didn't and (*long pause*) ... and he lived in a (*sigh*) persistent vegetative state. I was actually very sad that that the fellow breathed [when the ventilator was withdrawn] because the father was very upset and when I think of it later the mother was just holding onto T.V. miracle-type situations whereas his Dad could see clearly that this was not going to come out well. He was trying hard because he was even thinking of getting a computer set-up so he could get his son to communicate. But he realised that it wasn't going to work on any long-term basis (*long pause*). Not after we'd passed the "window" *[policy: 2 day's heavy sedation & rest on ventilator, then 5 more days if necessary]*. Gordon gives the impression here of empathising with Luke's parents – especially his father; there may have been an element of vicarious suffering (putting himself in patient's place) given his earlier discussion of quality of life: EMOTIONS-Sorrow (moderate) (PF).

Luke's father came to Gordon a second time during the five day 'window period' to express his concerns: [I felt it was] just a warning, "Look guys - on the farm we don't let animals suffer - are we going to let him suffer" and if so, shouldn't you do something about it NOW!(*Gordon's emphasis)* This second and stronger challenge from Luke's father, alluding to the suffering of animals and his perception of his son's suffering, demands a response or explanation from Gordon. Gordon is silent on the issue of how he interacted with Luke's father. By implication they did not have a meaningful discussion otherwise he would have told me about it: INTERACTIONAL ENGAGEMENT (low) (IF). As described, Luke was in a vegetative state and had been sedated prior to this. It is unlikely that he would have been suffering in terms of pain, perceived threat or loss. The tone of the father's warning to Gordon and his inferred emotions of anger and anguish suggest that he was suffering. Time taken here by Gordon for a discussion of all the implications of Like's condition might have ameliorated some of this suffering.

Gordon did have the option when Luke was first admitted to elect not to initiate extraordinary life-supporting measures. Given Luke's very poor prognosis, Gordon could have chosen instead to conserve resources for a patient with a better prognosis. Once these extraordinary measures were in place, however, he was obliged by policy to continue them. Once Luke's ventilation was withdrawn and he was breathing spontaneously, indications were that his brain stem was functioning. While Gordon showed distress about Luke's vegetative state, he is 'obliged' to continue all appropriate medical support. To accede to Luke's father's implied request here to end his son's life and thus his suffering would have been murder: ACTIVE AGENCY (high) (IF) and PERSONAL RESPONSIBILITY (high) (PF). It seems that the most important **key decisions** are those associated with the initiation of life-supporting measures

Afterwards it was almost [as if he were] saying, "I told you so". And [it felt] that we'd almost let him down but then there's the debate that we may have let him down in his expectations for his son but his wife probably hadn't worked through something [grieving process]. So a more prolonged death and a later death may have been more beneficial for her. [But] - that's not up to me to decide and I actually feel that you've almost got to follow a protocol - you just have to do it and make the decisions later on. Gordon seems to be needing to support his decision not to withdraw treatment for Luke. This is the first time Gordon has mentioned Luke's mother. By implication, until this point, Gordon had not spoken to her at all, otherwise he would have mentioned this. Instead of the sound clinical reasons and unit policies he used earlier, he now bases his rationales on the possible benefits for Luke's mother of his decision to maintain treatment (i.e. that no early decision to withdraw treatment was made). It seems that as Gordon's faith in the 'system' is challenged, he too turns to the 'one can find quality of life somewhere' arguments: INTERNAL CONFLICT (moderate) (PF); EMOTION – REGRET (moderate) (PF).

You have to have those things [protocols]. You have those brakes because if I was to become the judge in those situation where you have a certain number of beds and an enormous demand for those beds and people actually have to weigh up the chances of the ventilated patients against the [hypothetical] young chap down in A&E needing a ventilator [what do you do?] If you think about that case of the young girl where I learnt a heck of a lot and considered her recovery nothing short of miraculous [*one of Gordon's formative experiences where a senior physician had said wait and Gordon could not see why and in 24 hrs she had recovered*]. If I'd have been making the decision then with someone with like her - I considered her recovery nothing short of miraculous - I would have switched the ventilator off. So therefore, I now cannot make that decision and I have to say this particular person is on the ventilator and bad luck to you [person in A&E] because you've come later. This is where a consensus decision must be reached because if it's up to me, I am manipulated by my prior experiences and I would possibly hang onto somebody who should possibly be switched off and so I think at that stage we'd have to have a big 'pow wow' with much input. Gordon's years of experience and knowledge development, his socialisation within the establishment appear to have 'taught' him that difficult decisions have to be made in the critical care environment and where possible, he would rather not be making them alone: HISTORICAL SIGNIFICANCE (high) (PF).

As Gordon recognises, the finite resources of ICU units result in challenges and decisions like the hypothetical Gordon describes above. At the same time, he indicates that experience has taught him his decisions may not always be correct and he would rather not feel entirely personally responsible-that he would rather not have to experience the accompanying inner conflict. He was 'comfortable' early in this scenario when following the guidelines of a clear policy. It appears that Gordon feels he would be more comfortable in difficult end-of-life decision-making situations if he could share some of the burden: VALUES-limiting personal responsibility (high) (PF).

I think, in that situation an experienced ICU nurse should have far more input than a registrar because a registrar just hasn't got the [relevant] experience. And that input has to be taken in as serious a light as say, my input. And if I say switch off and they say don't switch off then that means that there is an impasse and somebody with equal or more experience must be called in to break that impasse […]. But both parties must justify their reasoning. The reasoning at that point is not a physiological thing, it's a - I've done biochemistry, and chemical pathology. It's not at that level - it's at a level of: "look we've got experience showing us that this sort of thing doesn't really work" and if I say "Oh no I've got one case which showed... " you know, then you have to bring other people in to give another opinion and say "hey let's go for that" and the more people you bring in and the bigger consensus you get, the better, because two out of three is not as good as three out of five. Gordon espouses consensus building and interaction with the families and nursing staff in end-of-life decision-making. The preceding story has not shown evidence of this. Gordon's arguments suggest that in practice he would respect the experience and input of all colleagues. This has not happened in the interactions in this particular story.

VALUE-consensus building (low) (PF); INTERACTIONAL ENGAGEMENT (low)) (IF); COMMITMENT to COLLEGIAL RECIPROCITY (low) (PF).

Table 8.3 Key factors in Gordon's story:

Contextual Factors • Clinical Severity • Perceived prognosis • Clarity of Clinical Situation • Clarity of Specific Policy For Situation • Decisional Urgency	• Severe • Indeterminate • clear • Moderately obscure • Low
Personal Factors • Personal Responsibility • Internal Conflict • Concordance with Rules of medical establishment • Historical significance • Values - Quality of life - Limiting Personal Responsibility - Consensus building • Emotions - Sorrow - Regret	• Low • High • Low • High • High • High • Low • Moderate • Moderate
• Interactional Engagement • Active Agency • Commitment to Collegial Reciprocity	• Low • Low • Low

8.4 PAUL

One case that comes to mind was a thirty-year old diver in another city who was diving at a major industrial facility. He was doing an underwater tank inspection when someone turned on the vacuum extraction for that tank and he was sucked down. His mate grabbed him. The force of the suction was such that it ripped off all his SCUBA gear. To find somebody to hit off the emergency switch, get him to the surface, then do the resuscitation, there was about a 15 minute down time. The resuscitation of this man (Eric) at the scene of this accident was a **key decision-making** moment in this story although it was not a decision made by Paul. Without speedy removal from the tank and initiation of effective cardio-pulmonary resuscitation (CPR) and expired air resuscitation (EAR), Eric would have died. With timely removal from the tank and effective CPR and EAR on the scene, Eric's prognosis could have been hopeful. In this case Paul tells us there was a 15 minute 'downtime' – the time taken before effective CPR and EAR was established. With this information in mind, Paul would have been aware that the sequelae for Eric in terms of brain and organ damage were uncertain but not hopeful. What were the options for Eric's workmates, knowing it took so long to get him out of the tank? Current Australian and New Zealand National Standards for occupational/ commercial diving requires the individual to hold a current first aid certificate (AS/NZS 2299.1:1999 : *Occupational diving operations - Standard operational practice*). As qualified divers, this man's workmates would have been legally 'obliged' to commence resuscitation. Likewise, paramedics arriving on the scene would have been required to continue the treatment of the individual until his recovery and transfer to hospital or death (see analysis of Ruth's story in families' analysis).

Paul continues, Early resuscitation attempts got him back very quickly but by that period of time it had been about 25 minutes since the original event had occurred. So he obviously was very unwell for a long period of time. He was brought in by the paramedics. When he arrived in […] the emergency room he had a pulse of 40 and no recordable blood pressure (*very severe cardiogenic shock*). He was intubated and given a couple of doses of adrenaline but with not much response. I suspect it (*the adrenaline*) was still stuck in peripheral circulation somewhere (*poor cardiac output, as indicated by the bradycardia and hypotension, would not have facilitated the drug's circulation*). When he had a blood pressure, I took him across to the C/T scanner straight away. [While there] he gave a cough on the 'tube and I had to paralyse him, which surprised me to see some basic brain function (*the cough reflex is one of the basic self-protective mechanisms mediated by the brain-stem (see glossary). That it is still extant suggests that the hypoxic damage to this patient's brain might not have been as profound as the history of his accident and resuscitation might have suggested*).

I thought my hospital wasn't the best place for him; we only had a very small intensive care with no neuro-surgeon and so I arranged for the same ambulance that brought him in to take him straight across to a major teaching hospital. They heard '25minutes of down time' and said, "Oh well there's no possible of hope of neurological survival." [They] waited till the relaxants wore off, [extubated him] he took a few breaths, they put him out to the ward, and he died that afternoon.

Paul made the **key decision** when Eric arrived at the emergency department to continue resuscitation efforts despite the history of 15 minutes' 'down time' and 25 minutes since original event. Resuscitation efforts until this point had not been effective and Paul describes a patient in severe cardiogenic shock (Romanini & Daly, 1994): CLINICAL SEVERITY (extreme) (CF). Paul's perception of Eric's prognosis would have been influenced by this man's prolonged period of hypoxia (see glossary). For some reason, Eric had not been intubated by the paramedics and so establishment of a reliable airway would be Paul's priority. At this point, Paul could theoretically have chosen not to have intubated Eric. He could have briefly consulted with his colleagues in the emergency room and decided that in light of his history and presenting clinical data, Eric's chances of returning to quality life were extremely poor and that he should be allowed to die. Such a decision would have required active agency and would probably have been met with horror by some of his colleagues.

In this case however, Paul chose to continue Eric's resuscitation. This is a decision that would have to have been made as Eric arrived in the emergency department: DECISIONAL URGENCY (high) (CF). In fact, the institution of a patent airway would have been virtually an automatic response on Paul's behalf to a perceived need in his patient. It seems that the overwhelming drive to follow the 'requirements' of the clinical imperative directs decisions, the sequelae of which, physicians and nurses in critical care spend the major part of their time regretting. In the previous narrative, Gordon spoke of being impelled by 'the rules' to do things, of having to just have to 'go for it' and then deal with the aftermath. I will deal with the issue of the impact of the clinical imperative further in discussions and conclusions. The initiation of these life-supporting measures for Eric would have preserved cardio-respiratory function but at this early stage, Eric's PERCEIVED PROGNOSIS (CF) would have been Indeterminate. Although Paul does not mention them here, it is probable that he was following protocols and algorithms (see glossary) as he worked to improve Eric's condition. I suspect that that he did not discuss these with me as he was aware of my critical care background and knowledge: CLARITY or SPECIFICITY OF POLICY for SITUATION (general) (CF).

The **key decision** taken by Paul to transfer Eric to the larger, better equipped hospital infers that he felt a) that this patient may have some chance of survival and perhaps improvement and b) that Eric deserves the best possible care to facilitate that chance. Paul's focus as he describes this scenario would seem to be the delivery of the best quality care for Eric: VALUE-Quality of care (high) (PF). Although Paul had good clinical data: the patient's history to date and his vital signs on arrival, he would not have been able to fully assess the Eric's prognosis until the cerebral oedema brought on by drowning and cardiac arrest had settled: (CF) CLARITY OF CLINICAL SITUATION (Obscure). Surprisingly, the presence of a cough reflex gave indication of some lower brain function and may have validated Paul's efforts to continue resuscitation to some extent. Like all the medical officers in this dissertation, Paul used the personal pronoun when discussing his part in the decision-making related to the case unfolding in his story - he took sole responsibility for his decisions: PERSONAL RESPONSIBILITY (high) (PF). In doing what he perceives to be his best for Eric, Paul did not move outside the protocols and general expectations for a patient with Eric's injuries: ACTIVE AGENCY (low) (CF).

The **key decision** taken by Paul's colleagues in the larger health care facility to withdraw treatment seems to be contrary to all the other decision-making trends and practices displayed by the medical officers in this dissertation. This was most unusual in that it required active agency on someone's part and would have required the actual cessation and withdrawal of Eric's ventilation. Paul tells us this happened within a matter of hours – by 'that afternoon' so this was not a process of determining brain death and then removing life-support. This was a unilateral decision based on Eric's history that life-support would be futile and Eric was allowed to die (or some would say was killed). From Paul's perspective this was wrong because: Certainly, the neurological outcome from the history was obviously going to be very poor, but it was always in the back of your mind that we didn't give him time to find out if the history was wrong. We didn't give him time to find out if nature was going to try and perform some miracle in this one?

The decision to cease/ withdraw treatment for this patient was taken by the medical staff at the receiving hospital. Paul does not say if there was any consultation with him before the decision was taken, indeed the receiving hospital staff were not obliged to consult with Paul about this decision. We are given the impression that a unilateral and fairly quick decision was made on the basis of the patient's early history of "25 minutes' down time": INTERACTIONAL ENGAGEMENT (absent) (IF). Although this decision was made at the receiving hospital with what appears to be no input from Paul, he seems to have taken on a great deal of the responsibility for this decision, using the inclusive pronoun "we" as he regretfully suggests the decision to withdraw treatment might have been a little too hasty: SHARED DECISION-MAKING (absent) (IF); PERCEIVED RESPONSIBILITY (high) (PF); EMOTION-regret (PF). This use of the collective pronoun by Paul here is interesting and instructive of the deep burden of responsibility that seems to pervade critical care physicians' perspectives of all decisions in their ambit, but particularly the end-of-life decisions. Paul was an entire hospital away from this decision and yet it is still fresh in his memory. The internal conflict and related suffering this decision caused has shaped his decision-making process since: INTERNAL CONFLICT (high) (PF). This experience seems to have formed a key point in Paul's historical perspective on decision-making in critical care ever since: HISTORICAL SIGNIFICANCE (PF). As a personal factor it has also affected his philosophical approach to the management of the withdrawal of treatment.

My approach had always been up until then and certainly since then, to try and give everybody 24 hrs and see what happens then. Often, as you know as a nurse, things develop by then and it becomes blatantly obvious. And I think that's the important thing when you're thinking of withdrawing life support-that it takes time for everybody to come to terms with the fact that you're not doing anything more for this patient by actually keeping them ventilated and on inotropic support and everything else. I think that's the biggest issue with intensive care. Everybody else here is about providing hope. When you're no longer providing hope, what you're doing really is extending a very miserable existence. However every staff member and family member and every doctor in every unit in some ways is just a little bit different in how long it takes to come to the decision that we're no longer providing the hope, that we're only providing a miserable existence and we should pull out and it's there where most of the conflicts, I think, come in. Every case is just that little bit different, you have to consider the feelings of everybody involved and some families just need some extra time to come to terms with things- that's fine, they need that extra time.

It would appear that Paul has taken the experiences of that early traumatic episode (and possibly others that he has not related here) to develop what sounds like a mature and gentle an approach to end-of-life decision-making in the ICU. Like many of his contemporary colleagues, Paul seems to have formed the opinion that QUALITY OF LIFE is an important factor to be considered when making end-of-life decisions. He speaks of knowing the difference between providing hope and extending a miserable or suffering experience: VALUE-Quality of life (high) (PF). At the same time, he recognises the individuality of all the potential decision-makers involved and seems prepared to consider their needs for time and information: VALUES-Interactional engagement (high);supported decision-making (high); engaging fully with others as human beings (high).

This needing time and information to come to terms with decision-making and its impact is echoed in the stories of some of the relatives in this dissertation and in the work of contemporary researchers (Burr, 1997; Mendonca & Warren, 1998; Kirchkoff et.al. 2002). Paul's recognition of this and his twin strategies of GIVING TIME and PROVIDING INFORMATION in his interactional engagement with peers and relatives may explain his experiences to date with end-of-life decision-making. The story he chose to tell does not directly illustrate his application of these strategies. His reflections on his experiences with end-of-life decision-making since though would suggest that the strategies he has developed are effective: It's interesting, I've never ever been faced by a situation where I've been told by a family "Please, you must do everything, keep, going, keep going!" I've never been faced with that. It's never been an issue at all. I don't know the reason for that. Maybe it's just an individual thing with me. I'll bring issues up early: I'll say, "This is looking very hopeless." I think they should be prepared. I don't think you should go along saying, "We can save," and, "We can save," and, "We can save," then all of a sudden say "No, we can't - we're going to extubate him this afternoon and let him die!" Henry (a colleague) is a perfect example of this - he's very up front and discusses all issues with the family and I try and do the same.

Table 8.4 Key Factors from Paul's narrative:

Contextual Factors	
• Clinical Severity	• Extreme
• Perceived Prognosis	• Indeterminate
• Decisional Urgency	• High
• Clarity of Clinical Situation	• Obscure
• Clarity or Specificity of Policy	• General
Personal Factors	
• Personal Responsibility	• High
• Perceived Responsibility	• High
• Internal conflict	• High
• Historical Significance	• High
• Value	
- Quality of Life	• High
- Quality of Care	• High
- Interactional engagement	• High
- supported decision-making	• High
- Engaging fully with others as human beings	• High
• Emotion	• High
- Regret	

8.5 HENRY

Henry chose to commence our discussion by summarising his experiences to date with end-of-life decision-making:

> All the ones I've been involved in [withdrawal of treatment scenarios], I've been comfortable with the decision to withdraw, but I tend to (*long pause*) apart from brain stem dead patients, I would not turn a respirator off. The way I get round it is to "draw lines in the sand". I'd make the decision not to dialyze for instance, or I'd put 'a cap' (*stop a certain dosage*) on the inotropes; or I'd put a cap on the oxygen level (*actually drawing the figurative lines on the chair beside him as he speaks*). Now, I do this with the support of the nursing staff - I ask them if they're comfortable, and I also get the support of the relatives.

At this early stage in our conversation, Henry gives the impression that over the years, he has developed a 'comfortable' strategy when handling these situations. Rather than making a decision to withdraw treatment per se, Henry conceptualises this as a gradual or piecemeal process, his "lines in the sand". He is essentially giving his patients and himself boundaries of maximal treatment: '…thus far and no further'. This strategy effectively puts a time limit and some objective measures on the decision-making process. For Henry these boundaries on intervention seem to be his means of establishing clarity in goals for patient care as well as a means of offering shared decision-making: VALUES-clarity in goals for care (high); shared decision-making (high). At the same time he indicates he uses these "lines in the sand" to work towards a consensus with the relatives while enlisting the collegial support of the nursing staff: VALUE: consensus building (high) (PF). Henry gives the impression here that he feels use of these strategies ameliorates some of the suffering around end-of-life decision-making both for himself and for relatives. A detailed example of Henry's 'lines in the sand' strategy with relatives is included at the end of this analysis.

Now I actually give the relatives an option for me to go onto the 'nth' degree with this. I certainly wouldn't go against the relatives' wishes. It might be a majority wish because I might actually have somebody who's not very comfortable with drawing lines in the sand, but usually we talk the relatives and me, we talk this individual member around. It's usually the spouse. I find the spouse, maybe on occasion is willing or wants to go the 'nth degree'. But the way I get round that is by saying, what would the husband or wife think, "If they were conscious, what would they want us to do?" So that way I feel that I'm comfortable with the decision. I do tend to look at a patient on a very personal level and I wouldn't do anything to a patient that I wouldn't want done to myself, or a member of my family, and I have experienced the death of my father [to reflect on]. So, basically I take it very personally. That's the only way I can survive, doing this.

This last paragraph from Henry is interesting. While he says that he would never go against the wishes of a relative, he describes a strategy in which he enlists the cooperation of one of the family to 'persuade' a dissenting member to agree to the consensus opinion: to '…talk this individual around'. As Henry concedes, this is often the spouse of the patient who wants maximal treatment continued for their loved one and he is essentially enlisting other family members' help to dissuade them of this. Aspects of this strategy are sound – family members of patients in critical care indicate that communication with the health professionals and the related provision of information to be one of the most important issues affecting their perception of their loved one's care (Burr, 1997; Azoulay et. al., 2000; Kirchkoff et. al., 2002).

The information Henry provides with his "drawing lines in the sand" could and probably would prepare family members for the decisions that need to be made when the question of treatment withdrawal is raised and so Henry's strategy no doubt eases the relatives concerned towards decision-making with the provision of information and time to decide. Henry betrays confusion about the aims of his strategy, however, and contradicts himself. While he takes the trouble to explain their loved one's problems and prognosis, when there is a member of the family who has not reached the proposed consensus decision (i.e. to withdraw treatment) this person is 'talked around' until consensus is reached. While the ultimate decision is probably in the patient's best interest, there would seem to be an element of coercion in this strategy: COMMITMENT

TO MEANINGFUL INTERACTION WITH RELATIVES (moderate)(PF); COMMITMENT TO REACHING CONSENSUS (high) (PF); COMMITMENT TO CONTROLLING CONSENSUS (high) (PF).

It seems that this is a strategy Henry has developed to allow him to reconcile the dissonance he perceives and experiences between the clinical imperative and his own values as he makes these end-of-life decisions. He indicates that he would never do anything for a patient that he would not do for a loved one or for himself, seemingly keeping end-of-life decisions and related communications at a very personal level. One is left to wonder though, how the one dissenting member of the family feels in the long term. It may be that this strategy works for Henry because of the measure of support he feels he is enlisting from the relatives as the decision about withdrawal of treatment is reached. Indeed, as he also indicates in his discussion of his perception of the nursing role, he endeavours to draw support form the nursing staff in his decision-making:

> And I would want the support of the nurses. I usually measure their concerns, and I just ask them am I right? What I would say is, "This patient's been on inotropes on 10 mls/ hour or 15 mls/ hour, should we cap it here? Are you happy with that?" And I just ask them, "Am I right?" I think I know them sufficiently well that I know when they're unhappy about it. But generally they're not unhappy about it because we've been treating the patient over a period of hours or days. They're professionals and they know that the prognosis is not worth it. And they're usually happy with lines in the sand. I haven't had an occasion where they've disagreed. And I think they can talk to me, I mean I don't sort of lord it over them or anything like that. I think that's… we're a team. I think that's the main thing.

Henry's use of the first person here is illuminating. He tells us that he would want the support of the nurses in the decisions made about withdrawal of treatment. His language in this exchange does not suggest though that this is a truly collegial decision-making situation he is seeking. His use of the terms, "I just measure their concerns", and "I just ask them am I right?" suggest that Henry is only seeking confirmation and support for his decision: PERSONAL RESPONSIBILITY (high) (PF). He is clearly using the 'lines in the sand' strategy with the nursing staff as he does with family members. He confirms this in discussion when asked about their interactions on those occasions when nurses are not supportive of his decisions.

Henry's words suggest that, like his interactions with relatives, he works with the nurses in his unit to achieve a 'consensus' decision about withdrawal of treatment. He gives the impression though that he expects these nurses to be 'professional' and recognise the 'appropriate' decision. While this is more than likely to be in accord with Henry's decision, there is an absence here of evidence of collegial discussion and movement towards an equally shared decision. In such exchanges one would expect to hear phrases similar to: ***"What is your opinion here?"*** or ***"Do you think we could/should make any other decision?"*** Instead, the impression one is given is of a paternalistic offering of entrée to the sidelines of decision-making: ***"…here's why I am making this decision, I hope you understand and are happy"*** :QUALITY OF INTERACTIONS (poor) (IF); SHARED DECSION-MAKING (low) (IF). Henry tells us that he perceives that the nurses he works with are usually happy with the decisions he makes and that they work as a team. Why is then that nurses in the critical care environment are not always of the same opinion? I will return to a deeper discussion of the differing perceptions of doctors and nurses around this concept in conclusions. Henry illustrated the application of his decision-making strategies in the following narrative:

We've got a patient at the moment; he's a 60'ish guy who's had an out of hospital arrest. He's probably had two down times. He's certainly had one down time that was of at least eight minutes. He's very sedated at the moment and currently we're lightening him to see what his mental (*cerebral*) state is like. This patient's preceding history, like many of the others in this dissertation involves an acute and prolonged episode of hypoxia, in this case as a result of an 'out of hospital arrest'. Henry refers to two 'down times' in his patient's history, indicating periods in which the patient's condition was so poor that he needed resuscitation. Permanent neurologic damage occurs if circulation or effective CPR is not established in a patient within four minutes of collapse (see glossary). As one of these periods was at least eight minutes in duration, then, as Henry's next words indicate, a major consideration in the decision-making related to this patient's case will be the extent of cerebral damage incurred by the hypoxic periods he has experienced: CLINICAL SEVERITY (severe) (CF).

The patient would have been sedated to facilitate toleration of endo-tracheal intubation and ventilation (Kidd & Wagner, 2001). He might also have required sedation to reduce cerebral oedema and/or irritation (Hanley, 1998; Hankey, 2002). In using the term 'lightening' Henry is referring here to the process of gradual reduction (weaning) of the patient's sedation with the short-term aim of assessment of cerebral function and perhaps the long-term aim of assessment for brain death. The presence of sedatives in the patient's system will cloud/ confuse both of these assessments and so their 'removal' from the patient's system before testing is a prerequisite of both these assessments (Romanini & Daly, 1994; Sullivan, 1999; Wijdicks, 2001; Fulde, 2004). Henry would have been automatically following a protocol at this stage in his decision-making: CLARITY and SPECIFICITY OF POLICY (clear) (CF). This is likely to have been a policy or procedure drafted by Henry and his colleagues in the unit. Indeed this may have been such an accepted aspect of his clinical practice (see literature review, page 72) that its impact on his decision-making has hardly entered his consciousness at the moment. Even so, the support of a clear policy at this juncture is likely to have eased the decision making process here for Henry as it did for Gordon.

The nurse has been involved with the patient the whole time. Come tomorrow morning, she can give me a lot of information […]. Maybe he's been making purposeful movements for instance, which is quite unlikely. But she's told me that he's got cogwheel (*jerky*) movement of his limbs and that in itself is probably a bad sign. These 'cogwheel' movements that Henry refers to are the rigidity and jerky 'ratchety' movements of the lower half of a person's limbs that is usually indicative of damage to the basal ganglia (O'Toole, 1992; Kidd & Wagner, 2001) and suggestive of profound cortical damage. It is instructive here that Henry's perception of the nurse's role in this decision-making process is one of information conduit only. One gets no sense of discussion between Henry and the nurse in this situation; of a collegial decision-making dialogue. Rather, the impression one gets is of unidirectional reporting of information, nurse-to-doctor to facilitate the doctor (Henry's) decision making: INTERACTIONAL ENGAGEMENT (low) (IF); SHARED DECISION-MAKING (absent) (IF). This impression is borne out both when Henry discusses the possible impact of this information on his decision.

Henry tells us he will be noting the data provided by nursing staff rather that seeking their opinions and yet he clearly feels that he is including the nurse as a peer in his decision-making for the patient in this scenario. This tendency to exclude nurses (albeit inadvertently) from end-of-life decisions is an issue affecting the experience of both doctors and nurses. This has been discussed at length in the analysis of some of the nurse's stories and I will return to this issue in conclusions.

I won't make a decision on whether to turn it [life-support] off tomorrow; […] we'll probably give him another 24 hours and see what he does. He's maintaining his blood pressure at the moment; so, unless he has another heart attack in the meantime, we may be able to get him off the ventilator. He is on inotropes at the moment, but by lowering him off sedation, we may actually be able to lower the inotropes (*a side-effect of sedation is hypotension; with reduced sedation, reduced inotropic support may be possible*).

Now this is not a wean situation (*withdrawal of ventilation*). It might be able to be done with a patient who's severely handicapped but […] we haven't turned anybody off. So that's a difficult one, that's a difficult one. (*Long Pause*)… but there again, you see, we will reduce; get him off all the sedation, all the inotropes and we may find, "Well, he's not breathing". Henry has inferred that he is already gravely concerned about this patient's prognosis. He does indicate, though, that he intends to wait another 24 hours before making a final decision about withdrawal of treatment. This would mean Henry will have waited 48hours from the weaning of this patient's sedatives to give him an opportunity to display some signs of cerebral function (voluntary movement, cough or gag reflex). This period of waiting is probably a function of the protocols of the unit Henry works in; it reflects the tendency to wait for 48 hours or more to 'allow things to develop' shown by Paul and Gordon as they discussed their decision-making in relation to cerebral insults. Here again then, presence of a clear and specific policy appears to be a supportive contextual factor in Henry's decision making process.

Henry's initial use of the first person in relation to this discussion suggests he considers his role in the decision to be made here is either of prime importance or that he feels he carries the major burden of responsibility in relation to the decision's ramifications. He changes his language to the inclusive third person shortly afterwards but the initial use of "I" here betrays the burden of responsibility he perceives that he carries in this decision-making scenario: PERSONAL RESPONSIBILITY (high) (PF). Henry seems to be saying here that from his perspective, the decision to withdraw treatment might be facilitated by the knowledge that a patient/ this patient has been severely handicapped by the sequelae of his collapse. It may be that like many other intensivists he feels that quality of life issues are an important consideration in these decisions: VALUE-Quality of life (high) (PF). Gavin and Gordon referred to the importance of quality of life issues in their decision-making. Review of the literature reveals that the issues of futility (Carnevale, 1998); (Parmley, 1999); (Ardagh, 2000 and quality of life (DePalma, 2001); (Woodcock, 2002) are hotly debated contemporary issues. Intensivists and critical care nurses who feel very poor future quality of life is sufficient reason to withdraw life-saving treatments tend to argue that there comes a time when the use of extra-ordinary life-saving interventions is merely prolonging the patient's suffering; that they are likely to have little further quality of life and that such an argument merits consideration of the withdrawal of these treatments (DePalma, 2001); (Woodcock, 2002). It seems at first that Henry might be of this persuasion.

In the next breath though, Henry tells us that such decisions have never been carried through in the unit where he works – "…we haven't turned anybody off". This may be a result of policy or of the views of the intensivists working in the particular unit. It is most likely a practice that has evolved as a result of input from Henry and like-minded colleagues. If one recalls his early opening words: "…but I tend to (*long pause*) apart from brain stem dead patients, I would not turn a respirator off", it would seem this is a practice he himself is uncomfortable with and as a senior physician in the unit, he may well have had some influence over the evolution of the tendency not to "turn anybody off" : COMMITMENT to MAINTENANCE OF LIFE-SUPPORT (high) (HF), INTERNAL CONFLICT (high) (PF) .

The preferred outcome for Henry in this end-of-life decision appears to be a finding of brain death: "… get him off all the sedation, all the inotropes and we may find, "Well, he's not breathing". This is now a diagnosis that is problematic and the source of contemporary debate (see chapter four). Henry is not happy to withdraw treatment from a patient who is breathing but for whom he concedes treatment is futile; treatment which he also concedes may be a source of prolonged suffering. He is however comfortable with the withdrawal of treatment from a patient who has be diagnosed as brain dead (is not breathing). Somehow this second outcome seems more favourable to Henry, but if the patient is not breathing surely they should maintain the life-support measures already in place? Henry seems to have formed the view held by many that brain-stem death is diagnostic of or the precursor to imminent death of the person (Pallis, 1987) and appears to be using this diagnosis as the final 'line in the sand'. With such a diagnosis, Henry has indicated he would feel confident in finally turning off the ventilator at the end of his "lines in the sand": We'll go to the relatives, say he's not breathing, not waking up, don't think he's going to wake up. We may be able to enlist the help of the relatives on this one. The nurse knows what score is anyhow. He's had one or two carers a day; they know what his prognosis is. It seems as if Henry will find the experience of decision-making much more comfortable here if he feels has enlisted the support of the family members and the nursing staff involved.

Henry outlined his probable interactions with this patients' family:

Well, first of all, when I talk to relatives, I usually ask them whom they've talked to, because they've probably talked to other doctors, and I don't want to say anything different to what they've been told. And it may only be slightly different, from relative to relative, but they may pick up on this. So usually what I say, is whom have you talked to, what do you understand by it, and I get them to talk to me first and then I will lead in. […] And so I will build on that and, I don't tell patients outright that there's no hope, but I sort of lead into it. The sort of things I will talk about is, "Well, so and so is on life support. That means they're on a ventilator, they're on inotropes." And then I'll go into, if they're on a ventilator, how much oxygen they need. I say, "We all we need 21%, but so and so is on 80%". And then I tend to talk about organ failure, usually I start off that if you've got one organ that's failed, you've probably got 50, 60, 70% mortality rate. If you've got two organ failure, you're up to 100% or thereabouts. I still put this forward as a sort of figure, to work on. I mean there's wide disagreement at these figures, but I usually put it forwards as a figure to work on. Then, if I think that the situation's not completely hopeless, I give them a little bit of ray or light, or hope. But if I think the prognosis is completely hopeless, I will say so: ' The chances of survival are very small'. And then I'll probably have, another talk after a few hours, or maybe the next day […] so I'll lead them into it gradually. Because I think, it's rather like being hit with a sledgehammer to tell them well, "That's it. Dad's going to die". […] I think it's most important is to keep them on side, and not to give the impression that you've sort of given up and that's it. Usually the relatives will actually come on side and, the other thing I would say is, 'We're very good at keeping patients alive'; And, "Do you want us to prolong the act of dying?" This is what they have to decide. So, try to make them think about the patients, perhaps, rather than thinking about themselves, but actually think of the patient. What would Dad have wanted? That sort of phrase. I get them on side. I think that's the point.

Table 8.5 Key Factors from Henry's Scenario:

Contextual Factors	
• Clinical Severity	• Severe
• Clarity and Specificity of Policy	• Clear
Personal Factors	
• Personal responsibility	• High
VALUES	
- clarity in goals for care	• High
- shared decision-making	• High
- consensus-building	• High
- Quality of life	• High
• Internal Conflict	• Moderate
• Commitment To Meaningful Interaction With Relatives	• High
• Commitment To Reaching Consensus	• High
• Commitment to Controlling Consensus	• High
Interactional Process Factors	
• Quality Of Interactions	• Poor
• Shared Decision-Making	• Low - Absent
• Interactional Engagement	• Low
Historico-Political factors	
• Commitment to Maintenance of Life-Support	• High

8.6 MURRAY

There has been an occasion, quite recently, where I gave the third opinion, where I did [talk to the family]. And that was a very moving experience. I remember concentrating very hard on being mindful that I have to keep this as simple as possible. Because I didn't think they'd take in the various parts of what I had to say, which is what I did. It was a desperately sad situation because the patient's illness, in itself, had been terribly complicated; caused dreadful stress in the family, disintegration of the family. The family members were there, and I was mindful of their background, so I was aware of keeping it as simple as possible. Murray's discussion of his mindfulness of the communication strategies he felt he should use here is both heartening and a little disturbing. He gives the impression that he uses the same strategy in preparation of the family as Henry describes: finding out who they had already spoken to, what they knew to date before moving on to give further information. His use of the term 'keeping it a simple as possible', which he repeats later is suggestive of a slightly patronising attitude on Murray's part here: Quality of Interaction (poor) (IF).

The child had had epilepsy, which had been extremely difficult to control. He'd been very well looked after by a colleague, who had decided to resort to the use of another anti-epileptic drug. And this is one of those rare instances where the patient then suffered devastating, full-blown complications with the drug, and eventually had to have a liver transplant. […]. The patient became better stabilized on the other medications. I mean the anti-convulsant that was causing it was discontinued; other things were tried. And, then he suddenly deteriorated and became comatose and couldn't be resuscitated. Well he could, enough to be brought into ICU, but not to the point of regaining consciousness. Sadly, many anticonvulsant medications have hepatotoxic side-effects and some patients react more violently to them than others (Galbraith, Bullock & Manias, 2000). This would appear to have been the case for this child (Tony). One of the more extreme manifestations of severe liver failure is cerebral irritation and fitting. As Tony was already predisposed to seizures, this problem would have been enhanced, causing the brain damage that lead to his loss of consciousness. Tony's clinical condition and prognosis at this stage were very poor: CLINICAL SEVERITY (severe) (CF); PROGNOSIS (very poor) (CF); CLARITY of CLINICAL SITUATION (clear) (CF).

Murray's input in this situation was as one of the three independent physicians possibly confirming brain death and so his involvement would have ultimately affected the decision made by the treating physicians. As Tony would have been ventilated and 'stabilised', there would have been no pressure for Murray to reach his diagnosis swiftly: DECISIONAL URGENCY (low) (CF). On the other hand, the decision to withdraw treatment for Tony would rest to a large extent upon the opinion given by Murray and two of his colleagues: PERSONAL RESPONSIBILITY (moderate) (PF). This confirmation is part of standard practice worldwide and would have followed a protocol in the hospital in which this story occurred (Sullivan, 1999; Wijdicks, 2001; Wijdicks, 2003): SPECIFICITY and CLARITY of POLICY for SITUATION (clear) (CF). As Murray tells us, he was aware, that his presence and his input were also contextual to the family's decision-making experience.

[When speaking to the family] I was mindful that part of the grief reaction often entails blame seeking. No doubt you've encountered it yourself. And so I was very careful to define exactly what the problem was, to define that all that can possibly be done had been done. I can only go on impressions of other members of the family, but it seemed to me that they were all accepting, which is as much as one could hope for. Sometimes they aren't accepting, but I see my professional role in that situation as making things a little less unbearable, and trying at all costs not to add to the burden. I mean, often there's nothing you can really do. And I think this is where we find the ultimate professional demands being laid on us. We do what we know has to be done, without looking for a particular reaction.

In these words we see some hint of the stresses which may cause Murray suffering in relation to situations such as these. It seems that he perceives himself to be carrying some of the burden of responsibility for the suffering of the families affected by these clinical situations and the decisions that may follow: PERSONAL RESPONSIBILITY (high) (PF). I recall Murray's tone and demeanour at the time of our conversation. These were entirely kindly and gave the impression of wanting to help the patient's family through a crisis with information and understanding. With the 'lens of distance' though, one can see another perspective here.

Murray also felt he had a responsibility to limit the suffering for the other physicians affected by the sequelae of this Tony's care. Murray speaks of the grief reaction and the natural tendency at times for individuals to seek the source or cause of their loss or injury (Wright, 1993). This response was seen in one of the relatives' stories (Sandra) as her brother in his anger wanted to see the doctor who he blamed for Sandra's husband's intra-operative cerebral injuries. Murray indicates that he was very careful to outline what the problem was and that the family were all 'accepting' of his explanation. One wonders, whether it was the information about their child's condition and prognosis that the family should be accepting or as Murray intimates, his reassurance that nobody was to blame that the family should have accepted? In his earlier outline of the events leading up to this child's current condition, Murray infers that apart from the choice to change his anticonvulsants, the sequelae of events were beyond the treating physician's control. This is probably so, but it is curious that Murray perceives that part of his role here is to shield his colleagues from blame: BLAME-SHEDDING (High) (IF). Although he does not mention it here directly, one wonders if some aspect of fraternal affiliation with his 'brother' physicians may have compelled Murray to assume this responsibility. The possible impact of fraternal affiliations upon decision-making at the end-of-life was raised in analysis of the nurses' stories (Jill) and I will return to a deeper discussion of this in conclusions.

In one way this becomes a responsibility, but if you know that you are doing what has to be done, and part of that obligation is making it as simple as possible for the relatives of the patient, then everything else will fall into whatever place it's going to find. By contrast, I don't feel you can specifically aim at getting a response of thanks. Thanks will come when one's done one's job. But you can't go into it from that point of view; you have to go into it as professionally as you can. […] People who are not confronted with life or death situations, can't begin to imagine what the professional boundaries are, what the professional objectives have to be, how simple they must be. And the older that those of us become who work in these professions, the more we know. But you've got to keep it simple, and keeping it simple is one of the most compassionate things you can do. And you must only do what has to be done. It seems that Murray is talking from the perspective of the collective-the medical establishment here. Although Murray's words give the sense that his overall objective is for the greater good of the family he is talking to, one also cannot ignore the impression that he also feels compelled to act within the constraints and or guidelines of his profession. Even though he is anxious to behave in a compassionate and empathetic manner when conveying the often sad news around the diagnosis of brain death, Murray is also concerned that he does this within the confines of his professional boundaries. It appears that the boundaries of the profession have become protective for Murray in some measure. The rules of the medical establishment that dominated Gordon's decision-making appear to support Murray to some extent in that he believes the medical establishment would say "keep it simple" when communicating bad news to relatives. Whereas Gordon appeared compelled to act as he did in his narrative by the medical establishment, Murray seems guided and supported: CONCORDANCE WITH RULES OF MEDICAL ESTABLISHMENT (high) (PF); (INTERNAL CONFLICT) (low). Murray clearly feels that feels that he can ease the burden of information assimilation and decision-making for the family if he "keeps things simple". This is terminology he repeated frequently in the course of our conversation and he emphasised his perception of its importance linking simple communication with compassion.

I'm always affected by the pressures [of these responsibilities] and it comes into other areas whenever I am dealing with a patient who has a fatal disease, and I have to break the news. I always then give myself time, ten minutes, quarter of an hour, no matter how packed or busy the day is, to give myself a bit of time to recover my composure. I allow myself to feel emotions, that I do feel, because just from my own personal lifetime experiences, those sorts of things do arouse feelings, and I have found that if I've had to do that sort of thing or become involved in one of these life or death crises, then I do think of those loved ones who I have lost. It helps me to cherish the memory of them, and I deliberately do that rather than push them away. I like to remind myself: Yes, I have this special feeling. Murray infers that he suffers a little every time as a result of the responsibilities he perceives he carries and as a result of the emotions he says are raised. These tragedies, and the empathetic suffering that Murray experiences are part of the job to some extent but he might be able to develop strategies to ameliorate their effects to some extent. Murray indicates that he has done this to some extent in the development of his own strategy of some quiet time in his busy schedule to acknowledge and work through his feelings.

There is no word though from Murray of the use of any form of external debriefing mechanisms: colleagues, formal counselling that he might use to talk through these difficult times. He says that he tends to cherish these memories rather than pushing them away. One wonders if this introspective tendency will be entirely healthy in the long run for this physician: Interactional Engagement (low) (IF); COLLEGIAL SUPPORT (Absent) (IF).

Table 8.6 Key Factors from Murray's Narrative

Personal Factors	
• Clinical Severity	• Severe
• Prognosis	• Very poor
• Clarity Of Clinical Situation	• Clear
• Specificity and Clarity Of Policy for Situation	• Clear
• Decisional Urgency	• Low
Contextual Factors	
• Personal Responsibility	• Moderate-high
• Concordance With Rules Of Medical Establishment	• High
• Internal Conflict	• Low
Interactional Process Factors	
• Blame-shedding	• High
• Interactional Engagement	• Low
• Quality of Interaction	• Poor
• Collegial Support	• Absent

As a post-script, Murray was also eager to speak to me of another case in his experience which was important to him in relation to the issue of the diagnosis of brain death. This is something he is called to do frequently in his practice and yet it is an aspect of clinical practice he has come to question. This interview was the genesis of my exploration in this area and so I have included the relevant excerpt here as a coda. At the same time, Murray's doubts about the clinical diagnosis of brain death have as he says given him increasing 'reservations' over the years. These CLINICAL RESERVATIONS may well in themselves be a personal factor (PF) impacting upon Murray's experience as he contributes to the diagnosis which may lead to an end-of-life decision.

> The case that sticks in my mind is of a lad who was only twelve years old, and who had been knocked down as a pedestrian and suffered grievous head injuries. About a week after the accident, he was still showing no signs of recovering. [In this case I was one of the three physicians pronouncing brain death]. They're procedures, which I might add that in more recent years I've had more and more reservations about. But I'd never say, yes I authorise turning off the life support.
>
> I was called in because I was not in any way involved in the management of this case, and because I had no involvement in any organ transplantation possible through his death. [I did not interact with this family beyond passing on my findings] but I reflect on his case from time to time, because in the years since, I've seen a number of patients who have survived, as far as I can tell, equally grave head injuries, after very, very lengthy treatment and painstaking rehabilitation. And they survived because the relatives had not given permission for life support to be turned off. And I guess I've seen perhaps a dozen of these patients. Now, three or four of them have actually become moderately ambulant again. All have learnt how to communicate at varying levels. Some have remained totally dependant on others for all of their personal needs. And so the spectrum is very variable.
>
> But the common feature of all is that they, they regained the ability to communicate, to feel, respond, and in all cases, according to their parents or relatives, that told me years later when I became involved, there'd been a discussion at the time about turning off life support, which they have not wanted. […] One thing I'm sure about, these people who do survive, are glad they've survived. I ask them, are you glad you're alive, and they always say yes. Even though they might be bed-ridden [they're happy with their quality of life.]

8.7 DISCUSSION:

In the analysis of the doctors' stories, as the key decision-making moments have been identified, many key factors were identified. These have been listed and arranged below in an effort to both summarise and outline the process of end-of-life decision-making from the doctors' perspectives as revealed from analysis of the preceding narratives. The identified factors are also listed in their categories: Contextual Factors, Personal Factors, Interactional process factors and Historico-political factors at the end of this discussion. Many of the factors, as one would imagine are common to each story, some are unique.

The contextual factors are common to each story which is not surprising in that the clinician's analysis of the patient's condition, prognosis, and the speed at which he/ she must do this are all aspects of clinical decision-making. The variability related to these factors though impacts upon the clinician's decision-making experience, as does the existence or absence of support structures for that decision-making: policies and protocols. If a hypothetical patient's condition is clearly severe or extremely severe and their prognosis is very poor and/or if the department's policies in this hypothetical situation are specific and clear i.e. indicating no need for initiation or maintenance of life-sustaining measures, then decision-making is relatively 'easy' and suffering for the decision-makers would be low.

Table 8.7 Process of decision-making as identified in stories told

Doctors' Factors	Suffering minimised if:
Clinical Severity	High to extreme
Perceived Prognosis	Poor
Decisional Urgency	Low
Clarity of Clinical Situation	Clear
Clarity or Specificity of Policy	Clear & specific
Personal/Perceived Responsibility	Low
Concordance with Values Of Medical Establishment	High
Internal Conflict	Low
Commitment to Consensus Building	High
Commitment to Collegial Reciprocity	High
Values Congruence - Quality of Life - Quality end-of-life care - Decisional responsibility	High
Interactional Engagement	High
Shared Decision-Making	High
Quality of Interaction	High
Collegial Support	High
Active Agency	Low
Opportunity to Debrief	High

If, however, in an alternate hypothetical, the patient's condition is just as severe but clinical data is not freely available or as clear so that the prognosis cannot be judged as easily and immediately (cerebral oedema often produces this dilemma), then decision-making is not so unambiguous. If, in this hypothetical situation, the clinician is required to make a decision urgently (an airway is needed) or if there is no clear and specific policy guiding these decision-making situations, then the decision-making is more challenging and may be the cause of suffering at the time or in the aftermath of the decision. Gordon in particular, speaks of "having to go for it" and "picking up the pieces" afterwards. The issues of clarity, decisional urgency and their impact will be returned to in conclusions where I will also explore the possible strategies that might be used to ameliorate the suffering for decision-makers in these situations.

The collected factors are an extensive and instructive list. When first I began this project and as I collected data, my assumptions were that communication processes, their quality and/ or absence would be the greatest contributors to my findings and recommendations for this project. On appraisal of the preceding list, though, sheer numbers suggest that personal factors were more influential when doctors made end-of-life decisions. No matter what their age, it would appear that physicians bring personal experience to these decision-making episodes that in turn shape their own history of experience still further and thus their future decisions. Some of the doctors recalled earlier decision-making episodes that had shaped future decisions forever (Gordon and his memories of the girl who had recovered despite his perception that her prognosis was hopeless; Paul and the young man who had treatment withdrawn at the hospital on receiving his transfer.

Noticeably, many of the doctors, whether specialists or registrars at the time, experienced and tended to suffer some degree of internal conflict as they struggled with the dissonance between their personal values related to quality of life or the reduction of suffering and the requirements of their medial profession/ fraternity/ establishment to preserve the lives 'entrusted' to them in the various critical care venues in these stories. The internal conflict and suffering for the doctors involved varied from high (Gavin, Gordon & Paul) to low (Henry, Max & Murray). Not surprisingly, increased internal conflict and related suffering was associated with situations in which there was actual or perceived increased moral agency for decisions. This was then associated with long-term negative emotions and unresolved suffering which had impacted future decision-making. The impact of the medical officers' own values upon decisions, or more importantly, the internal turmoil many of them seem to face as they comply with the guidelines and expectations of their profession and the 'establishment' is an issue that arose in the nurses' stories too and I will be dealing with this in depth in conclusions.

The issue of responsibility is raised either directly by some (Max feels decision-making is his responsibility alone) or indirectly throughout each story in this chapter. Most of the doctors talked of the decisions made in the first person, inferring that they too perceived these decisions to be their sole responsibilities. There has also been a noticeable absence of attempts to share these responsibilities, even in cases where doctors have said they value or work to include the input and perspectives of families and nurses (Max, Gordon, Henry). This apparent commitment to sharing decisions coupled with a perception that their strategies used in decision-making met the needs of families and were inclusive of nurses was characteristic of several doctors' narratives (Gordon, Paul, Henry). These perceptions were not supported by the evidence of their stories and do not match the experiences and perceptions of most of the nurses and families members in the preceding chapters. This mismatch of perceptions is probably one of the most instructive aspects of this dissertation – two of the doctors in this chapter have said they have had no relatives asking them to persist with extra-ordinary measures (Henry & Paul). They have essentially intimated that they have had no complaints. At the same time though, Henry tells us of his strategy to 'persuade' dissenting relatives to his point of view. I will discuss and develop the issues around the mismatched perceptions related to communication and decision-making in conclusions for this dissertation.

Finally, one of the most important interactional process factors to be mentioned throughout this analysis, but to be significant in its absence is support for the decision-makers, whether it be collegial support from peers or some form of formal counselling. Some of the doctors in these stories speak of the need for support, either during or after decision-making (notably Max). For others (Gavin, Gordon) the opportunity to debrief with me in our interview, though this was years after the fact, would seem to be an indication that this sort of a resource in their work situation could facilitate easier decision-making in the future and ameliorate some of their suffering at the time. This issue too will be explored in the next chapter.

Table 8.8 Factors Identified in Analysis of Doctors stories:

Contextual Factors	• Clinical Severity • Perceived Prognosis • Decisional Urgency • Clarity of Clinical Situation • Clarity or Specificity of Policy
Personal Factors	• Personal Responsibility • Perceived Responsibility • Historical Significance • Internal Conflict • Commitment to Meaningful Interaction with Relatives • Commitment to Reaching Consensus • Commitment to Collegial Reciprocity Commitment to 'Fully' Informed Consent • Values - Quality of Life - Utilitarian use of resources - Standards of practice - Quality end-of-life care - Collegial appreciation - Trust - Taking decisional responsibility, **or** - Limiting Personal Responsibility - Consensus building - Interactional engagement - Supported decision-making - Engaging fully with others as human beings • Emotions - Anger - Contempt - Fear - Sorrow - Regret
Interactional Process Factors	• Interactional Engagement • Professional engagement • Shared Decision-Making • Quality of Interaction • Collegial Support • Active Agency • Blame-shedding

Historico-Political factors	• Submission to Medical Establishment • Influence Of The Medical Establishment • Commitment to maintenance of Life-support

CHAPTER NINE: DISCUSSION AND CONCLUSIONS

This chapter presents the 'construction' and contextualisation steps of Critical Interactionism. In analysis, the interactions around the decision-making in each narrative were interpreted, key factors identified, listed, categorised and then organised into tentative explanations of the process as described by the relevant group of participants. The aim of the following section of this chapter is to demonstrate how the major concepts link together in an explanation of the process of ELD-making (construction) and to situate this explanation within the context of the contemporary social world with examples from the world of the participants (contextualisation).

Presentation and discussion of the theory arising from this project will be followed by discussions of the recommendations for practice, education and research originating from this study. Finally, an overview and conclusion to the project will be presented.

9.1 CONSTRUCTION AND CONTEXTUALISATION

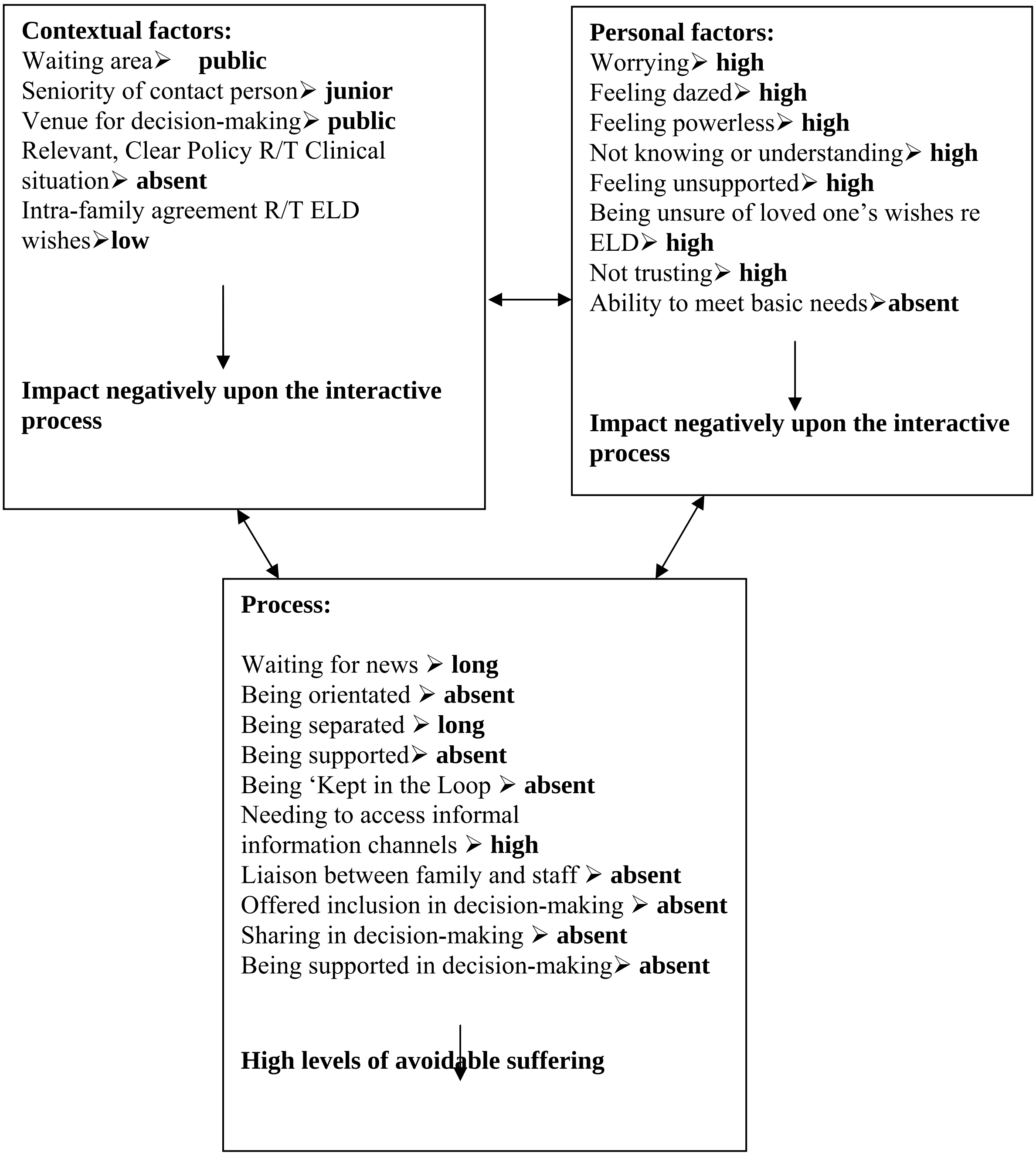
This section of the chapter presents the inter-relationship of the personal, process and contextual factors and their impact upon the phenomenon of ELD-making in the critical care (CC) environment. Construction and contextualisation appear together as models of each group's perspective of the decision-making process is discussed and then interwoven with examples from the data to contextualise theorising.

9.1.1 Theory Development

For the purposes of this discussion, contrasting models of ELDs are offered. A 'worst case scenario' representation of the ELD process from the perspective for each group will be used to demonstrate the inter-relationship between key factors identified during analysis and how these contribute to additional suffering. This model will then become a foil for recommendations. As a summary of the discussion for each group, a second model, representing recommended ‘best’ practice will be presented.

9.1.1.1 The families:

Figure 9.1 ELD-making from families’ perspective (worst case)



Contextual factors:
Waiting area➢ **public**
Seniority of contact person➢ **junior**
Venue for decision-making➢ **public**
Relevant, Clear Policy R/T Clinical situation➢ **absent**
Intra-family agreement R/T ELD wishes➢**low**

Impact negatively upon the interactive process

Personal factors:
Worrying➢ **high**
Feeling dazed➢ **high**
Feeling powerless➢ **high**
Not knowing or understanding➢ **high**
Feeling unsupported➢ **high**
Being unsure of loved one’s wishes re ELD➢ **high**
Not trusting➢ **high**
Ability to meet basic needs➢**absent**

Impact negatively upon the interactive process

Process:

Waiting for news ➢ **long**
Being orientated ➢ **absent**
Being separated ➢ **long**
Being supported➢ **absent**
Being ‘Kept in the Loop ➢ **absent**
Needing to access informal information channels ➢ **high**
Liaison between family and staff ➢ **absent**
Offered inclusion in decision-making ➢ **absent**
Sharing in decision-making ➢ **absent**
Being supported in decision-making➢ **absent**

High levels of avoidable suffering

From the family's perspective, the process of ELD-making, as represented in figure 9.1 (page 290), was triggered by a loved one's injury, collapse or deterioration. The inter-relationship of the factors in this model and their impact upon the decision and decision-makers may be subsumed under the following higher order categories that are expressed in positive terms. For families, less suffering occurs if they experience:

- Being oriented;
- Meeting informational needs;
- Meeting basic needs;
- Meeting spiritual and emotional needs;
- Inclusion in decision-making.

9.1.1.1.1 Being oriented

When a relative arrives at ICU for the first time, they will already be shocked/ dazed by the news of their loved one's admission. The impact of the CC environment is a compounding stress. If they are not prepared for the environment and for the sight of their loved one (and others) attached to the technological paraphernalia of ICU, then they are likely to feel overwhelmed and not be able to absorb or integrate information they are given. This finding was supported in research by Azoulay, Chevret, Leleu, Ponchard, Barboteu et al. (2000), and Kirchhoff et al, 2002 who found that relatives' initial and then subsequent experiences of the critical care environment are impacted by the quality of information they receive form the health professionals they interacted with. Indeed, Azoulay et al. (2002) subsequently designed and tested orientation information sheets which proved to enhance relatives' understandings and experiences of the critical care environment.

Many relatives were dazed or expressed awe when confronted by the critical care environment. Lloyd, for example, found the area a "... *a very off -putting place to walk into…"* describing his first sight of his partner (Judith, with the large benign liver mass), *"…here's someone looking absolutely dreadful with more tubes and wires and God only knows what sticking out of them and in a very distressed state themselves".*

Awe of the environment affected all participants to some degree and extended to awe of the health care professionals (HCPs) within the environment-especially the doctors. The combination of these cognitive and emotional stresses tended to constrain the relatives' capacity to question information and decisions, regardless of prior experience. Hannah, a critical care nurse, felt it was not her place to question the doses of morphine being given to her father as he fought to breathe upon extubation after a diagnosis of brain death. Lloyd, with no medical background, also felt he had no role in questioning decisions even though he perceived a difference of opinion between doctors seeking consent for a liver transplant for his partner.

Recommendation 1: Relatives should be orientated to the ICU environment and the potential appearance of their family member before first entering the area. This orientation would be most effective accompanied by pictorial and written material. There should be an orientation manual in the relatives' waiting room as well as FAQ pamphlets they can take with them.

These recommendations could be implemented by the Liaison nurse whose role will be detailed shortly

9.1.1.1.2 Meeting informational needs

9.1.1.1.2.1 Being 'kept in the loop':

Relatives arrive at critical care (CC) venues following news of their loved one's urgent admission and usually find themselves waiting to see their family member for the first time. Alternatively, they may have been there for some time and be waiting for news of progress or results. Relatives in this position are usually separated from their loved ones who have left for tests or surgery or have been receiving treatment or care in the unit. If relatives are not kept up to date: 'in the loop', during this time, then the separation from their loved one is distressing, but the absence of news raises relatives' anxiety (possibly unnecessarily). This aspect of their experience troubled many relatives in this study-several waited for extended periods; Sandra's wait of over four hours being the worst example (while her husband's rising ICP was 'treated' in theatre). This too is consistent with contemporary research. Burr (1997) studying the needs of families in critical care and McHaffie (2001) talking to parents in neonatal intensive care units consistently found these relatives desired more frequent news.

Recommendation 2: Relatives of patients in CC should not have to wait more than 10 minutes for initial contact with clinical staff. They should receive regular (at least once a shift), accurate updates regarding their family member's condition, care and prognosis throughout their time in critical care.

9.1.1.1.2.2 Accurate and adequate information:

Nurses in this study withheld information from relatives- this was apparent in stories from both the relatives' and nurses' narratives. This is consistent with contemporary literature (Mendonca & Warren, 1998; Kirchhoff et al., 2002; Zaforteza, Gastaldo, de Pedro, Sánchez-Cuenca & Lastra , 2005) and links the practice to increased stress for the families. Possible causes for the problem included:

- Perceived power imbalances and attempts to avoid conflict with physicians despite recognition of the negative impact on the family (Zaforteza et al., 2005),

together with suggestions that:

- giving such information was not within the scope of practice of the nurse (Zaforteza et al., 2005) or
- taxed the complex and poorly defined role of the ICU nurse in this area (Burr, 1997).

By interesting contrast to the above research, Kirchhoff and Beckstrand (2000) surveyed 300 critical care nurses and found the perception that six out of the top ten obstacles related to dealing effectively with patients' relatives at the end of life related, in these nurses' opinions, to '…not fully understanding' a number of issues (p 96.) - obstacles that might have been addressed with information perhaps?.

If relatives do not receive adequate information from the HCPs treating their family member, then they may resort to informal information channels such as the web, or friends in the health care profession. This information may be inaccurate or may not apply to the peculiarities of their relative's case, raising unfounded hopes or causing further confusion. Sandra's experience best exemplifies how the need for information can add to the suffering surrounding the ELD process. She was provided with explanations of her husband's impending tests and surgery from the anaesthetist and surgeon. She did not, however, receive any clarifying explanations of his manifestations of rising ICP from nurses or medical staff in ICU until his apparent 'brain death' and her suffering was unnecessarily increased. She used alternative informal information channels but as these were medical contacts outside the unit and they did not know the specifics of the case, nor were they specialists in neuro surgery, they could only offer moral support.

By contrast, Harry received regular updates about his mother's care and condition throughout her illness from the medical staff as her Necrotising Fasciitis developed. Harry and his family seemed to have been well informed and well prepared for decision-making, ameliorating their suffering to a degree.

Importantly, if relatives do not receive these information updates in a timely manner, there is a danger that when they do finally realise what is happening, they may feel betrayed and angry or become profoundly shocked by the events unfolding around them. When Sandra was informed of Grant's 'brain death' she describes a visceral response to the shock, while her brothers became angry, railing against the doctor who '*did this'*. Lloyd too, whose partner's bleeding oesophageal varices required her transfer to ICU, was only informed of this problem as she was swept past him out the door (yet oesophageal varices are a predictable consequence of liver damage and varices often bleed). He was still shocked into silence as he remembered the episode several weeks later during interview. This aspect of relatives' distress could be ameliorated through the adoption of the previously made **recommendation that: All relatives should receive regular, accurate updates regarding their family member's condition, care and prognosis throughout their time in critical care.** This recommendation too could lie within the purview of the designated Liaison nurse – to be expanded in recommendations shortly.

9.1.1.1.2.3 Seniority of contact person:

If the information relatives do receive is not accurate or is couched in terms which they cannot understand, then they are unlikely to find this either trustworthy or useful when participating in decision-making. In this study, the ability to impart quality information seemed to be directly related to the contact person's seniority. Senior staff are empowered to deliver the relevant information. If, however, the contact person does not have a strong enough knowledge base, information may be erroneous and if their experience is limited, their communication skills may not equip them for the challenges of these situations (delivering bad news, assessing knowledge bases & understanding in the listener, dealing with anger and aggression). Azoulay, Chevret, Ponchard et al (2000, 2002) reported similar findings, attributing relatives' inadequate comprehension of patients' illness and care to deficiencies in physicians' experience and consequent poor communication.

Harry indicated his increased satisfaction with the communication skills of the more senior intensivist in his experience, contrasting his patient/ caring approach with the '*blunt'* approach of the younger registrar they dealt with. This senior registrar/ intensivist who Harry noted to be 'a bit older' took the time to ascertain the family's base knowledge and then he used terminology understandable to the family. Harry found the use of 'percentages' by the intensivist as a demonstration of his mother's prognosis to be a useful tool:

> *Thinking back on it - I think possibly [they used the percentages] to give us an idea of what was happening with her and I think - it was a way of saying the chances are more against than for and it was possibly better for them to talk in percentages rather than saying, "it odds on she's going to die."*

This is also a tool which two of the doctors indicated they found useful in discussions with relatives (Henry and Paul - chapter 8). The use of language was an important point in Ruth's case too as her mother-in-law's cerebral aneurysm was diagnosed and its sequelae dealt with. The explanation of 'brain death' as, *"Every part of Marg that you know is gone – every part of her you know is gone!"* is a clear, though possibly harsh, explanation which, nonetheless Ruth felt, '*…made the* *decision for them'*. In Sandra's experience, it may have been the inexperience of the nurses in recovery and ICU that affected the dearth of information she received (or it may have been that they did not feel empowered to speak).

Recommendation 3: This dissertation recommends creating learning experiences about communication skills related to ELDs and bad news and that these be incorporated within the curriculum of all health professionals.

9.1.1.1.2.4 Venue:

When HCPs do talk to relatives about their family members' condition and treatment, if this occurs in at the bedside, in the corridor or on the way out the door of the unit, then discussion held in this impromptu context in a public area will not be conducive to quality communication from either party. The issue of provision of 'structural' privacy or its need is not an area that has met great attention in contemporary research as yet although Ponchard, Azoulay, Chevret, Lemaire, Hubert et al (2001) in a quantitative multi-centre trial found that depression and anxiety were directly linked to absence of a dedicated room for family meetings together with the absence of regular meetings with medical and nursing staff to obtain updated information on their loved ones. They further suggested that the anxiety and depression experienced by the families might impair their abilities to make rational and ethically acceptable end-of-life decisions. It should be noted though that all these researchers were medical intensivists who might have had some investment in maintaining control over the decision-making process.

With the exception of Ruth and her family, all communication between family and HCPs occurred in public venues. The rushed, possibly noisy environment of CC and the entrances to these areas is likely to interfere with people's attention. Moreover, relatives, given the impression that the doctor is stressed or hurried, are unlikely to question information they have not understood. Finally, public communication venues have the effect of constraining relatives' free expression of emotions, increasing their stress and reducing their copping skills. If, however, a dedicated quiet area existed for discussion between HCPs and relatives, the ambience would be more conducive to quality interaction while preparation for the actual interaction (shepherding relatives to this area and sitting down together) should focus those involved on the interaction in hand.

Recommendation 4: all CC areas should have a dedicated area for private discussion between health professionals and relatives. It should have comfortable seating and an X-ray viewing box to allow doctors to illustrate their explanations.

9.1.1.1.3 Meeting Basic needs

If relatives have to wait in the corridor or the annex by the entrance to ICU, then they wait in public and their suffering is amplified as their grief and inter-personal communication is open to public display or is closed off entirely. None of the relatives in these stories was afforded the comfort and privacy of a dedicated waiting space during their experience. Most of them spoke of sitting ‘outside’ ICU or X-ray while they waited to speak to HCPs or waited for their family member to return from theatre or tests.

At the same time, if they sat beside the bed on their own for hours, with busy clinical staff moving around them watching the machines and their loved one, they were likely to feel lonely and unsupported. If they had to go and find themselves a cup of coffee or tea or look for a public phone to call family or work, then they were unsupported at this difficult time. They felt isolated and their anxiety and their grief was exacerbated. Already stressed and feeling helpless, relatives who have to then try meet basic needs are likely to drain their own coping resources This distress was recognised by Mendonca and Warren (1998) and referred to as the ‘vortex’ by Kirchhoff et al. (2002).

Many relatives spoke of finding themselves refreshment while they waited for news; waiting in public places for long periods. Harry, for example, spoke of the family arranging their own motel accommodation during his mother’s illness. His tale of finding his father in tears on the public phone in the hospital foyer illustrates the added unnecessary suffering relatives may experience if measures are not taken to meet their basic needs.

Recommendation 5: a private dedicated room should be provided for the comfort of relatives of ICU patients (specifics to be expanded shortly). This area should be separate from the previously mentioned meeting room to afford privacy to those involved in discussions/ decision-making.

9.1.1.1.4 Meeting Emotional and Spiritual needs

When relatives receive news from doctors, family suffering will be minimised if a compassionate nurse is present. The nurse's presence may lend emotional support to the relative at the time and may facilitate later reiteration and explanation of points that have not been clear. It also allows the nurse to know exactly what has been said to the relative thereby providing grounding for future explanations and insight into the relative's possible needs for social, emotional and spiritual support. This is perhaps a role that could devolve to the previously mentioned Liaison nurse. The nurses involved in direct care for the patient would however, have an investment in participating in this discussion if they are to effectively support the relative at the bedside and participate in later decision-making. It is important though that the nurse in this position be able to display and convey genuine empathy and emotional support when needed. If this does not happen and the nurse is perceived as witness (Sandra and her husband with the rising ICP), distant (Hannah and her father with the early diagnosis of brain death), their presence may augment rather than ameliorate the relatives' discomfort during the interaction.

If, however, relatives are included in the ELD process but left unsupported either by family or the HCPs involved, then the absence of emotional, spiritual, informational and social support at this time is likely to drain the relatives' coping skills and add to their suffering. When a decision has been made to withdraw treatment and/ or a patient is dying in the CC environment, provision should always be made for social work and pastoral support for the relatives involved. If the relative is not supported; if they are left alone at the beside or in the hospital corridors and annexes as withdrawal occurs and in the minutes or hours as the patient dies, then the relatives may feel discarded, lonely and isolated. The relatives contributing to this study experienced varying levels of support during and after decision-making. Ruth and Harry both spoke of pastoral carers being present although this was something Harry's family had arranged for themselves. Hannah noted the absence of a comforting arm or shoulder to cry on during her horror as her father unexpectedly fought to breathe. Sandra's decision-making experience was particularly lonely in that she received no support from staff or family. These findings were supported by research internationally. Warren (1994) in the United States of America, Furukawa (1996) from Japan, Mchaffie (1996, 1997) in Scotland and Burr (1996, 1997) in Australia all found that spiritual and emotional needs (more often than not unmet) were cited by relatives as a source of stress and distress when their loved one was needing critical care(Mendonca et al (1998). More recently, Azoulay et al. (2000) and later, publishing as Ponchard et al (2001) in France demonstrated that the spiritual and emotional needs were still not being met for relatives of intensive care patients.

Recommendation 6: Nursing staff 'should' be able to lend emotional support at the bedside during treatment withdrawal and a patient's death but at the same time, all CC units should have a specific policy requiring that a minister of religion or pastoral care officer be contacted and invited to be present to support relatives during this period if the family wishes.

The clinical staff themselves require support at these times and this issue will be discussed very shortly.

Once the patient's treatment is withdrawn, there is no need for monitoring and the slowing 'blip' of the patient's heart rate on the monitor screen confuses relatives, extending suffering unnecessarily. Ruth's story exemplified this phenomenon. She found it '*awful'* to have to sit with a younger cousin who would not believe her mother was dead until the monitor flat-lined.

Recommendation 7: All CC units should write into their policies that bedside monitors be turned off or removed once treatment is ceased.

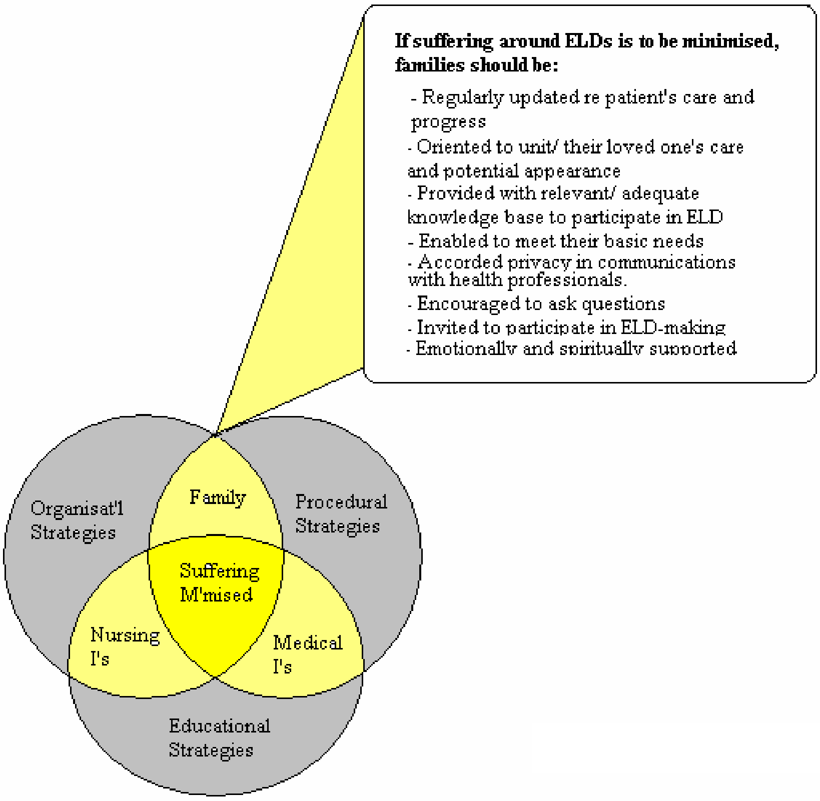
9.1.1.1.5 Decision-making

9.1.1.1.5.1 Sharing in decision-making

If the family have not been invited to participate in decision-making, then they are most unlikely to fully concur with the decision reached or be ‘happy’ with the final outcome of their family member’s care. This may manifest as long-term guilt and grieving or it may manifest as public disagreement/ fighting to change the decision both in the middle of ICU and through the court as transpired in the Messiha case (Jones, 2004). These findings are echoed in the work of Prendergast and Puntillo (2002) who also suggested that an ‘inclusive’ consensus approach (especially related to withdrawal of treatment) reduced confusion and anger. In this study, Stephanie, (whose mother’s final collapse in heart failure had been precipitated during care for Stephanie’s invalid father) was included in decision-making from the outset by virtue of her close association with the health facility. Although the exception to the rule here, this should perhaps become the benchmark for ELD-making in CC.

Recommendation 8: The family of patients in CC should be invited to participate in all ELD-making. In order that they may do this in a fully informed and supported manner, and so that the nurses and doctors involved in this decision are similarly supported and included, the optimum context for ELD making would be a shared or ‘case conference’ scenario.

Figure 9.2 Minimising Family Suffering



If suffering around ELDs is to be minimised, families should be:

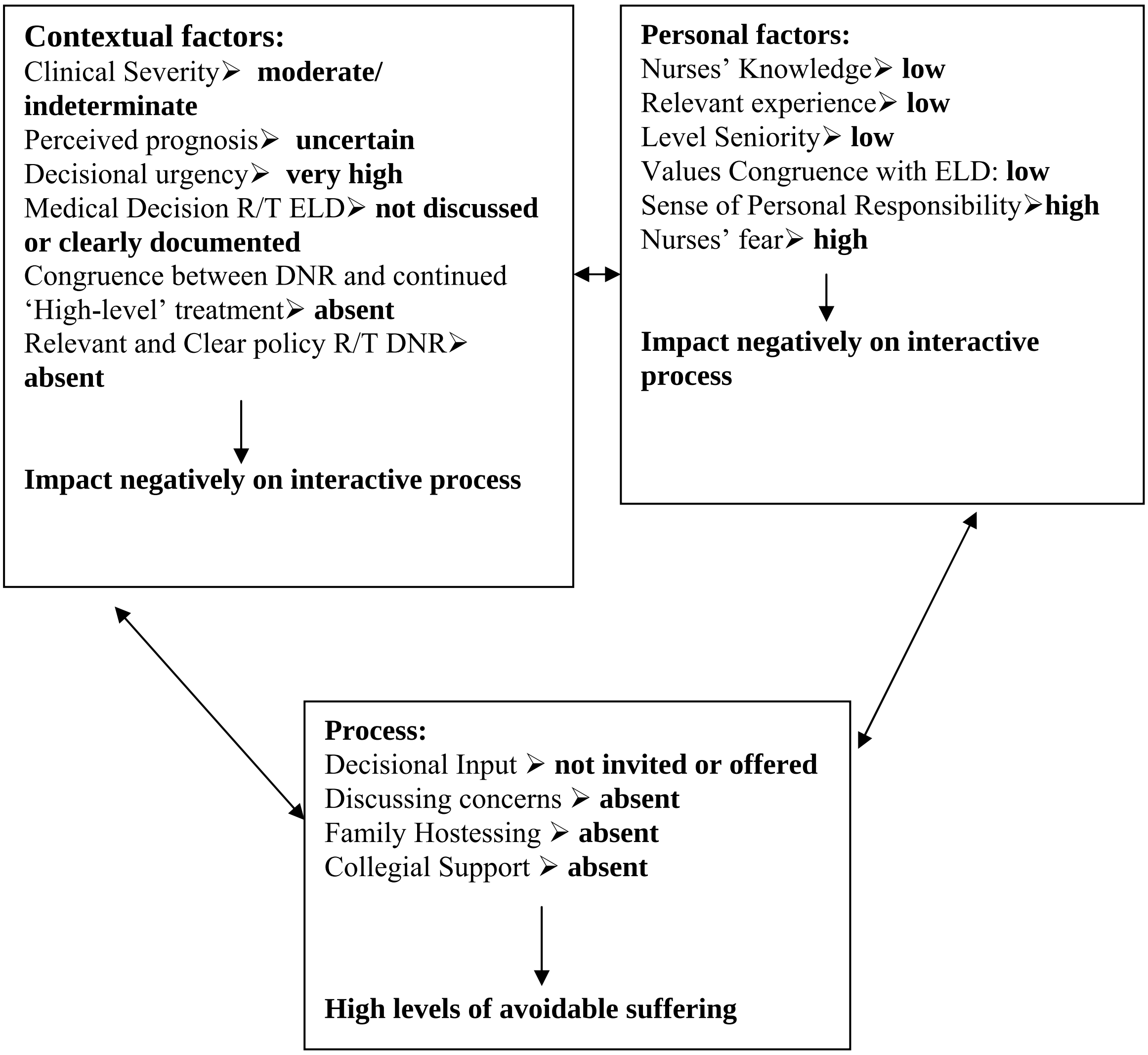
- Regularly updated re patient's care and progress
- Oriented to unit/ their loved one's care and potential appearance
- Provided with relevant/ adequate knowledge base to participate in ELD
- Enabled to meet their basic needs
- Accorded privacy in communications with health professionals.
- Encouraged to ask questions
- Invited to participate in ELD-making
- Emotionally and spiritually supported

Summary:

If the recommended strategies and procedures are adopted, then the experience of ELD-making for relatives in the critical care environment should proceed as summarised in figure 9.2. If ELD-making in the critical care environment occurs within this supportive framework, then avoidable suffering should be minimised for the relatives involved. At the same time, HCPs working to implement these steps within a supportive framework should find their own related suffering minimised as the following discussion outlines

9.1.1.2 The Nurses

Figure 9.3 ELD-making from nurses' perspective



When considering the perspectives of the nurses involved in of ELD-making (figure 9.3), the process and its impact as represented by the nurses contributing to this dissertation may be subsumed into five higher order categories:

- The fear factor
- Policies

- Discussing concerns
- Family Hostessing
- Decision-making

9.1.1.2.1 The fear factor

From the perspectives of all the health professionals in this project, there were some contextual factors that impinged directly upon their decisions and decision-making experiences. These were not factors that could themselves be modified, yet they significantly contributed to the nurses' sense of responsibility and fear in decision-making.

9.1.1.2.1.1 Clinical severity

If the severity of a patient's clinical condition is not easily determined, then decision-making for the nurse is fraught with ambiguities and possibilities that cannot be clarified until the patient's condition evolves (e.g. the evolving head injury). A decision made at this juncture carries increased responsibility and the associated suffering may be increased.

9.1.1.1.2.1.2 Perceived prognosis

Any uncertainty about a patient's prognosis, must be considered in conjunction with clinical severity, and adds to the challenges and suffering around ELD-making. In effect, when nurses are confronted by a patient whose clinical condition is extremely severe and whose prognosis is extremely poor, then there is certainty about their outcome. With certainty ELD-making is likely to be less challenging and the associated suffering reduced even though the situation itself will be sad. Uncertainty, on the other hand increases decisional ambiguity and the related suffering associated with decision-making

9.1.1.1.2.1.3 Decisional Urgency

ELDs did not always occur in contexts allowing prolonged consideration of the patient's clinical severity and prognosis (Camille and patient with complex history and multiple arrests). If the decision was made urgently-before all the facts could be gathered and considered, then the picture was further 'obscured' for the nurse, whose sense of personal responsibility and level of fear was very high, increasing suffering (Nurse in coronary care ambivalent about NFR order). Ideally then, as far as possible, ELDs should not be made under pressure of time and a 'conservative' decision taken at the time. The challenge here though is what constitutes a 'conservative' decision and this is the nub of the challenges around ELD-making. Making a conservative decision generally means the safe decision for the health care professional – resuscitate and deal with the consequences later. Nurses in this study expressed anger and frustration when this was done.

9.1.1.2.2 Policies

The level of perceived responsibility and associated fear experienced by nurses involved in ELD-making might be ameliorated if they perceived themselves to be supported.

One foundation upon which this support might be based is clear policies. In the absence of clear policies directing the nursing and medical interventions and decisions discussed in this study, nurses experienced and displayed frustration, ambivalence and lack of collegial support.

9.1.1.2.2.1 Not for resuscitation orders

The most significant area of policy that needed addressing related to DNRs. Nurses complain that there is no clear policy outlining:

- How DNR's should be documented
- How this information should be passed between staff from shift to shift
- How the patient should be cared for following documentation of DNRs
- How this issue should be discussed with family

then ambivalence about the existence of a DNR for a patient in critical care may lead to the situation that developed in the scenario Camille recounted where nursing ambivalence and a new registrar in the unit resulted in the countermanding of an existing DNR. This finding was echoed by research in Canada (Thibault-Prevost et al. 2000) in a survey of four-hundred and five critical care nurses found at the time that clarity of documentation and poorly articulated rationales for DNR orders caused confusion and the perception that patients and relatives were suffering.

In the case of DNR orders, these will be confusing if the order is not clearly passed on from shift to shift, both between medical and nursing staff. This might be best achieved through the use of some special large stamp on the front of the patient's notes, but, once a DNR has been documented for a patient, their continuing presence in the CC unit seemed incongruous to most nurses and doctors, causing ambivalence about future treatment should the patient arrest.

Recommendation 9: DNR decisions should be documented uniformly, (clearly and conspicuously) throughout the health care facility, possibly signified by a large bright stamp in the patient's notes which can be 'filled in' by the designated HCP .

Recommendation 10: Once a patient has a documented order for 'no further resuscitation' or no CPR then a uniform process of communicating this formally between shifts and between health care professional should be written into CC policy.

Recommendation 11: Once a patient has a documented order for 'no further resuscitation' or no CPR, then that patient should be moved to a private room in another ward (or a side room in the unit) and this should be written into CC policy.

This move would also avail the relative and their family of privacy.

9.1.1.2.2.2 Clinical Supervision

Nurses wanted to initiate discussions about treatment decisions they found concerning, and they wanted to participate in decision-making but they felt silenced and excluded. There were occasions when referral to senior clinicians for support or help was advisable. If they are not aware of the lines of referral/ clinical supervision available to them, then their perception of their personal responsibility/ related fear is likely to be very high. At the same time, uncertainty (or ignorance) of the support available to them when troubled by a line of treatment or a decision is likely to reduce the likelihood of timely challenges and increase the likelihood of unnecessary suffering for patient, family and nurse.

There were times in many of the stories told by these nurses that referral to a senior nursing colleague might have helped. In Jill's case, distressed about the continued treatment of the patient in ICU whom she described as a 'ventilated corpse', she could have asked her nurse supervisor for advice/ assistance. This person in turn, could have asked the medical director of the hospital to speak to the specialists who persisted in treating their friend and colleague. Bernadette could have enlisted assistance from the nurse unit manager, as an objective senior, voice to suggest resuscitation of the aboriginal woman with the global infarct had persisted long enough before 3 hours had elapsed.

Recommendation 12: All hospital policy manuals should include an 'organisational structure' flow chart outlining options for referral when concerns arise regarding a clinical situation.

The phenomenon of horizontal violence both within nursing and across the health care professions is well recognised (Wicks, 1998; Sundin-Huard & Fahy, 1999; Manias, 2001). It is not inconceivable that referral of frustrations rather than concerns could be used as a threat or that overuse of this mechanism could be used to browbeat less resilient members of staff. This tendency could be reduced through emphasis upon the aims of this policy during orientation and education. At the same time, in recognition of the reality of workplace politics, some form of monitoring and formal grievance procedure should be adopted at unit and healthcare facility levels. **Orientation to the hospital and then to critical care should include provision of a hard copy of this flow chart and discussion of the importance to staff and**

patients of its use (i.e. optimal patient care; enhanced communication and support rather than a potential vehicle for horizontal violence).

9.1.1.2. 3 Discussing Concerns

9.1.1.2.3.1 Collegial Support

If nurses do not proactively engage with their medical colleagues, discussing concerns and offering support, then they are unlikely to receive support in return. We read of nurses complaining of having to 'play the game' to exist comfortably with their medical counterparts (Warelow, 1996; Wicks, 1998; Manias, 2001) but the nurses in this study were noticeably unsupportive of their medical colleagues, despite being aware of their personal histories (Camille's account of the registrar's fixed ideas with respect to CPR; Jill's account of the specialist's sad experience of unsuccessfully truing to resuscitate his own child). This would possibly have been because the nurses themselves were distressed, but in ignoring or not recognising the contribution of their colleagues' own distress to the unfolding situations, these nurses themselves contributed to the suffering occurring for themselves and others. Similarly, nurses who do not invest in supporting their nursing colleagues are unlikely to receive meaningful support from that direction. Peta for example found the 'joke-telling' of her nursing colleagues singularly painful.

9.1.1.2.3.2 Timeliness of discussions

If nurses do not raise their concerns early enough with their medical colleagues, ELDs may be left too late because of emotional entanglement, fear, past personal history or similar personal factors. Further, if a particular nurse's values are not congruent with the ELD that has been made, then he or she is likely to suffer frustration, anger and even grief in response to the decisions made. The stories told by nurses in this study reflected a nursing tendency to 'brood' on the issues that troubled them (Jill, who waited until exasperated by the situation with her patient on extraordinary levels of inotropes), or to discuss issues within the cliques in the unit: *"None of the nursing staff talked to the consultant [about this decision]. In this unit you can't say too much - sure we talk amongst ourselves and to the residents and registrars".*

Recommendation 13: All health professionals' education should include training in inter-personal and intra-professional communication techniques.

Recommendation 14: To promote discussion of 'concerns' between disciplines, regular 'sit-down' case discussions should be held in the designated communication room mentioned earlier, perhaps at the change of afternoon shifts. This should be written into policy so that relief can be found for the registrars involved.

9.1.1.2.3.3 Level of seniority

Level of seniority significantly contributed to the nurses' ability to communicate effectively with family and colleagues. If the nurse involved in an ELD was new to the unit and also relatively inexperienced, then they were unlikely to have a strong enough knowledge base to assess the decision-making situation accurately and comfortably. If this nurse also happened to be 'in charge' of the unit for that shift (eg Bernadette's experience when caring for the aboriginal woman with the global infarct), it was unlikely that he or she was able to cope with the demands of the situation and provide for the emotional and informational needs of the family. Kennard, Speroff and Puoplo (1996) who analysed the data from 696 nurses contributing to the SUPPORT trial mirrored the above finding. They reported that nurses were more likely to be involved in decision-making and having discussions with the relatives in relations to these decisions if they: were 'older', had more that five years' experience and had 'more' education.

Recommendation 15: In small CC units (i.e. two staff on at night), one staff member should have at least six months experience in that unit so that they are aware of policies, procedures and decision-making processes.

Recommendation 16: All CC staff should be 'work-shopped' through ELD scenarios at orientation and throughout the year. These scenarios should be drawn from 'real life'

9.1.1.2.4 Family Hostessing

9.1.1.2.4.1 Meeting family needs

Nurses need to be supportive and sheltering of the relatives who find themselves with loved ones in critical care and possibly confronted by ELDs. Relatives need to be relieved as much as possible of extraneous stresses (i.e. provision of physical comfort) so that they may deal 'best' with the crisis at hand. When faced by the emotional & spiritual challenges of ICU & their critically ill relatives – they need support or facilitation of that support. At the same time, their needs include the clear and adequate information previously discussed so that they a) actually know a decision is impending and, b) are prepared/informed to participate in that decision. Nurses need to supply this information and/ or make sure this supply is facilitated. If and when a relative is distressed/ shocked/ suffering & can't question for some reason, the nurse needs to be there for them and advocate/ support/ encourage questioning. The process of meeting these needs might be broadly conceived under the banner 'Family Hostessing'. To assist and facilitate in this process, CC nurses would recruit the assistance of the facility's social worker and pastoral care worker, but out of hours the responsibility will devolve to the nurses.

9.1.1.2.4.2 Liaison nurses

Nurses perceiving themselves to work in isolation or worse, against powers that constrain their inclusion in decisions, may not have the energy to consider the basic needs of the relatives around the patients in their care. This is a vital aspect of CC nursing that can enrich the nursing experience when practiced effectively. The recommendations regarding education in communication techniques and 'sit-down' case discussions should address these issues in some measure. These elements of '*family hostessing*' are most important to the family just at the time when the nurse is also stressed and so this is why I suggest

Recommendation 17: All CC units consider the incorporation of one or two Liaison Nurse/s per shift within their staff profile depending upon their size:

The nurses, whose role, qualifications will be discussed in recommendations in detail would augment rather than replace the family hostessing aspect of the 'bedside' nurse.

9.1.1.2.5 Decision-making

9.1.1.2.5.1 Participation

If nurses are not invited to share in the process of ELD-making or do not proactively participate by voicing and discussing their concerns with their medical colleagues, then nurses will continue to feel excluded from decision-making, doctors will continue to feel burdened by the sole responsibility of the decision and ELDs may lack the balance multiple voices can bring to these difficult situations.

Recommendation 18: All health professionals significantly involved in a particular patient's care should be invited to participate in an ELD meeting and have their opinion sought (consideration should be given to numbers in a room).

9.1.1.2.5.2 Documentation

Once an ELD has been discussed and reached, uncertainty will continue if this is not unambiguously documented in the patient's notes.

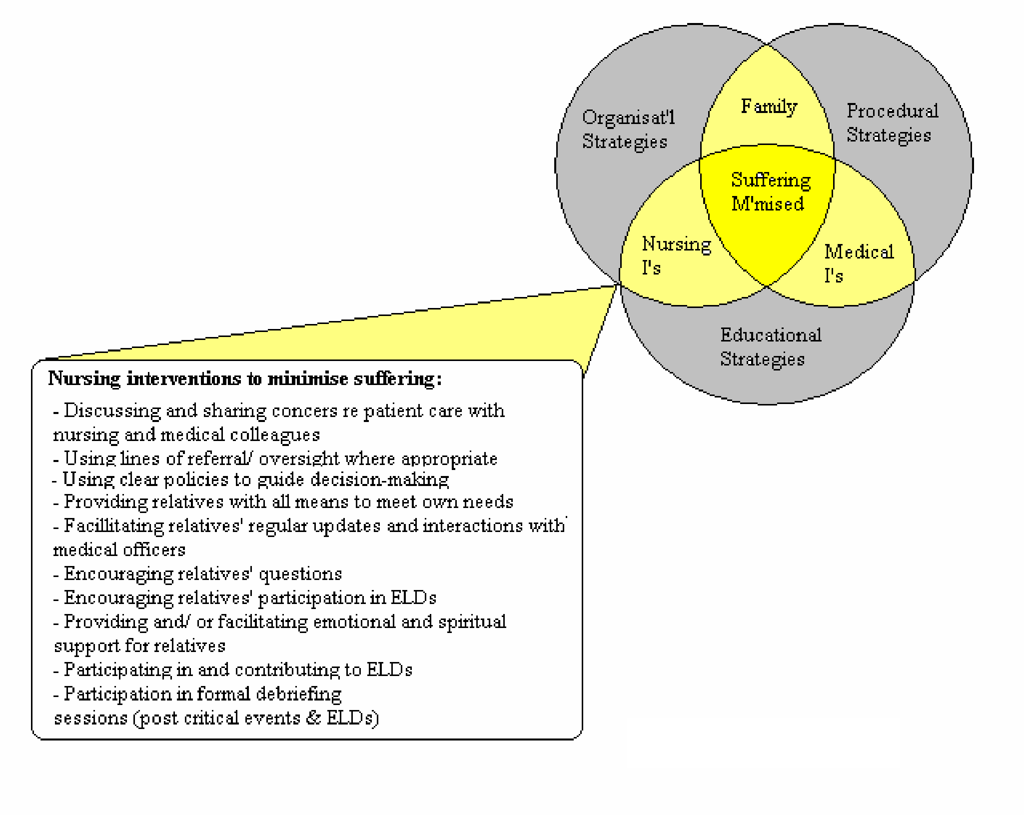
Recommendation 19: All ELDs should be clearly documented in the patient's chart together with specific criteria where necessary eg 'may have oxygen but not to be ventilated'.

9.1.1.2.5.3 Support and debriefing

Finally, nurses need support during and after the ELDs that are made. If they are included in the case discussions and ELD's in a shared conference context, then an increased level of support should exist for all HCPs involved in these decisions.   All the nurses contributing to this study though, clearly carried long-term unresolved grief and/ or resentment related to their experiences. Telling their stories had been a means of catharsis (many cried, some curled up like babies as they talked) and seemingly the only means of debriefing or support following their experiences had been informal discussions with colleagues in the various units. Camille (resuscitation after documented DNR) and Jill (long-term ventilation of 'corpse') for example spoke of the staff talking about their incident 'for weeks' afterwards.

Recommendation 20: All critical care units should consider introducing formal debriefing structures for all their clinical staff to be held following critical incidents and withdrawal of treatment.

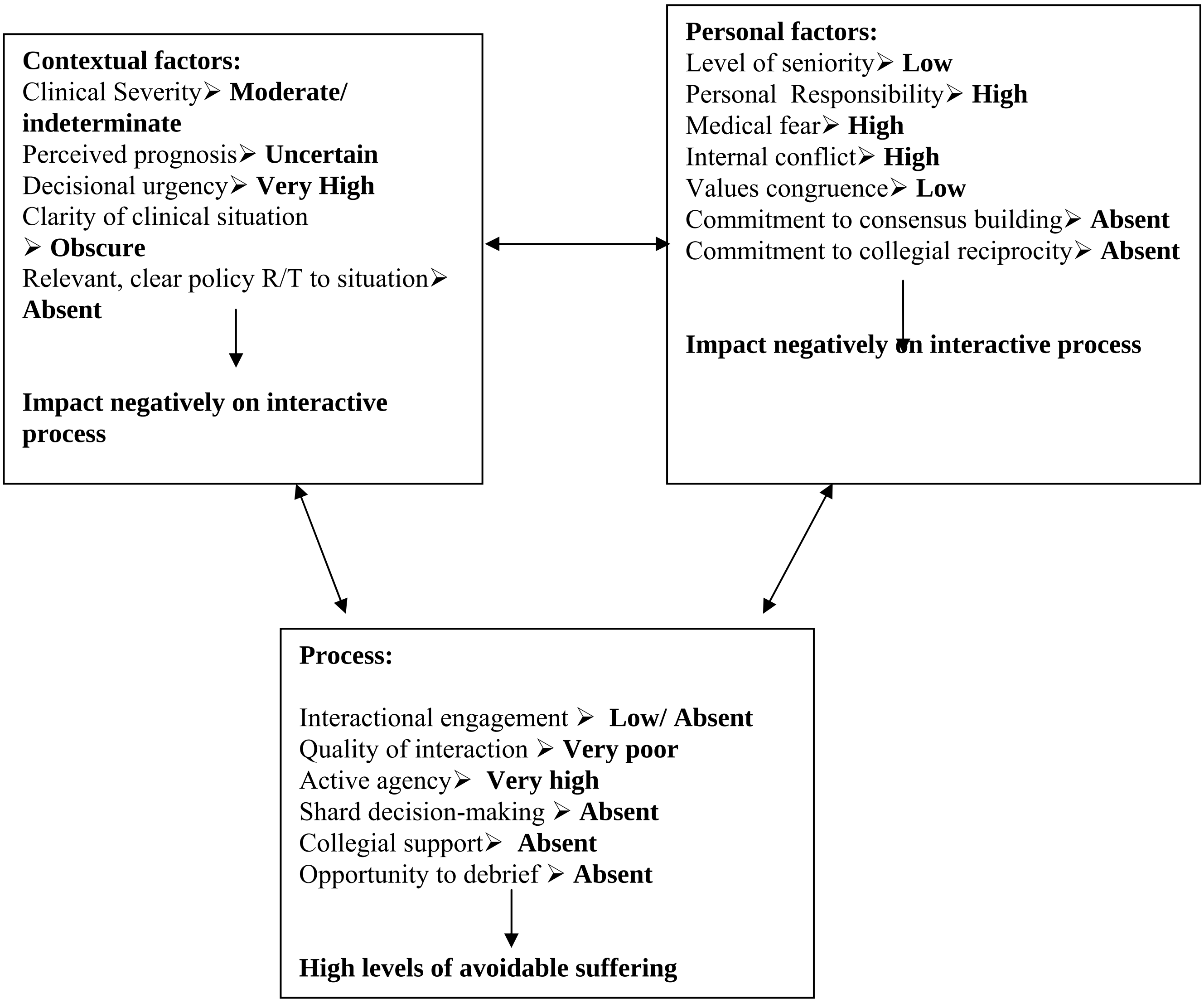
Figure 9.4 Nursing Interventions



Nursing interventions to minimise suffering:

- Discussing and sharing concers re patient care with nursing and medical colleagues
- Using lines of referral/ oversight where appropriate
- Using clear policies to guide decision-making
- Providing relatives with all means to meet own needs
- Facillitating relatives' regular updates and interactions with medical officers
- Encouraging relatives' questions
- Encouraging relatives' participation in ELDs
- Providing and/ or facilitating emotional and spiritual support for relatives
- Participating in and contributing to ELDs
- Participation in formal debriefing sessions (post critical events & ELDs)

Summary: Figure 9.4 summarises the process of ELD-making from the nurses' perspectives 'as it should happen' if suffering is to be minimised. When nurses are appropriately supported and empowered, they are then able to facilitate the empowerment of the relatives of the patients in their care. Adoption and application of the policy recommendations outlined in the preceding discussion will also allow the nurses to facilitate the empowerment of their own nursing and medical colleagues (see summary diagram, figure 9.6, page 317).



9.1.1.3 The Doctors

Figure 9.5 ELD-making from doctors' perspective

When considering the perspectives of the doctors involved in of ELD-making (figure 9.5), the process and its impact as represented by the nurses contributing to this dissertation may be subsumed into four categories:

- The fear factor
- Policies
- Communication
- Support and debriefing

9.1.1.3.1 The fear factor

9.1.1.3.1.1 Clinical condition:

When involved in ELDs, doctors too are affected by the clinical severity and prognosis of the patient. An indeterminate clinical picture in terms of severity and prognosis makes decision-making increasingly challenging. Many factors might be affecting the patient's condition and should be ruled out before proceeding. In such cases, time would clarify these uncertainties but by then the clarity often reveals the clinician's worst fears. This is why there is so much suffering around these decisions.

9.1.1.3.1.2 Decisional Urgency:

If the ELD involves an element of urgency, this increases the difficulties and suffering for the doctor, particularly if they do not have any supporting information at the time. Gavin was placed in this position when, as a registrar, he arrived in the birth suite to be confronted by a miscarrying mother with no background information other than the child's gestational age. Although Gavin was a specialist at the time of interview and confident of his practice and ability, he still harboured some measure of 'guilt' about the decision made as a registrar.

9.1.1.3.1.3 Active agency:

If the situation also involves a high degree of active agency and personal responsibility, then the level of fear for the doctor involved will be raised and their suffering increased. Thus when placed in such a position, conservative treatment of a potential ELD is likely to be accompanied by a reduced measure of suffering. Conversely, not actively resuscitating a patient e.g. the 'miscarried' infant in Gavin's narrative carries a high degree of moral agency and just as this decision troubled him, absence of action in these situations carries its own measure of responsibility.

It is this responsibility and the potential repercussions of inaction that results in the ambivalence or entrenched attitudes seen in Camille's story, leading to the turning aside of a patient's expressed wishes and documented DNR.

9.1.1.3.1.4 Seniority:

If the doctor involved in the ELD process is relatively junior and therefore aware that the decision made is likely to be scrutinised by seniors upon whom professional progression depends, then the level of fear and suffering associated with ELDs is raised. Further, when the sequelae of an ELD is treatment withdrawal, if this aspect of the ELD is also left to the 'junior registrar' without clinical supervision, their level of fear will be raised and their actions when confronted by unexpected circumstances, may be inappropriate or worse. The registrar in Hannah's story appeared to suffer from lack of clinical supervision in her approach to the unexpected situation unfolding before her as her 'brain dead' patient fought for breath (a second or senior colleague may have said "*I think we've made a mistake hear – Bill is not brain dead*"). **As per recommendation 13: Policies in all CC units should outline 'organisational structure' for medical officers to refer to when requiring professional oversight. There should always be two CC medical officers or one critical care medical officer and an anaesthetist in the unit during extubation of a patient for treatment withdrawal.**

9.1.1.3.2 Policies

As was the case for the nurses, the presence of clearly documented policies should support decision-making for the doctors, relieving their sense of personal responsibility to some extent and thus the related level of suffering. Gordon (cared for young man found face down in water in his car) found the presence of clear clinical guidelines were essential both in his own decision-making and in the broader picture when rationalising resources:

> *You have to have those things [protocols]. You have those brakes because if I was to become the judge in those situation where you have a certain number of beds and an enormous demand for those beds and people actually have to weigh up the*

> *chances of the ventilated patients against the [hypothetical] young chap down in A&E needing a ventilator [what do you do?]*

By contrast Gavin did not have any procedures or protocols to guide him and this may have been a factor adding to his suffering.

Recommendation 21: All critical care units should develop and maintain clinical procedure/ protocol manuals specific to their area (in hard and electronic copy). Staff should be made aware of these manuals on orientation and their knowledge updated and evaluated regularly.

9.1.1.3.3 Communication:

When the doctor involved in the care of a patient had no commitment to including the family in decision-making, in fully informing the patient and building towards a consensus decision, then the family was less likely to be in full accord with one another and with the ELD the doctor 'advocated'. The family was likely to be confused, angry and the ultimate outcome was likely to be increased unnecessary suffering for all. This was especially the case if the nurse/s involved had not been keeping them updated. Gordon, Henry Paul and Murray all gave examples of caring, empathic communication with relatives, although Paul and Henry gave the impression of wanting to 'persuade' the relatives to a particular decision rather than working to reach consensus. Max, on the other hand gave the impression of a very gruff, abrupt approach to interactions with relatives (poorly resuscitated patient from private hospital). This was possibly due to his relative youth or reflective of his chosen career path: ED specialist.

If discussion about a patient's clinical condition occurs in a private, 'sit-down' context, then, as previously discussed, meaningful/ useful interaction is more likely to occur. While preparation for and participation in this form of interaction may initially be perceived as time consuming, the potential long-term benefits of understanding, concord and consensus between all decision-makers is likely to be time-saving. Most importantly perhaps, as previously mentioned, relatives are likely to feel empowered within this process. Thus as previously recommended: **Everyone significantly affected by an ELD (i.e. families, nurses and doctors) should be invited to participate in discussion related to the patient's condition. The role of the liaison nurse will include facilitation of formal interactions between relatives and doctors. The designated liaison nurse should attend these in order to answer follow up questions and interpret clinical language where necessary.**

9.1.1.3.4 Support and Debriefing

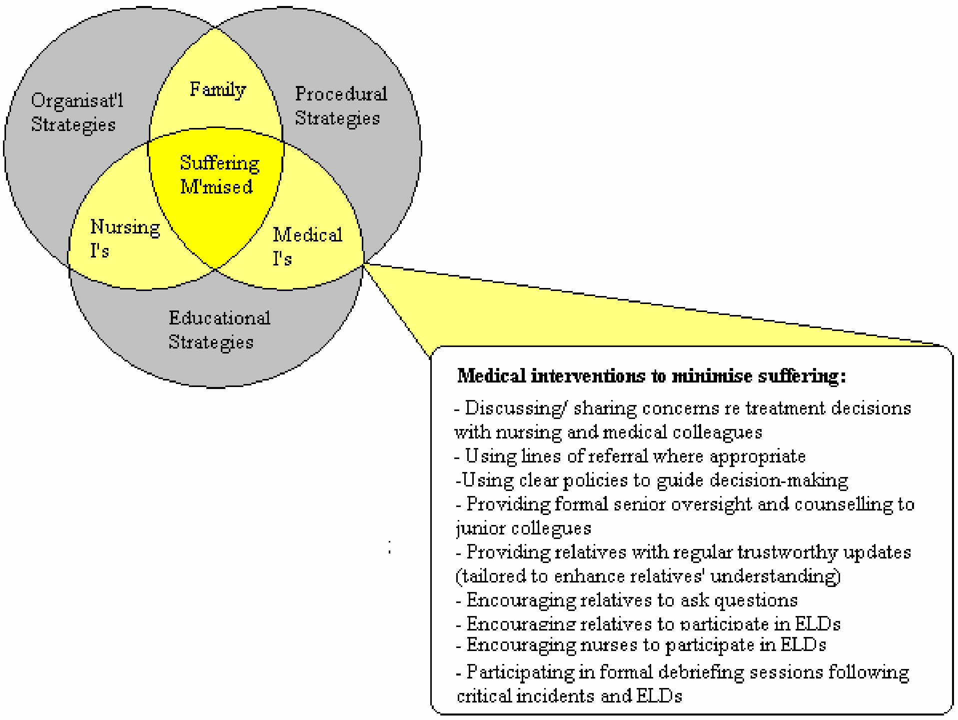
The absence of collegial support or formal debriefing was a significant issue adding to the suffering for the doctors who contributed to this study. Max (with the poorly resuscitated old man in the ED) specifically spoke about this issue:

> *No one talks to us about it, ever. We get zero debriefing. I get angry that there's absolutely no support for my staff or me. It's got to be meaningful. I'd like another specialist. That's what I want, someone who understands, someone I can talk to.*

Several doctors used the interview for this project as a cathartic process. Gordon (with young man found face down in ditch after MVA) talked for three hours as he explored issues that troubled and challenged him. Murray (spoke of dealing with diagnoses of 'brain death') outlined the strategies he had put in place to cope alone with the stresses related to his practice. The absence of support, debriefing and its impact themselves or the profession tends to be discussed *in camera* by the medical fraternity but its public expression has been seen a little more of late (Smith, 2001; Kmietovicz,2002; Allen, 2005).

For the doctors engaged in ELDs there will always be some personal factors such as their own personal history and values that will impinge upon their decision-making. Where the decision challenges the doctors' values and is also likely to involve a high level of active agency, then this is likely to cause great internal conflict, and a perception of intense personal responsibility and fear. These factors themselves can not be modified but their impact upon the doctor and the patient might be ameliorated if the doctor's colleagues (nursing and medical) lend some support through timely collegial discussion and sharing of decisional burden. This process will hopefully be facilitated when the recommendations regarding communication and relevant education are put in place. At the same time, peer debriefing both throughout and after the event, should allow the medical officers to feel supported in their decision-making. Thus empowered, they in turn will be able to empower the families in their care and their HCP colleagues (see summary figure 9.6).

Figure 9.6 Medical Intervention



Medical interventions to minimise suffering:

- Discussing/ sharing concerns re treatment decisions with nursing and medical colleagues
- Using lines of referral where appropriate
-Using clear policies to guide decision-making
- Providing formal senior oversight and counselling to junior collegues
- Providing relatives with regular trustworthy updates (tailored to enhance relatives' understanding)
- Encouraging relatives to ask questions
- Encouraging relatives to participate in ELDs
- Encouraging nurses to participate in ELDs
- Participating in formal debriefing sessions following critical incidents and ELDs

9.2 CONCLUSION

This project has answered the question, *"How might avoidable suffering related to the process of decision-making that accompanies the implementation, maintenance* *or withdrawal of life-sustaining treatment in the critical care environment be ameliorated?"* In the preceding chapters, relatives', nurses' and doctors' experiences of ELD-making have been unpacked in an effort to understand the process of ELD-making, the interactions between the key decision-makers, and those aspects of the process that were amenable to change if avoidable suffering were to be minimised for those involved. The thesis that this study has argued to support is that: *unnecessary suffering for families, nurses and doctors in critical care related to end-of-life decision-making can be minimised through a combination of nursing and medical interventions when they are supported by appropriate organisational, procedural and educational strategies.*

The first section of this chapter acknowledges the limitations of this study and discusses its strengths. The following section revisits recommendations made throughout the previous discussion, expanding where appropriate and adding recommendations for research. The chapter and dissertation will end with closing comments.

9.2.1 Strengths and Limitations of this research

This study has examined ELD-making from the perspectives of all decision-makers and thus developed a multi-faceted and yet more complete understanding of the process that has allowed theory development. The project has examined the structural/ organisational aspects of the decision-making process and so this study is able to offer concrete recommendations.

A major strength of this study has been the rich data upon which the understandings of this project are based. This information has resulted in the development of a complex and complete understanding of experiences the respondents would understandably have rather kept locked away in their memories. That they felt comfortable in revealing such personal and sometimes painful stories in such detail is a result of the strong and trusting relationships developed between the respondents and me - a second strength of this study.

A further strength has been my own critical care background and experience which has given an insider's understanding to the stories I was being told, especially with respect to the workings of the health care system and political norms of the critical care environment. My own clinical knowledge and experience has facilitated informed probing of the stories being told at interview as well as explanation and critical examination of relevant issues during analysis. Thus the reader of this dissertation need not be a critical care specialist to understand the information and draw learning from it.

On the other hand, it might be argued that my values as a critical care nurse have influenced the study. It has been influenced by my values and experiences while they in turn, have been significantly influenced by the findings of this study and my journey through this project. Some readers may therefore challenge the legitimacy of this project on the grounds of bias. Such a claim could come from the positivists who hold paramount the ideal of value-free 'objective' understandings of phenomena. This study however has been based in the critical paradigm and has embraced the post-structural notion that there are many possible perspectives of the '*truth*' for any given situation. In light of this ontological perspective, what one perceives will be profoundly affected by one's personal values and political perspective. If we accept that all qualitative research is based on values and assumptions, then it follows that these values should be included as resources rather than eliminated (Denzin & Lincoln, 2000; Olsen, 1994). Qualitative researchers thus aver that it is better science for those working within this paradigm to demonstrate awareness of their values, beliefs, thinking and behaviour as it applies to their study (Morse, 1994; Reason, 1994). Consistent with this practice my own story was told and discussion of my values was incorporated within the introduction to this dissertation.

At the same time all qualitative research and critical research in particular, is fired by the researcher's passion. Critical research is aimed at problematising and deconstructing an aspect of the social world with a view to constructing it anew and hopefully for the better. This 'reconstruction' process intimately involves and impacts upon the researcher. One must declare one's values and beliefs at the outset and consciously suspend those values during analysis and interpretation as I have done in this study. I do not feel, however, that one can be impassioned about the subject matter of this project and not portray this in the writing. Indeed, I agree with those who suggest that to do otherwise smacks of arrogance (Kincheloe & McLaren in Denzin & Lincoln, 2000).

As discussed in methodology, the participants in each group contributing to this study come from diverse backgrounds and reflect a broad range of age, gender, socio-economic backgrounds, experience and knowledge. The stories they tell are drawn from a wide variety of critical care units, large and small, public and private. The respondents contributing to this study, however, were all of Australian or European backgrounds and thus English speaking and only one person told a story which did not involve a patient of non-western ethnicity. The study could thus be said to be biased in terms of the ethnicity of the participants and could not therefore be generalised to non-western healthcare facilities. I do not lay claims to generalisability but this study has made twenty recommendations which I feel are practicable and transferable to any western critical care unit. Further, I feel that many of the recommendations are applicable to health care areas involving intense relative-HCP interaction, such as oncology, either immediately or after piloting.

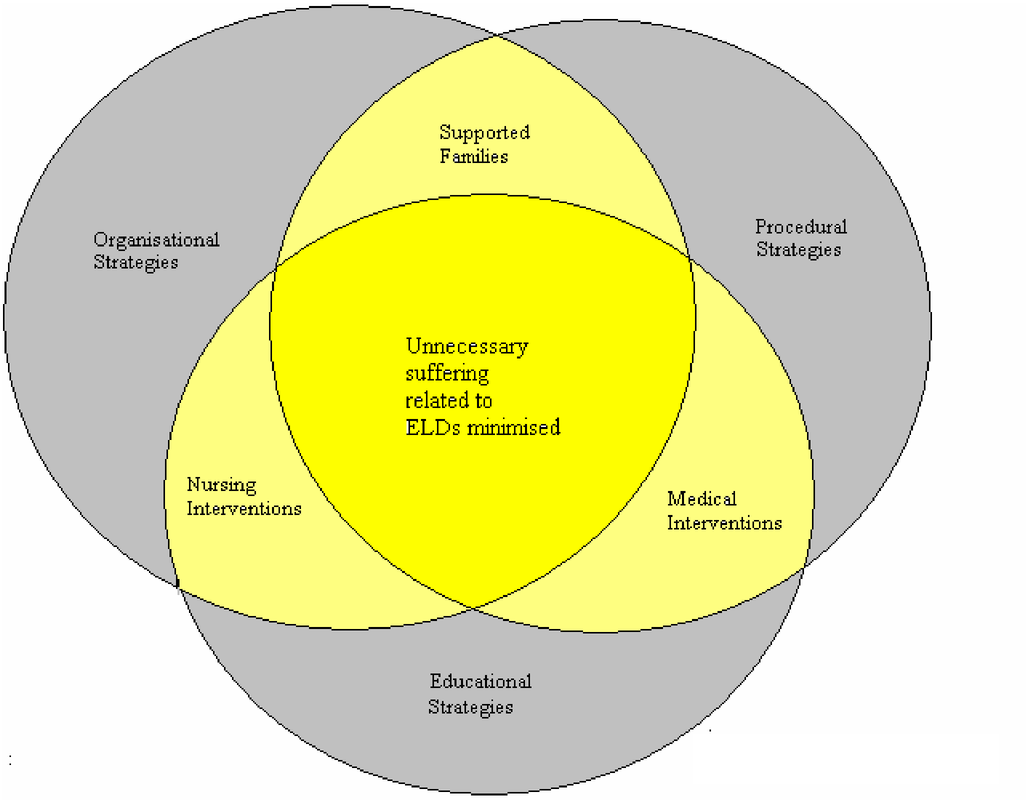
Methodologically, this project could have examined this problem ‘ideally’ from a case study perspective, collecting all the data and all the perspectives of those involved in one or a few ELD scenarios. Indeed, this is an ambition I still harbour. The logistic and ethical challenges surrounding this approach and my rationale for abandoning it were addressed in chapter one. The approach used in this project has I feel produced sufficient and rich enough data to answer the research question.

9.2.2 Recommendations

I had planned to use a constructed paradigm case to illustrate best practice and application of interventions designed to minimise suffering related to ELD-making. My efforts to produce a scenario that represented the ‘ideal’: interaction, collaboration, shared and supported decision-making involving all three groups of decision-makers certainly reflected the complexity of the issues. Perhaps my critical care experience is a double-edged sword: construction of a plausible clinical situation and illustration of recommended interactions and interventions for the three key groups of decision-makers resulted in a very lengthy, tortuous document.

Clearly, one could not represent ELD-making as a linear process in a scenario when considering all key decision-makers. The 'ideal' ELD-making situation in critical care is best conceptualised as an interlocking inter-dependant process as represented in the summary model below (figure seven).

Figure 9.7 Minimising Suffering



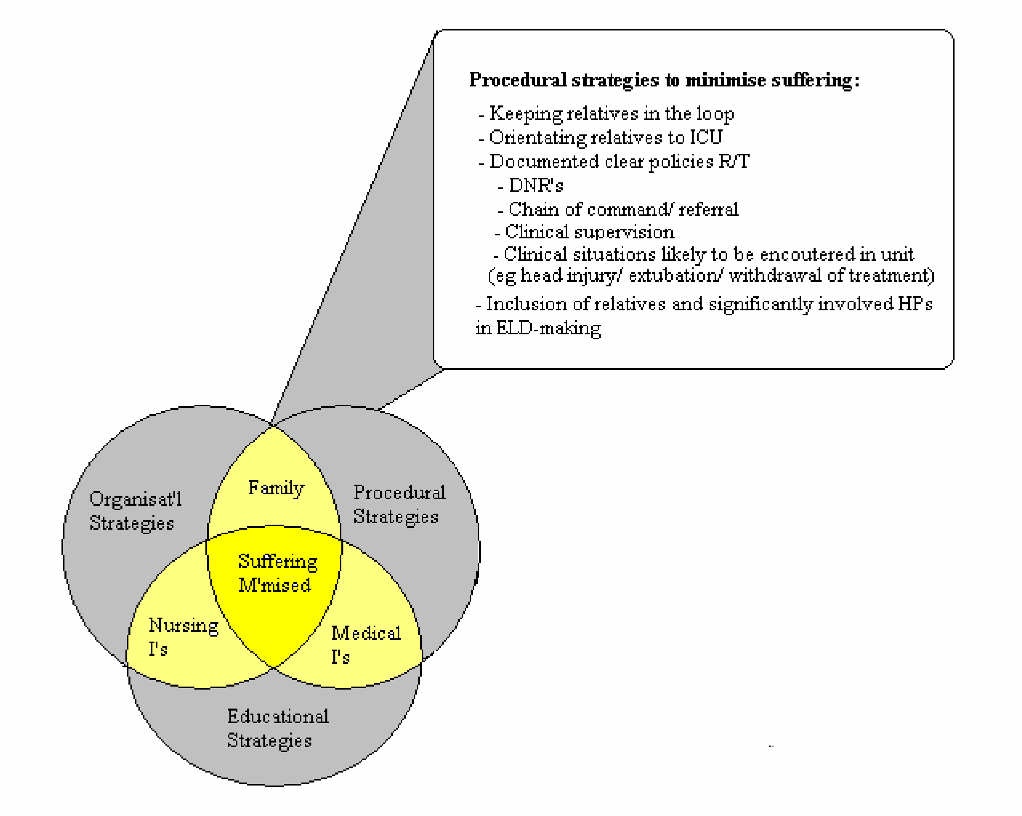
When faced by the challenge of a critically ill loved one, relatives needed information if they were to be empowered to make the necessary decisions related to their care. They needed social, emotional and spiritual support during and after decision-making, and they need assistance in meeting basic needs. In the absence of support in these areas, avoidable suffering occurred for the families.

In order to facilitate this support, nurses and doctors, too, needed to be provided with and avail themselves of support. Preceding discussion has recommended a number of nursing and medical interventions that should ameliorate avoidable suffering around ELD-making. Those interventions, in turn need to be supported by strategies at the organisational, procedural and educational level. In the absence of this support, avoidable suffering occurred for nurses and doctors. This section of the chapter enumerates and expands upon those recommendations made during discussion.

9.2.2.1 For Practice

Recommendations for practice encompass both procedural strategies (summary diagram, figure 8) and organisational strategies (summary diagram, figure 9).

Figure 9.8 Procedural Strategies



Procedural strategies to minimise suffering:

- Keeping relatives in the loop
- Orientating relatives to ICU
- Documented clear policies R/T
    - DNR's
    - Chain of command/ referral
    - Clinical supervision
    - Clinical situations likely to be encoutered in unit (eg head injury/ extubation/ withdrawal of treatment)
- Inclusion of relatives and significantly involved HPs in ELD-making

- Relatives should be orientated to the ICU environment and the potential appearance of their family member before first entering the area. To illustrate explanations and prepare relatives for entry to the unit, orientation could be enhanced with a book/ album of de-identified photographs. As relatives are still likely to be dazed following this initial visit, they could also be supplied with pamphlets which include:
  - Short introductory paragraph
  - Answers to frequently asked questions
  - Hospital and Unit telephone numbers
  - Visiting hours
  - Hospital floor plan
  - Space for names of Intensivist/ attending doctors and designated Liaison Nurse (to be filled in by the relevant HCPs)

Spare copies of these pamphlets should also be available in the relatives' waiting room.

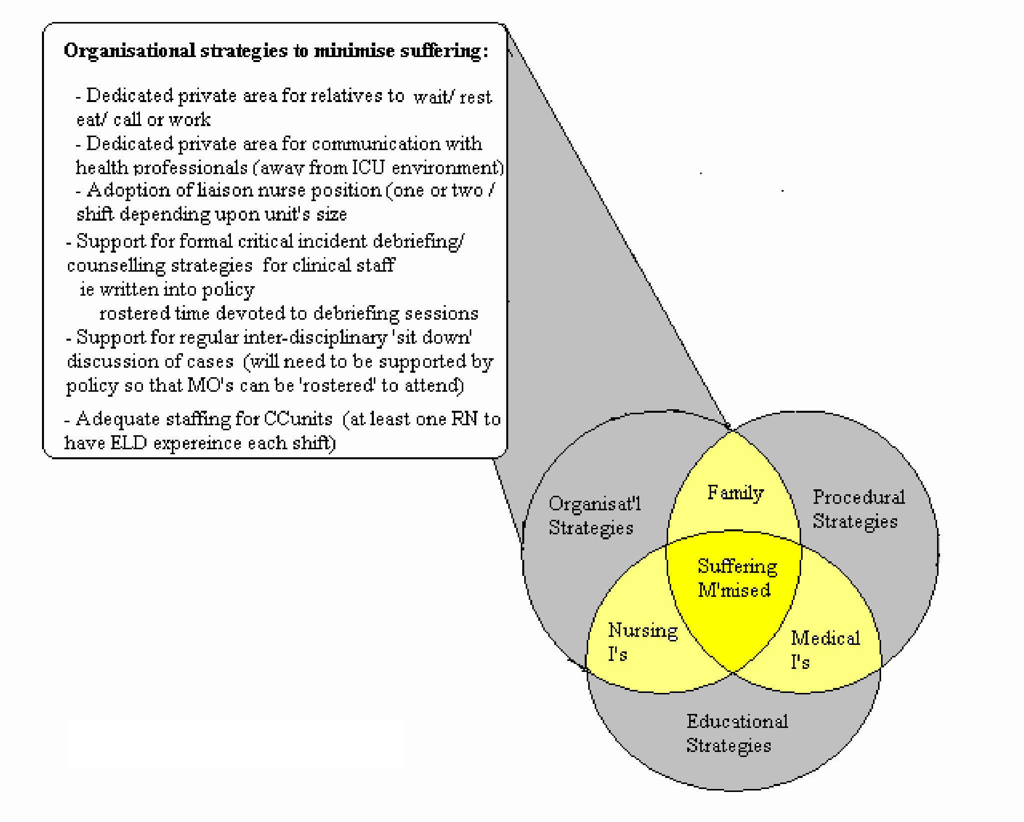
- Relatives of patients in CC should not have to wait more than 10 minutes for initial contact with clinical staff caring for their loved one. They should receive regular (at least once a shift), accurate updates regarding their family member's condition, care and prognosis.

- The family of patients in CC should be invited to participate in all ELD-making. In order that they may do this in a fully informed and supported manner, and so that the nurses and doctors involved in this decision are similarly supported and included, the optimum context for ELD making would be a shared or 'case conference' scenario.

- All health professionals significantly involved in a particular patient's care should be invited to participate in an ELD meeting and have their opinion sought (consideration should be given to numbers in a room).

- DNR decisions should be documented uniformly, (clearly and conspicuously) throughout the health care facility, possibly signified by a large bright stamp in the patient's notes which can be 'filled in' by the designated HCP.

Figure 9.9 Organisational Strategies



Organisational strategies to minimise suffering:

- Dedicated private area for relatives to wait/ rest eat/ call or work
- Dedicated private area for communication with health professionals (away from ICU environment)
- Adoption of liaison nurse position (one or two / shift depending upon unit's size
- Support for formal critical incident debriefing/ counselling strategies for clinical staff
  ie written into policy
  rostered time devoted to debriefing sessions
- Support for regular inter-disciplinary 'sit down' discussion of cases (will need to be supported by policy so that MO's can be 'rostered' to attend)
- Adequate staffing for CCunits (at least one RN to have ELD expereince each shift)

○ A private dedicated room should be provided for the comfort of relatives of ICU patients (specifics to be expanded shortly). This area should be separate from the previously mentioned meeting room to afford privacy to those involved in discussions/ decision-making. The room should contain:

- Facilities for relatives to make hot and cold drinks, have a phone with external line, lounge chairs and a daybed so that visiting/ waiting relatives are able to meet their own basic needs.
- If for any reason, it appears that a relative is going to be on their own for an extended time, then arrangement for some form of social support/ company should be organised: either family or friend. Failing that, the social worker attached to the unit should be contacted. Within working hours, the social worker would/ should also organise meals and accommodation. Out of hours, this undertaking would devolve to the nurse.

- All CC areas should have a dedicated area for private discussion between health professionals and relatives. It should have comfortable seating and an X-ray viewing box to allow doctors to illustrate their explanations.

- All CC units should consider the incorporation of one or two Liaison Nurse/s per shift within their staff profile depending upon their size. The Liaison nurse is a new position in critical care. The focus of this nurse's position would be facilitating the meeting of all the relatives needs discussed. These nurses would be responsible for:
    - orientation of all 'new' relatives to the unit;
    - their continuing 'education' during their family member's stay;
    - facilitation of liaison between the relatives and all the relevant health professionals
    - ensuring that relatives are updated on the regular basis mentioned throughout this discussion;
    - facilitating those aspects of family hostessing mentioned previously without supplanting the 'comforting' role of the bedside nurse.

The Liaison Nurse should have a CC education and be employed at CNS level to have the appropriate knowledge base, experience and seniority within the unit. Depending upon the size of the unit, there should be one or two nurses each shift who can be designated to liaise with families. In very small units and after hours, this role may devolve to the nurse in charge of the shift. If this is likely to be the case, nurses likely to be in this position should be educationally prepared and supported with the other policy recommendations made in this chapter.

- To promote discussion of 'concerns' between disciplines, regular 'sit-down' case discussions should be held in the designated communication room mentioned earlier, perhaps at the change of afternoon shifts. This should be written into policy so that relief can be found for the registrars involved.

- All hospital policy manuals should include an ‘organisational structure’ flow chart outlining options for referral when concerns arise about a clinical situation. Orientation to the hospital and then to critical care should include provision of a hard copy of this flow chart and discussion of the importance to staff and patients of its use (i.e. optimal patient care; enhanced communication and support rather than a potential vehicle for horizontal violence).

- Once a patient has a documented order for ‘no further resuscitation’ or no CPR then a uniform process of communicating this formally between shifts and between health care professionals should be written into CC policy.

- Once a patient has a documented order for ‘no further resuscitation’ or no CPR, then that patient should be moved to a private room in another ward (or a side room in the unit). This move would also avail the relative and their family of privacy.

- All CC units should have a specific policy requiring that a minister of religion or pastoral care officer be contacted and invited to be present to support relatives during treatment withdrawal and a patient’s death during this period if the family wishes.

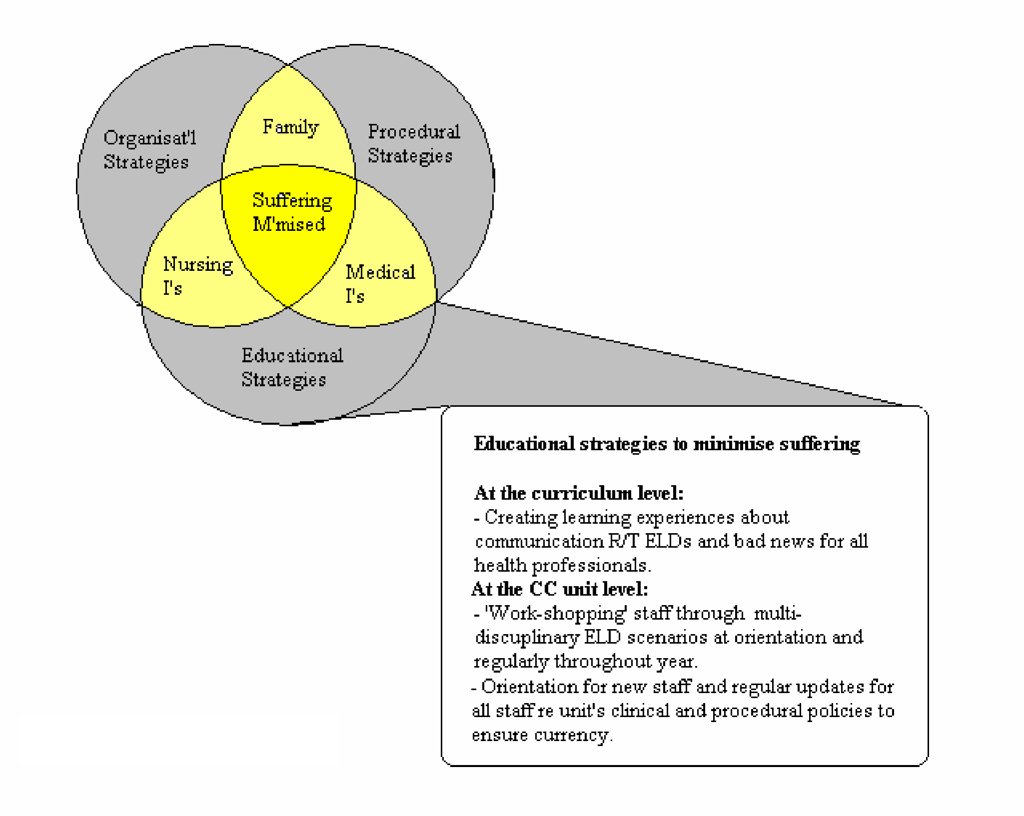
- All ELDs should be clearly documented in the patient’s chart together with specific criteria where necessary eg ‘may have oxygen but not to be ventilated’.

- All CC units should write into their policies that bedside monitors be turned off or removed once treatment is ceased.

- All critical care units should consider introducing formal debriefing structures for all their clinical staff to be held following critical incidents and withdrawal of treatment.

- In small CC units (i.e. two staff on at night), one staff member should have at least six months experience in that unit so that they are aware of policies, procedures and ELD-making processes.

Figure 9.10 Educational Strategies



Educational strategies to minimise suffering

At the curriculum level:
- Creating learning experiences about communication R/T ELDs and bad news for all health professionals.
At the CC unit level:
- 'Work-shopping' staff through multi-discuplinary ELD scenarios at orientation and regularly throughout year.
- Orientation for new staff and regular updates for all staff re unit's clinical and procedural policies to ensure currency.

- All health professionals' education (undergraduate and post-graduate) should include training in inter-personal and intra-professional communication techniques.

- This education should include learning experiences about communication skills related to ELDs and bad news and that these be incorporated within the curriculum of all health professionals.

- All CC staff should be 'work-shopped' through ELD scenarios at orientation and throughout the year. These scenarios should be drawn from 'real life'.

9.2.2.3 Recommendations for future research

- This project was conducted in the qualitative paradigm and examined the experiences of those interacting around ELD-making. Now that a theoretical understanding of the factors that impact upon the experiences around ELD-making has been posited, the next useful step would be to quantify and operationalise those factors and observe the impact of the implemented recommendations of this project.

- It has been acknowledged that this research has been conducted in Western health care facilities and with English speaking respondents only. Although I am confident that the results would not differ greatly, the findings of this study would be strengthened if it were repeated in critical care units in non-western countries.

- As previously mentioned, this problem would be ideally investigated on a case study basis with participant observation of the decision-making process, collection of all relevant data influencing decisions and interviews with all parties involved. I recommend such a study be attempted and I foresee such a study being more practicable conducted on a multi-disciplinary basis.

- The absence of clinical supervision and peer debriefing was identified as a major negative influence upon the experience of the health professionals in this study with consequent impacts upon their colleagues and the relatives in their care. The emergent implementation of clinical supervision in the mental health field has shown positive outcomes for clinicians and their clients. I recommend a multidisciplinary project, action research based project exploring the implementation of clinical supervision in the critical care environment.

9.2.3 Closing Comments

This study aimed to understand the interactions between those affected by ELD-making in the critical care environment in the Australian context in the hopes of developing strategies which might reduce the avoidable suffering associated with those situations. Previous studies have examined associated issues peripherally in Europe and the United States. There have been no studies to date in Australia investigating how all the stakeholders involved in the decision-making are affected when a person is critically ill and in need of support or in need of judicious consideration of its withdrawal. Those overseas works investigating ELD-making have tended to be logico-empirical studies in the main and those qualitative studies interested in the problem have not focused on all stakeholders in the one study as yet. This investigation has rendered a more complete understanding of the complex process. This project has offered concrete recommendations that should ameliorate suffering for families, nurses and doctors who become involved in the challenges of end-of-life decision-making.

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APPENDIX I - THE VOICES

1.1 INTRODUCTION

In this section the individual participants' voices will be heard as their stories are presented in the form of edited personal narratives. I feel this is the space within the dissertation for the 'narrators' of these stories to speak here with as little interruption as possible. As they do so, their often-poignant stories will highlight many issues-more than I am able to do justice to within the limits of this project. One major issue this project focuses upon is the avoidable suffering for all participants emanating from the decision-making processes associated with use of life-sustaining treatments in critical care. As an initial step in analysis, moments of avoidable suffering and their related cause will be identified within the participants' narratives. Aside from this I have kept my own voice to a minimum, using it to introduce the participants and comment on the individuals' body language or to make brief explanatory comments about the cases they discuss

Three different fonts will be used to indicate the different sources of data being presented. The individual participants' voices will appear in normal font while *my voice will appear in italics to introduce the participants and comment on their body language and/or responses as their stories unfold.* [Bracketed] words appearing in the text are those added to the story for ease of comprehension or reading while […] denotes repetitious phrases or sentences removed for the same reason. Moments of avoidable suffering will be identified in Arial narrow.

One of the most significant challenges I have had to face with this dissertation has been: how to present this section of the dissertation. During data collection I was to discover that relatives told stories, usually rich in context and detail; nurses told stories and then focused on the issue that angered or interested them; but doctors tended not to tell stories. They focused on the issue straight away. Even when asked to illustrate their point with a story, they tended to speak in staccato bursts of information without context, rather than in sentences. It was clear that the issues they raised were very important, both to them individually and to this dissertation. I was tempted to name the sections of this chapter: the relatives' stories, the nurses' stories and the doctors' issues but clearly this is inappropriate as all three groups of participants had issues they wanted to voice:

1.2 THE RELATIVES' VOICES

HANNAH:

Hannah is an academic from NSW. She has a background as critical care nurse but has been involved in research for the last five-six years, recently completing her PhD. While Hannah's story and experiences had occurred approximately four years ago, the emotions these evoked were still raw and she was able to relate this story in rich detail

Dad collapsed at home […] there were several attempts at resuscitating him on site [...] and they transported him very quickly to a hospital close by and of course as a result he was actively resuscitated. He was already admitted to intensive care when I received a call to say my father had had a "heart attack" and that he was in intensive care. Immediately, with my intensive care background, I put two and two together and I thought: "This isn't good!" Because I also knew that the hospital that he was admitted to had a coronary care unit (*i.e. if he'd been ventilated his prognosis was very poor).*

When I arrived I wasn't able to see him-they were still they were inserting lines, I guess. They had resuscitated him to the point where he had a rhythm and in the process, well, a colleague of mine, an anaesthetist, was involved in his resuscitation and he explained to me what Dad looked like and what had happened: […] he'd been defibrillated many, many times; they'd lost count after seventeen. Consequently he was in a bit of a mess […]: he had several fractured ribs, he had an inter-costal catheter in place with all of the sort of lines that go, you know, with critically ill patients. We waited quite some time before we were allowed in. I knew what was going on inside the unit but I wanted to be there and I often wonder about that, about relatives that we make wait outside - whether in actual fact there's anything wrong with having them in while all this is going on if that's what they want? You know, I just wanted to be with him, be near him, to let him know that someone was there for him. Someone else you know not, not, not strangers, but someone, someone else. He collapsed on the Friday, at five o'clock; […] I got to him […] about an hour and a half later (avoidable suffering related to prolonged separation from loved one and waiting for news).

On the Saturday morning about ten o'clock, the same anaesthetist approached me with the news that they had assessed Dad's status. […] basically they said that he was brain dead. As an intensive care nurse of course I knew what that meant**.** Well I thought I understood at the time what that meant. I guess what I understood at that time was: **"**Oh my God, it means that there's no real hope for him, but there's also the possibility that he could be a lingering vegetable"**.** I guess I was always, also very, very aware of that and that was the last thing that I wanted for Dad. And that he wouldn't have wanted that for himself.

It was assumed [that I knew what they were talking about]. Probably, because I taught the course locally for many years on the one hand […] I guess you're expected to know, whereas on the other hand in those situations you suddenly become, you do, you become a lay person. You know you feel like a layperson. In hindsight I could've asked too, but I didn't think to ask. You go into a mode of…it's all 'surreal'. The whole thing, the whole process was almost like, "Oh my God, I don't believe this is happening". So you're not really in a position to ask questions. If anything, I think the onus is on the health carers to actually provide the information and not make any assumptions (avoidable suffering/absence of support (information giving): related to health carer's assumption's re level of knowledge).

What I couldn't really understand or reconcile for myself with my intensive care background, was that they defibrillated him as many times as I was told, if indeed that was the case. It certainly wasn't my experience, being an intensive nurse or being involved in providing that level of care. You know, there comes a time when you say, "Okay enough's enough". So, you know, I was a bit perplexed about that. But the explanation that I was given was that, my father was fifty-nine at the time, but at fifty-nine he looked, if he was lucky, forty-nine. He had a very, very youthful appearance. He wasn't a good looking, handsome man, he was obviously quite overweight as well and I was told that they kept resuscitating him because they thought he was much younger than what he was. I mean, not that age should make a difference these days anyway. But still I guess, maybe they felt that they had to justify why they did what they did. And of course at that time they certainly wouldn't have connected his name to me, although some would've I guess. The anaesthetist I spoke to would've connected his surname with my maiden name.

Then, he was pronounced brain dead in the morning and the anaesthetist told me that they were going to reassess him again with a view to taking him off the ventilator the following day, Sunday. […] I have two brothers, but both of my brothers chose not to come in. They had planned the weekend away on a football trip. They proceeded with their weekend and neither of them wanted to see Dad the way he was at that time in intensive care. This was their way of coping. I had my husband with me, and my mother. Mother and father had been separated and divorced for twenty-one years but they were still friends; they socialised occasionally together. […] We waited, waited for a while, I think we did go, come, go, come back home and then we went back in the afternoon.

He was reassessed that afternoon and he was brain dead so the plan was still to take him off the ventilator the next day and I actually said to the anaesthetist, "Well why wait, why not do it now?" My brothers obviously, had made it clear that they didn't want to be around and there was no point in prolonging anything for Dad or for us. I think by that stage it was about seven o'clock in the evening. I helped provide some care for him, I didn't force myself, but I really, really made it clear that I wanted to help, I really wanted to help: "No, no, no, you can wait outside the curtains. I said, "No, no I really want to do this". And that was probably the only time that I really asserted myself in that whole process and that's because I knew it would be good for him and for me that I was involved and I guess that's what I would've liked much earlier.

Anyway, I think, you know with ICU you have to wait for the team, so eventually, a couple of medicos turned up to extubate him. And I was there for that...so were my husband and my mother, I think. When they extubated him I didn't expect to see him struggle as much as he did, or that's my "word", I'm starting to feel a bit... (*short for words here and crying*). I don't believe I've ever seen anybody struggle so hard to breathe and when I say struggle, in my, in my own mind I'm thinking scientifically: his glottis obviously wasn't doing what it needed to do, because he was sucking it in, sucking the air in with all the might that he could conjure up. And making this most grotesque noise, you know. Gasping isn't a strong enough word; it was a horrid sucking, like a snoring, like a deep snore with each, with each breath and his whole body was, was almost lifting off the bed to pull the air in…(avoidable suffering related to mismanagement of patient's condition).

I was quite distressed at the sight of that and I think I said something like, "Oh no, oh my God". All I was thinking, at the time was, "Oh my God he's struggling, you know, this could go on for ever, this could go on for hours", but I didn't actually say that. There was a female anaesthetist on that night in the unit and she was a relatively young woman, cause I could remember thinking earlier, "My God, you know, I'm showing my age now", particularly when I think that I was once an intensive care nurse at the ripe old age of twenty-one, twenty-two providing this sort of life saving care for people and I never really thought about what the relatives thought of me, you know, 'young whipper snapper' providing this sort of life or death care and here's this anaesthetist who looked up and looked 'wet behind the ears' to me. But never the less, I was grateful because she moved very quickly. There was a lot of hurried action, you know, like the nurses' response was hurried, the anaesthetist on call, she looked, and these are just my thoughts, I have nothing to base it on, but she looked like she was intentionally going outside policy, that either she'd taken a queue from me, I don't know and decided to deal with it her way, not, not the hospital's way.

Prior to extubating him they already had IV lines in, art lines in. They had dosed him up with morphine on the basis that he would have had pain with the mess that they created in his chest and with my exclamation: "Oh my God, oh my God, Oh No!", the female moved very quickly and gave him a bolus dose of morphine and gave him another one and another one and another one and I can remember very clearly feeling relief. And she kept giving him these bolus doses and I don't know how much she gave him. I did ask, but she, I guess she refused to answer me and it was none of my business as a relative, but I felt that I had to know how much he'd been given. I could see the ampoules being cracked open, you know, one after the other. And of course eventually he did, he did calm down and at the time I have to confess I was relieved, you know and eventually of course he, he did stop breathing. Anybody would with that amount of morphine on board. She also increased the IV input, you know, she turned up the flow. So he was getting morphine IV as well as the boluses that she gave him. And…it wasn't until later, much later, much, much later that I started to think about what happened there, you know, and I still do; I still think about what happened and I wonder whether in actual fact that we made the right decision because, because he struggled so hard to breathe. I now wonder whether in actual fact he was as brain dead as what they said he was. (Ongoing suffering related to unreconciled questions at time of experience- ?avoidable)

{*At this point in the narrative I raised the point that the recognised criteria for brain death include the absence of purposeful movement and apnoea, Hannah continued regarding her concerns for her father's diagnosis*}: He had both of those that's right, that's right. So you don't know, his pupils might have been dilated but you know we might've seen that reverse in time. They'd have done a cold calorics, I would think but you know, hey how do we know that that doesn't reverse in time as well? Because we don't…{*I remarked here that these tests are incredibly difficult to interpret*}: Exactly, but I was just, like I said so shocked! As I said, in my own experience I had never seen anybody struggle so much and it does play on my mind, you know that he was struggling to live…and effectively and I've never, I've never said this to my mother, I've never […] given it a voice because to do that would give it primacy, even my concerns, I've never discussed them with my husband and my husband's sitting in the lounge room at the moment and I don't know whether he's listening or not, but I've been too scared to because it's been a secret concern of mine for some time. It's been a big one yes, …and I keep thinking no, no, we made the right decision, but, but of course the other thing I know is that, that I believe this was euthanasia.

{*I remarked here that it <u>had</u> sounded like a large dose of morphine her father had been given*}

Yes, it was, it was and this practice occurred in a hospital that is a catholic hospital. It provides palliative care but is dead against the practice of euthanasia and yet this is what was practised [in this case]. I'm not [sure about the practice], in actual fact I believe that perhaps there's a place for it, you know in what I've seen over the years. But in this situation… because Dad wasn't in a position to say "Yay or nay"… I made the decision for him. We never ever talked about end-of-life and what he would prefer because I mean we didn't expect that he would die so suddenly. Like I said he, he was a young, relatively healthy looking man. […] and the closest I got to ever talking about his health was saying to him, "Dad you really should get your blood pressure checked".

[At that stage] I was aware of the absences of staff, which is interesting because under those circumstances I might've expected that a nurse or somebody might have come and at least put their arm around me- to give some sort of comfort under those circumstances. Do you know what I mean? (avoidable suffering related to absence of emotional support) But perhaps because they knew I was a nurse and of course I was teaching at the university as well, perhaps that was another compounding factor. I don't know. I mean I do know what nurses talk about, about relatives you know, but, you do talk about them and word gets passed around and perhaps, by that stage it was already widely known that I was a nurse, an ICU nurse. I mean I taught the ICU course as well and that's how I came to be working with the anaesthetist concerned. So I guess it would've been widely known and perhaps, perhaps, perhaps that's why the young woman anaesthetist took the cue.

At the time the staff was scared. […]. I'm not sure whether that it was because of me, [a nurse] or whether it was that he had been diagnosed as brain dead, this was a relatively young looking man and they were going to withdraw treatment and perhaps, they're not really prepared in their training to cope with those sorts of situations. And I think it would've been nice for them to be (*long pause*) I would've liked more comfort. I had no idea how mum and my husband were coping, you know, I wasn't able to give them any support […] and they were in, in my mind all the time, as well, they weren't getting any comfort or support. (avoidable suffering related to absence of support/emotional)

You know, it happened too quickly when I think about it. I guess I have regrets about making the decision in [the time frame I did]. Perhaps if I hadn't been told that he was brain dead and that they were reassessing him in the afternoon almost the same day when you think about it, in a twenty-four hour period you know that maybe I wouldn't have made that decision. Perhaps if they'd have gone more cautiously and again that's been my experience in the past too, when I think about it as an intensive care nurse. That more time is taken with making these diagnoses, I mean he, he basically arrested at five o'clock in the afternoon and by the morning of the first, well by the next day he had a diagnosis of brain death and then that was reconfirmed by the afternoon and he was off the ventilator, dead. It all happened too fast- definitely too fast. (avoidable suffering related to trajectory of illness/decision-making).

Coda

It's definitely every Christmas that is comes back to mind again, I mean in the first twelve months or the first two years it was hard and I kept pushing it back to the back of my mind, pushing it down, not even to the back, the back of mind it's like pushing it down, repeating the thoughts and thinking, no, this is crazy, this is crazy, don't be so stupid and over time, like every Christmas I think about it and I think my God, and the more, as the years have gone by, the more I think the opposite I think, no you're not stupid, you know, I think, my God, Dad must have been so aware that, that he, he struggled to breath, that he wanted, he wanted to, and, what if he wanted to say goodbye to my brothers?

Who was I to say: "Do it now"? This is something that's been on my mind for a long time and I keep thinking I'm going to take this to the grave with me. But, but you know the alternative! Like for me…the alternative isn't necessarily all that palatable either. But nevertheless, if in actual fact brain dead is not really brain dead, or if they're diagnosed inaccurately as we're led to believe then that's not good enough. You can't, you just can't play with people's lives like that.

STEPHANIE

Stephanie is a nurse administrator. The story Stephanie tells took place in a facility where she had worked for many years. Stephanie's experience was especially "raw" – her parents had only died four and five months prior to this interview. She particularly wanted to share her perspective of the decision-making related to her mother's illness and care.

We were expecting Dad to go before I moved up here. Jan (partner) and I moved up here to Queensland a little over a year ago. Prior to that I'd basically been the care giver and support person to both my parents because I lived closest to them and because I had pretty much the better relationship with my Mum and Dad [than my other sibs, Helen and Wendy]. My father was an alcoholic, which kind of exacerbated itself once he retired - he retired early at the age of 54 - and he was 71 when he died. So he basically started drinking when he woke up and by about 3 in the afternoon, he was well and truly cactus. He had alcohol-induced diabetes. He had a long-standing heart complaint. It wasn't really life threatening he didn't have any arrhythmias. It would give him a bit of trouble, but it was exacerbated by his drinking. Just before we moved North, he developed Lupus which they believed may have been a chemically induced problem which just went hand in hand with all his other dramas. Then he developed hepatic encephalopathy and was basically "off with the fairies" more than he was here.

Now, the unfortunate bit about all of this was that because I was there more that my siblings they didn't really know what was going on with Dad, but more importantly with Mum. When Dad was put into hospital it wasn't anticipated that he would come out. However, he managed to rally and he responded quite well to whatever treatment they were giving him and he was discharged home where he subsequently hit the bottle and within 24 hours he was back in again. He became extremely debilitated, very disorientated and quite - well, we used to call it "pixilated" because some of the stories he'd come out with were absurdly funny. It was suggested by the medical staff that he go into care. Mum was actually happy with that because my Mum was only 5'1" and my Dad was 5'10". Mum, at her heaviest was 7½ stone and she just found Dad far too difficult to manage. She was a bit older than Dad - she was 72. I was up here (in Queensland) and my two sisters (in Sydney) decided they would take over Mum and Dad's primary care. The manifestation of that was that they decided that Dad required more support than Mum and overruled Mum's decision that she could not deal with Dad on her own. Dad was confined to bed, he could not stand, he could do nothing for himself and in his moments of delirium, he would manage to get himself out of bed and halfway to the ensuite where he'd fall and sit. Now, Mum being as little as she was, had no way of getting him up and back into the bed. So even though she had made it very, very clear to the girls that she couldn't mange him and had no desire to try to mange him, she was over- ruled. The girls called her lazy and non-caring. Dad's wishes should come first - his primary wish was that he come home.

Any way the upshot of this was that Dad went home on Sunday; on Monday Mum collapsed while trying to assist him, Dad called the Ambulance [and she was transferred to the emergency department of a metropolitan level three facility]. If it were within my power I would not have allowed them to do anything in the emergency department. It would have been preferable for them to make her comfortable and let her go instead of all the "gunho" rubbish that the medical side of the world do. They all act like little gods, little life-savers, you know. In my opinion, nurses are far better diagnosticians than medical officers - they have a different ethic - you know. […] I mean at the end of the day - she was ready to go - her heart was failing her. She'd had renal stenosis for many years, her kidneys were failing her, she had petit mal epilepsy - oh it was just awful. It should have just been conservative care in emergency. Had they not done all these life-prolonging things that they do in emergency then she would have gone to God if they'd left her alone. And that would have been preferable to me rather than the 10 or 11 days that she endured pain as a result of being tubed etc. It was very uncomfortable for her.

Anyhow she ended up in ICU. They did initially think that [Mum had a stroke] but she had always had a leaky heart valve and it was put to her after her first pregnancy that she really shouldn't have any more - but she did. She had also had a bout of the 'flu that was around at the time and she had finished her course of antibiotics but apparently there was some residual fluid around her heart. The exertion of trying to lift Dad just exacerbated everything. They couldn't do a great deal because she was so worn out. They did actually manage to get most of the fluid build up away from the heart but the lungs had started to fill up by then.

She was ah *(tears, & choked voice)* maintained on life-support for about a week - they extubated her at the end of that week and she was reasonably, 'with it' in as much as she knew who everybody was, and she knew her fate, and I believe that she had made a very, very conscious decision that she would, for the first time in her life commit a selfish act, and that was, she wasn't going to be there - she wasn't going to be part of it - and, she, rallied for a couple of days then […]. The good part of it was that I had worked at (this particular level three facility) for 22 years and therefore I knew all of the staff and they were keeping in very close contact with me. My sisters would make a decision - mother was not able to - and the staff would ring and say, "This is what's afoot."

Because of my close relationship with Mum and Dad, I knew how they both felt about life support and quality of life issues and all that sort of stuff. We [Mum, Dad & I] spoke about [quality of life and care at the end of life] - We had often discussed this because I had sustained a very severe neck injury and had extensive reconstructive neck surgery - so I've spoken to Mum and Dad and said, "if anything ever happens and I do ultimately end up a quad, I will <u>not</u> be maintained on life-support and I'd like you to do everything you can to ensure that that doesn't happen" and Mum and Dad had both agreed over many years that neither one of them wanted to be maintained on life-support if there was no way that they were ever going to make a full recovery - if they weren't going to be active and able to do for themselves. Now Dad was at the stage where he couldn't do for himself and hadn't been able to do for himself for almost a year - and ah (*tears & choked voice*) Mum <u>was OK</u> - she'd been able to look after herself and the house and everything - she just couldn't manage him.

It had been put to Mum that she really did require tubing again and she just shook her head and said "No". My sisters were down there insisting that she be 'tubed and the medical staff was in somewhat of a dilemma because one of my sisters can be very, very forceful and she was tending to lord it over Mum a bit (? avoidable suffering related to conflicting family values and aims). So, the medical staff rang again and said, " Look this is what your Mum is indicating; you are the oldest sibling - what do you want?" I said:(*tears, & catch in voice*) "Whatever Mum wants". And Mary, the Charge Nurse who was looking after Mum called me and said, "Look, I'd like to start your Mum on morphine, do you know what that means? I said, "Yes. I do" She said, "You understand?" I said, "Yes" She said "You're OK with it?" I said, "Yes". She said "Will your sisters be, or not?" and I said "Be that as it may." Because by that stage Dad was back in hospital and they (her sisters) had switched their attention once again from Mum to Dad. Anyway that was it - morphine as you'll understand was the beginning of the peaceful end for Mum and that was great. Mum went to God and I was very happy about that - I was quite happy for her (*tears*).

Then it was pretty much as if everything happened for Dad- I mean Dad was really, really "shot", everything was shutting down. Again the Christian part of Helen (sister) said "life at any cost" and I said, "Helen, there's no quality here - Dad doesn't know who he is, let alone who anybody else is ". And she said, "We have to do everything we can" and I said, "No, what we have to do is let him go. You can't mange him. You refuse to put him into care, Mum's not here; Wendy can't manage him and wont. I'm in Queensland. What do you think is really the best thing to do?" She said, "We have to try to do everything we can," I said "Well I'm sorry but I'm going to overrule that". So there was a case conference with Dad. All of his physicians attended the case conference and there was a telephone conference about what would be the best way to manage Dad. Again I said that there is no light at the end of the tunnel for Dad - it can either be a slow prolonged death or we can withdraw all but conservative treatments and just see what happens. That was the course that was decided on. Dad had died within fourteen hours.

SANDRA

Sandra is a legal secretary; she had learned of this project through a mutual friend. I had spoken to her over the telephone and arranged to come to her home to talk to her about her experiences surrounding the death of her husband. Sandra was most articulate as she told me her story and it unfolded it became clear that she was normally a motivated, proactive individual.

I was greeted at the front door of her large well-furnished home by Sandra and her huge golden retriever, Max. We talked in the kitchen over a cup of coffee. The walls of the lounge, the kitchen even the fridge door reflect memories of Grant, her husband, who died only five months prior to this interview. From the very first moment Sandra started to recall and describe the events surrounding her husband's death her face was bathed in silent tears. Grant, 44, an artist, was to have elective surgery to release the trigeminal nerve causing his neuralgia. He had already had all the nerves in his teeth on that side of his face removed in an effort to thwart the pain but that had not been effective. Sandra started by describing the impact of the neuralgia upon their lives:

He'd had it for two years. Grant couldn't shave on that side, he couldn't sleep on that side, he couldn't eat on that side; when he smiled it'd ache. I couldn't kiss him on the lips because it would hurt too much. Then it would leave him and I'd make a lovely meal and he just couldn't eat it. He was on Tegretol and Neurofen– just to get through the day. And then he'd feel like a Zombie with the Tegretol. So that was no way to live. Every day he'd have to take the tablets with his breakfast and if he didn't take them he'd have miserable day. He was getting frustrated and he thought 'there's only one way out of this-I've got to get it (the surgery) done and rectified and have a normal life.'

The surgery was performed in a large private metropolitan hospital with intensive care facilities. Sandra saw her husband briefly in recovery. At that time he was lucid but nauseated, and complaining of a severe headache:

Grant was nauseous, but that's a part of the deal when you have brain surgery - it's just like concussion-he was throwing up. [I thought] this was a great sign because that means he hadn't had a stroke and he didn't die on the table. I'd researched the chances for this: 2% for stroke or 1% for death on the operative table. I asked him "How are you?" and he said, "I've got a terrible headache Sandra." I said, "Be patient, wait for the pain killers to kick in." They were giving an intra-venous one [pain-killer] plus one that takes a little longer- they'd given him suppositories. He said, "its alright for you, Sandra, you haven't got the pain." And he's saying "Oh my head, my head, my head." They had the cold pack on his head and all. I said to his sister, "We can't do much here, let's go and have a cup of tea" (avoidable suffering related to inability to understand significance of Grant's symptoms and absence of clarifying information) .

So we went and had a cup of tea and I said good-bye to his sister because she had to go home. Then Anna (friend) and I went up to his room and waited. It was about 9 o'clock and I was sitting on the bed and I said, "Anna- we should do something nice for him *(tears)* when he comes home. Then the phone rang and it was the intensivist who said "Look he's had a bit of a turn for the worse. We're going to take him down for a C/T scan and you can meet us down there."

So we met him down there and the surgeon met us. He told me: "Sandra there's something going on in his head, he's got a bit of pressure up there. I don't know if he's bleeding where I was today or if he's got brain fluid. So we're going to do a C/T scan and we're going to see what's up there". So they did the C/T scan and they came back and they said "Well he's not bleeding he's just making a lot of fluid and they said it's because his brain's been, not tampered with, but handled a lot in that area today and its saying to itself, 'I'm going to repair myself' and it's producing a lot of fluid'. And he said, "we'll take him down to theatre and we'll put a shunt in." I said, "Well that's fair enough." And then I said, "You're not going to give him another anaesthetic and put him through that again, cause he was very drowsy at six o'clock when I saw him after the first one." They said, "We'll only give him a very light one 'cause he's still very drowsy from all the pain killers too." I thought that was good 'cause another anaesthetic-that was going to take him longer to get over the surgery, you see. So as we were entering the unit, I saw him on the stretcher and he was snoring and I said to Anna, "He does that at home he must just be tired." He was going into a coma. I didn't realise that at the time. (avoidable suffering – absence of appropriate information/explanation).

We waited from 9 o'clock to I think about 1 or 2 o'clock in the morning (avoidable suffering related to prolonged separation from husband without information on his progress). The surgeon came back and was absolutely exhausted because he had been working all day. He said, "Sandra, that shunt in his head – it took me so long to get it in – but it's in there. We're going to monitor him and we're going to see if we can release all that fluid and we'll see what tomorrow brings. He was the only one in intensive care on the weekend. So he had all the care and attention. They said "We've put a breathing tube down there so when he wakes up-we'll give his brain a rest–he'll be tossing and turning–we need to give his brain the best chance." I said "Fair enough" So he's sort of breathing away there – they're breathing for him. I think Terry, his brother, stayed with him that night, and then I kept ringing the hospital during the night to see if anything had changed because one of the nurses had said, "I want him to rip this thing out (*the E-T tube*). ["I want him to say"] 'I don't want it any more- get it out of my throat - get it out' - we want him breathing for himself".

Then the next day they did some tests on him – they tickled his feet, they tickled his fingers, they did all the tests, and he seemed to be coming in this way (*demonstrating decorticate gesturing*) instead of going the outward way. I said "That's good!" and the nurse said to me "No, not really, it should be the other way." [She didn't really explain what that meant.] - and I didn't sort of like to hear that negativity at that early stage because I said to her, "Any sign is a good sign", because I haven't got very much medical experience(avoidable suffering –absence of appropriate information/explanation). So, that was on the Thursday, I guess, and he was still the same on the Friday and I rang all my friends up here and all my medical contacts and they all kept saying, "Hang in there, Sandra, its early days, hang in there." Nothing changed.

Saturday morning came and they called us all in. Another two neuro-physicians came in and he (*the intensivist)* said, "We've got to do two independent tests, an hour apart and we're going to see how he goes." One fellow did his test and then the next fellow did his an hour later. The first fellow came and he says. "I'm sorry, he's failed his exams."(avoidable suffering related to blunt, uncaring communication style) He just had this look on his face and when he said it this shiver just went up the right side of my body. I thought 'This is for real this time!' *(tears*) Because you hear of people being in comas and coming out it! I had the music going - I had his favourite music going - I was talking to him. Then this other Neuro guy came in and did obviously the same tests but he said "I sorry he's failed the tests - at this stage he's brain dead." They more or less said that they had not much hope for him at that stage (avoidable suffering related to blunt, uncaring communication style). While I'm getting this news there was always one nurse always standing around with her arms crossed as if she had to be there to " be a witness". She also patted Terry (brother) on shoulder when he was crying but she seemed more as if she was there to "witness" what the Neuro guy was telling us (avoidable suffering related to perceived absence of support/emotional). [The nursing staff] just kept on looking at monitors and things and I kept on asking, "How's he going?" and they'd say, "No change- no change." and I guess that's all they could really say without really elaborating on what the doctor has already said (avoidable suffering related to absence of support/ information) . And of course - the brothers, they're beside themselves, thinking where's that doctor who actually did it? I'm going to skin him alive! - But it wasn't his fault it was just circumstances

And so it went on for a couple more hours and then they said, "I don't think there's anything we can really do and you'll probably have to make a decision. You don't have to make the decision right now - talk amongst yourselves. I went in and saw him again and thought, 'What will we do?' I thought 'is there any chance here? Is there any point in lingering? Is it going to change? And physiologically there wasn't any hope of change because his brain had died-his brain stem had died and he wasn't getting any nutrients so he was virtually–no he wasn't even a vegetable – he was dead. I thought I can't bring him back; no doctor could bring him back at this stage so I think that's what he'd want and I said to the doctor before he, well the nurses did it really. I asked, "How long would he last if we just left him like this?" She said, "Five days possibly, his heart would go out." And I'm sitting there before all of this is happening and I'm thinking, "Now, I might have to go back home, take him to a nursing home and look after him for the rest of my life like this!" I did not know how these sorts of situations were looked after and that was the vision I had - it was overwhelming. The nurses said, "Well there's no nursing home will have this. It's only a hospital situation." Well that sort of nearly answered [my question] there.

Then I went back out to his family and said, "What would you like to do?" They said, "You make the decision-you're next of kin." So I said, "Well, he's 'brain-dead', they're just keeping him alive and I could hear Grant saying (*tears and very choked voice here*) 'What are you waiting for? Turn it off!'" Because he hated people who couldn't walk, he was always very active and not to be able to get on his horse, he wouldn't like that. So I think he'd say, "Finish it!" I said, "Right, we'll finish it." So the priest was there, who read him the last rites, a couple of nurses were there, his sister wouldn't come in but his brothers were there. We were all standing around and they just switched it off and it was so fast, it only took two or three minutes-very fast. 'Cause I said to her (the nurse) "How long is this going to take?" and she said, "Not long at all, once they've switched it off." He was a beautiful pink colour and then he went not a light brown but a very -what's the colour- grey? That was it and we walked out. (avoidable suffering related to absence of support/ Pastoral??)

Coda

Now, I'm still feeling angry with myself for not knowing everything I could about the operation – not knowing all the odds [despite all my research]. But it was Grant's choice to have the operation-to try and have a quality of life. You have to balance the pros and the cons; the dangers against the possible benefits. The main feeling though is disappointment: for the surgeon who'd done all the work and found the problem and wouldn't see Grant wake up and say, "Oh that feels better"; at missed time with Grant- not getting to find out and hear how good he felt post-op; at not finally being able to give Grant a kiss without him saying, "No, that hurts too much." Why did this have to happen to Grant- why did he have to be the one in a hundred? I was told the cause of death was cerebral oedema [and the results of the post mortem confirmed this]. Grant was an artist so, with the Trigeminal Neuralgia, he hadn't been able to concentrate and do much painting and the Tegretol was changing his character. I was looking forward to him taking up all the commissions he had waiting for him when he came home. It was just like a journey from when we started looking into the operation – its pros and cons – you start here (*laying out an imaginary line on the table top*) and you end up here (*pause*) without him. It's just like (*tears*) Grant's done this so I can move on to something else. And I am, I suppose, meeting new people in my job and doing new things.

RUTH

Ruth is a registered nurse with over five years' experience; she is now studying for her master's in midwifery. She was keen to share her experience and perspective as a family member faced with the decision-making related to a loved one's final illness in critical care. Ruth's experiences were perhaps shaped by the fact that both she and her husband, Nigel, worked in the hospital in which this story takes place.

Nigel's Mum, Marg, collapsed at home on the Friday night, after she came home from work three years ago. Marg was 42, so she was only very young. She was doing the vacuuming in her uniform. She just hit the floor unconscious . We got a call from Nigel's sister, Anne, who was 15 at the time: "I can't wake Mum up!" [I asked] "Have you called an ambulance?" "No!" "Right, get off the phone and call an ambulance and then call me back" So she called an ambulance-didn't call me back. I'd said, "Take her to … (the level three health facility in town) and we'll meet you there." Anne raced over the road and got the lady over there and they rolled her on her side. The paramedics went out, luckily, because they didn't know what they were dealing with. She was intubated at the house and taken to A&E.

We got to the hospital and the ambulance wasn't there. We were waiting for the ambulance to come. They really didn't know what had happened; whether she had had contact with one of the young girls where she worked who had died of meningitis about 2 weeks previously. So they thought meningitis; they didn't know whether it was a drug overdose-they were covering all the bases.

I had great trust in the doctors. I think from the moment we got there (and I think that's scary actually) it [her care] was handed over. So, it was automatic; I felt like the best that she could get was given and she wasn't just another patient. She was our mother – and they really took care of her. It was hard for the nursing staff too because a lot of them knew us and it wasn't just someone else's mum it was Ruth & Nigel's mum: it was our Mum. Yeah I had trust in them. I knew I could go away and come back and they were taking care of her. And they would find out what was happening, they would work out what was happening and they would fix it, like:

meningitis – they've got her on the antibiotics – they'll fix it. (belaboured this point – avoidable suffering R/T anxiety/ inherent lack of trust & knowledge of the system?)

She had a C/T scan that night and it showed just cerebral oedema and bleeding. They couldn't see a source of bleeding at that stage. She was intubated and ventilated; she had no spontaneous respirations. She moved her arm when they slid her from the trolley to the ICU bed and she might have had one breath then, as they moved her onto the ICU bed and that was all. That was the only reflex-type-the only movement they saw. So she was ventilated on the Friday night. Of course, I went home Friday night to pack a bag, thinking, you know- "She's going to be fine, she'll wake up." They waited overnight Friday night to see what was happening. Then over Saturday, Sunday there was nothing. They C/T'd her (*a cat scan of her head*), they did everything Saturday morning. Then she had a lumbar puncture and another C/T in the morning and by that Sunday I started to think. "She's not waking up!" We had nothing, no eye movement-nothing and looking back; how dumb were we? (Avoidable suffering R/T slow clarification of information). We saw that C/T on Friday night; we saw that swelling of the brain and they kept saying to us, "Has she been unwell?" and we said, "No she's been fine." They said, "With the severity of that swelling you would think she'd have had some symptoms previously." Then Monday morning came and everyone had reviewed her. They'd had Dr… from private practice in to review the C/T scans on Saturday; they'd had two different consultants from the hospital in to review her-everything, all the blood tests you could imagine. They'd treated her with antibiotics thinking it was Meningitis; they just did everything. And then it wasn't until post mortem that they found a berry aneurysm was the cause of the haemorrhage. So there it was and it just popped, so we didn't know that until the results came back. That was the story.

Over the weekend she was just so cold and you're sitting there and you think she's going to blink and you think she's going to squeeze your hand. And we just talked to her: "I'm feeling well and I can feel the baby moving (*Ruth was pregnant at the time*)" and I can: remember Princess Diana had died at the same time. So we're sitting there, in ICU with the TVs on watching her funeral and I'm thinking "God!" And. that's like a reminder every year too, every year it's like: "its so many years since Diana died" and I think: "Tell me something we don't know". Yeah so that's like a reminder every year. I still had hope, as much as I should have known that there was no [hope of] recovery, I still thought "She's going to wake up and she's going to talk to me and she's going to come out and wash the [new] nappies with me, like she planned to on Saturday". Yeah, I still thought, we still thought, that was the on the Saturday, by the Sunday Nigel and I thought: "She's not waking up …" We still had hope (avoidable suffering r/t unrealistic expectations).

Nigel and I went home on the Sunday night and we thought, 'She's not waking up!' We knew in ourselves, and I mean you still have hope all through that weekend: 'It's just an infection, the antibiotics will kick in and she'll wake up' and all that sort of stuff. Then Monday came and Dr … (intensivist) came in and talked to Nigel and me and Archie, Marg's partner, he's a man who's never made a decision in his life. She was always the decision-maker and the planner in the family. She would always lay out his clothes for work every day. He never decided anything except what sort of car they wanted. So he looked to Nigel and I to make that sort of decision (avoidable suffering r/t burden of decision-making – might be shared). Being in the field, I think he trusted our opinions.

She didn't have dialysis or any thing like that. She was just on all these different drugs, you know, Adrenaline, Dopamine, Dobutamine and so many different things that I can't remember them all. And that kept going; at no time did they cease anything. Then she had two physicians review her – checking for reflexes - to see if there was any response. That was done Friday and Saturday & Sunday and there was nothing. So come Monday morning we had a family meeting– she had seven brothers and sisters and their partners and us, and my mother was there to give support for Anne being 15, you know, just not knowing what was going on. And Marg's Mum and Dad were there. So we had the meeting with the 'voices', the knowledge and they said this is what's happening, "There's no response"

[There were the] two consultants who had been in over the weekend and a registrar who knew Marg's case and two physicians who had been in over the weekend – they had their notes as well to say what they had found and we'd spoken to them as well.

Any one who'd reviewed her came and spoke to us and told us what was happening and Nigel and I would translate for the rest of the family (avoidable suffering R/T burden of supporting family in their own grief), and you say it quite simply: "This is what is happening" and they say "Oh right" but you still think in the back of your mind, "it's going to be OK, she'll wake up" you know. "She'll be fine."

And then on Monday, this is what's happening: We can continue like this indefinitely. Her systems will gradually stop working and we'll have to put in counter measures to
like "pick the kidneys up" was what I remember. She's had no spontaneous breathing. She's had no spontaneous or involuntary movements since Friday night. They said that one arm movement was probably just a reflex or a bump during movement from the trolley to the table. They couldn't definitely say it was voluntary movement until they saw more. There would have been about twenty-five people in that room (avoidable suffering R/T overwhelming communication context/venue). Everyone was there and they went through everything from admission – this is what we've done, this is what we've found, this is what 's responses are and this is the outlook – any questions from the family? Her brothers asked are there any other tests, or could you have operated? That was a big one – cause I was thinking if it's a blood clot - could you have stopped it happening? But with the location - we found out later with its location of the aneurysm – you couldn't have clipped it. So there were a couple of those sorts of questions

[She just had a massive bleed] and the oedema was so massive by Friday night that they thought it had been going on for a long period of time – that's how they didn't understand how she'd been well so long. Earlier in the week she'd bent down to pick something up and said "Ooh!" and that was it! You know; how many times do people have a headache, take a Panadol and keep going? She'd done that and I'd thought at the time, "It's nothing". But looking back… But when the decision was made to turn off the life support - Nigel and I made it (avoidable suffering R/T burden of decision-making). Her partner, Archie made, well set the time. But the decision was made based on the information given to us and I felt it was honest and it was substantially backed up by other doctors. It wasn't just one person's opinion – we had several people's opinions and it was people with different levels of skill – like some were the anaesthetic doctors – some were physicians. We had the C/T experts – the radiology experts up there reviewing the scans – cause the next day they could say –"There's the source!" – by the next day they could trace the source of the bleeding 24 hours gave a different picture – so as hard as the decision was it really wasn't our decision – it was made for us (avoidable suffering R/T sense of loss of control).

So that was Monday morning and the decision was made really. They said I remember: "Every part of Marg that you know is gone – every part of her you know is gone!" So we thought, the decision is made. We couldn't see her suffer like that for another two or three weeks or whatever – it was finished. It just had to finish. So that morning after that family meeting we went away – they'd taken Marg's father away and sedated him – he has a heart condition and he wasn't coping. So we couldn't do anything at that stage, we had to wait for him to wake up. The decision was made: "Yes, we need to turn off this machine." And then it was up to Archie, her partner, for a time, you know, when will we do this? "We'll do it 5 o'clock this afternoon." That was just terrible because the three of us as a family: Nigel, Anne and I needed to do it then! We needed closure, because we didn't want her to suffer another 6 hours. Yeah we just didn't want to prolong it. But then I thought he was her partner and he needs to be here so we said 5 o'clock, which was good because everyone had that day to say goodbye.

That was good, every one had time to say good-bye because the staff was really flexible. All the brothers and all the sisters got a chance to spend some time with Marg. And Father R… (pastoral care) stayed with them while with Father T... stayed outside with the family. It was a really long day, cause everyone was watching the clock, you know, "…only an hour to go". And then we said a little prayer, they just turned the machines off and they extubated her and everybody sort of left then. I stayed and sat with Cheryl who is her sister, because her heart was still beating – and you still think she's gong to breath! (avoidable suffering R/T to 'technological death'). We just sat there until her heart stopped beating. Cheryl wasn't going to leave her, I said, "come on Cheryl it's finished." And she said "No, her heart's still beating.' So we waited, and waited – (*sigh*) and what really struck me having been a nurse for years at that point, she was cold so quickly and the colour just drained. As soon as the machines were turned off the colour just drained- she was blue- as if she had been gone since Friday- just the way her colour drained so quickly.

In hindsight? Knowing what I know? [what would I do?] Oh I would have left her on the floor at home (*whispered*) but that's with all the knowledge that I now have yeah I would have sat on the floor at home and held her hand, But then I think "How can I take that time away from her family?" Ah the girl would do that just to save all that suffering from Nigel and Anne. I would just…but you don't. We didn't know what was happening. Yeah, I would have liked to say: "Just sit on the floor and hold her hand and we'll be there." And then gone and there and both held her hand. And that would have been a nice peaceful, less invasive, less prolonged death than that intensive care, controlled: "You will die at 5 o'clock this afternoon." You know, it really was controlled – everything down to your pressure area care. Every 2 hours we will turn you from this side to this side. We will brush you teeth now because this is time we do it, we will wash you now – and these were her last three days on earth (avoidable suffering R/T controlled technological nature of death).

LLOYD

Lloyd heard about my study through a third party and indicated his interest in contributing his story and experiences to the project. Lloyd's partner required admission to critical care because of secondary problems related to a large hepatic mass. The detail of her medical condition will become apparent as the story unfolds. While Lloyd saw the moves to ICU as being vital to his partner's well being, he did not see himself as being directly involved in the decision-making. He shared his experiences in a telephone interview:

Not that I was involved in decision-making as such. At times, often I had to ask a question: Why or what's going on here - because people were just doing their jobs

They know who your are and they treat you with a great deal of respect and kindness, but information-wise you can still be in the dark a little bit unless you ask a few questions of the right people at the right time. It's very hard to know what to ask

- because you're uneducated, really as to what people are doing. Really the only reason that I was aware that Judith was going to be placed in ICU was the simple fact someone came and said "Look we've got a problem" - and then she's off, she's there! That was when it *was* possible to see her - that was that evening - we would have gone probably from the middle of the day to that evening until I could see her (avoidable suffering related to absence of support/information).

Her original problem if you go right back to the start of things appears to be a massive benign tumour on the liver. This tumour has been described by two individuals as massive. We started off with this problem 6 - 7 months ago - there were a number of biopsies done. One surgeon who did the original thing looked at it and was quite taken aback at the size of the tumour and the amount of liver damage. He described it as massive and really couldn't understand why it wouldn't be malignant with the size that it was. He referred her on to the specialist in transplant surgery, he believed this would be the only possible way it would come to any conclusion or solution. That man has then gone on and done similar work only to a greater extent trying to ascertain what they were dealing with - but it proved to be a benign thing that's associated with the liver. They'd gone in and done a rather major biopsy. They put her into ICU the first time - that was just after she was operated on - because of the ascites that was attendant with the problem. She lost about 6 -7 litres of fluid around the tummy area when they opened her up to have a look. With that major fluid loss, at that stage of the game she was listed as dangerous and placed in ICU for about 2-3 days.

From that she went back to a normal ward. She was there for about 3 - 4 days, progressing along quite nicely, in a lot of pain, which is to be expected. They were controlling that with the use of the morphine in a little pump with the trigger that you press when you need it. They'd been putting in enormous amounts of fluids - about 6-7 litres in and about 6-7 litres of the ascites would drain out and what little bit of urine there was.

Suddenly her haemoglobin levels dropped quite markedly. *Bang* - they've gone immediately into action. Its quite surprising how quickly people can get things to happen really. But any way, they've organised with the critical care unit...(*at this stage of the interview there was a sudden profound silence on the other end of the phone, long enough to prompt me to enquire if Lloyd was still there).* I'm back - they organised with the critical care unit to take her on up there, ah... There is a point when there's some things that you just can't help, you tend to ah, pray a bit. They're not exactly pleasant memories. […]. At one stage, they started that process off and you stand there with your jaw on the floor. (avoidable suffering related to trajectory of loved one's deterioration and absence of support/ information).That's probably the first time I'd really become - oh, lost the plot emotionally I suppose, much the same as I am now. Any way as they wheeled her off up there, the nursing staff - there were a couple of nursing staff there and they just took one look at me and came over, had a few words and one in particular was off on her break and she grabbed me by the collar and said, "I'm buying you a coffee". And she just got me out of there and sat me down. She was a nurse with transplant experience, she more or less just sat me down and brought me back to earth, calmed me down quite a bit. Something I was very grateful for and still am.

I didn't know why or what was going on until later that evening. The first I knew about the internal bleeding would have been just before I saw her that evening, whereupon the registrar from the ward where she was taken from told me what was going on and the fact that she had these veins at the bottom of her oesophagus that had ruptured, burst or done something. They'd taken about 2 litres of blood from her stomach and they put several units back into her again and her condition was not real good but stable (avoidable suffering related both to absence of information/ news, and waiting or prolonged separation from loved one). Next step was I was allowed to see her and the nurse who was actually looking after her met me in the corridor briefly. She had a reasonable sort of smile on her face introduced her self to me: "Don't look so glum you'd be amazed what we can do in here" and I was.

And that's something that can be said for nursing staff I've met as a rule right through, but particularly for staff in ICU. They're well concerned for relatives themselves, whether it be real or imagined, but that is definitely the impression you get. Given that a lot of [their work] is fairly mundane. They're sitting there hour after hour monitoring what's going on and changing things that they need to. Yeah so that probably helped me a little bit that way rather than to front up into a room full of different people in all sorts of attitudes with all sorts of gear hanging off of them and I will say they are a very off putting place to walk into, there's no doubt about that - busy, noisy. There's some very sick people scattered around a very big room, just one big open plan, there's all sorts of equipment making all sorts of noises. You sort of waltz across and here's someone looking absolutely dreadful with more tubes and wires and God only knows what sticking out of them and in a very distressed state themselves - you know, not totally lucid - but know that you're there - panicky - not panicky - but knew that she was in a lot of trouble.

[I wasn't involved/ included] in decision-making at that point and not really at any point at that stage. They just more or less did what they had to do. Their biggest problem at that point was to stop this bleeding which they explained to me earlier, "We may be able to - we may not be able to". Being where it was - down at the base of the oesophagus and trying to get access to it - really there was nothing I could make a decision on - it was just a case of being aware of the situation as it was going on - depending upon how successful these people were and what they were attempting to do. After that it was just a case of being there and letting her know that I was there - at which point she was quite distressed.

A lot of things had been decided prior - but you wouldn't want to say you were kept in the dark as such. They would make a decision on what to do or they would think, " Well we'll do this " and then they'd come to you and say, " We're going to move her or do this or do that". You did get to a certain level of involvement in the decision - they'd say, "this is better, that's right and this is right and so now she's good enough to go back to a much better environment". Even those people would admit that ICU is a pretty wild place to be (avoidable suffering related to sense of powerless/lack of control).

At that stage of the game I felt pretty ordinary, but from previous experience, when she came from her operation to the intensive care unit as she was pretty groggy and then started to come out of her anaesthetic - probably a bit more prematurely than they were expecting her to do - then at that stage of the game she looked up to me and I just burst into tears. That led her to conclude that there was something amiss that she wasn't being told so after that I avoided being upset around her at all. Which ain't easy any way - just don't do it, her mental state is just so fragile - just don't do it! Yeah *(sigh)* - so while she was in that second bout or the main bout of intensive care we avoided that sort of thing like the plague. I was upset, of course from time to time but I'd just have to duck away around a corner or down the corridor for a second and come back so that I didn't transmit my concerns to her. It needs to be said she could pick up on my reactions extremely quickly. You just have to rein in your emotions as much as you can - it's extremely hard - you still get the watery eyes but you can disguise that a bit. Judith's - you know not as high as a kite but fairly well knocked out the pain killers - the morphine and whatever.

I think it might have been that day or the following day - no, it was that day - the same day that he'd explained to me about her condition - the surgeon who Judith had been under when she'd initially come into hospital was on the phone. This fellow said "Come over here and talk to this doctor [the surgeon] - he wants to talk to you and talk to me" - so we had a bit of three way conversation via the phone whereupon the intensive care doctor stood beside me and handed me the phone and I talked to the other fellow and he said "I believe Judith has had a couple of better days" - he was the only one who did - the intensive care doctor beside me was just about ripping his hair out! You could see him mentally thinking "Whoa back pal! - You're throwing too many decorations on this one" He sort of said you've got this problem still there and you've got all these other problems - her kidneys still weren't working all that well- who knows what else? That man was obviously very concerned about her ability to survive that next 24 - 48 hours. Here I had one man telling me things should be OK and the other man who's doing the job going "Oh I don't know about that" He didn't want to tell me that nor did he express that in words to me but his body language was good enough - you didn't have to be a psychologist or a rocket scientist to work out what was going on. But at the same time the man [intensive care registrar] was quite supportive and reassuring - he was the only one I really spoke to about what was happening - what was going on.

They were making sure that I was aware that transplant was in at that stage. That I understood that was the only way we could go forward at this stage. I said, “Yeah, we’ve talked, there won’t be any problem getting Judith to consent to that particular process - she knows that’s it”. Actually, the day that they decided they were just baby-sitting her, [the day before she was transferred back to the normal ward] a whole clutch of them including the main man came down and politely and pleasantly said, “Transplant’s in because there’s no other action we can take”.

Probably the only other thing that really gets you on edge apart from the fact that the joint is noisy all the time is the fact that people gather at the end of the bed. Yeah, good this case is very medically interesting, someone’s going to write a nice paper when it’s all finished one way or the other - but when you get groups of 5 or 6 doctors and lord know who else, sometimes you don’t know who these people are, having great discussions at the end of the bed in a very impersonal way: “we’re the only people in this room - blow the rest of you”. I wouldn’t call that emotionally good for anyone - anyone with the patient or the patient themselves. It makes you angry at times it really does, because they’re distressing the person that’s on the bed and you can see that distress. They’re not happy about themselves being talked about or them talking about the persons on the other side or anything else. I know it definitely angered Judith, she told me it did - very much so. She was very upset about the whole idea of that - not the idea of being referred to as a piece of meat or anything like that - but the noisy discussions that go on all hours of the day and night. I think time became hard to pick for her - the joint never stops - the lights never go out – it’s organised chaos because obviously they’re dealing with people who are very sick, probably just about as close to dead as you are going to get. And you’ve really just got to put up with - well not put up with, but be aware that these people need their help as well, you know, you’ve just got to wear that, but it is a bit off putting, particularly if you’re not used to walking into such a place. (Avoidable suffering related to communication venue/lack of privacy)

The doctors that I came in contact with - really there was only one that I had a lot to do with at the time - really you would not complain about their attitude or their compassion or anything really. They didn’t pull any punches, they’d tell you the full story - you do need to know the full story - whether you want to hear it or you don't - if you don't want to hear it at first - later on, when you've pulled it together, yeah - you need to hear it. But this is all part of the process - I think if some one had withheld things from me I would have got quite upset thereafter.

I mean things happened and people did what they had to do. You're there and they realise that you're an important part of the whole procedure - but when it comes to the meat and potatoes part of the whole deal you've just got to stand back and let the people who know what they're doing do what they do best. Which is in the long term pretty damned obvious - they knew what they were about. When things did go astray the gear was there, the expertise was there - if she hadn't been there it's highly likely she wouldn't be here today.

HARRY

Harry is a science student. Harry told me the story of his mother's admission to intensive care and final illness. His mother, in her early fifties, had had an extensive and complicated abdominal surgical history. This had started with an appendicectomy at age 18 which had been complicated by septicaemia and adhesions. Prior to the story that Harry relates, a variety of surgical interventions had been tried over the years to reduce and avoid the adhesions that plagued his mother's life. This history culminated in the story Harry shared with me. Harry talked in a quiet, controlled voice dropping, at times, to whispers. Throughout most of our interview, his eyes brimmed with tears but these were not shed until those times when he was talking about witnessing his own father's emotions:

Each year, probably for the last five years, my mother's been going in and having surgery to relieve adhesions and having a couple of different techniques to try and prevent them growing back- one of them being a 'wrap' to go over the bowel. [This time she was to have] a new procedure – the introduction of Introgel - they put it into the abdominal cavity to coat all the abdominal organs to stop the adhesions growing. Mum was willing to try, not necessarily anything, but she trusted Dr X. He's been her surgeon for the last five or six years and came recommended to her when she moved up to Queensland. Mother had got to the point prior to surgery where the pain was pretty extreme-she was on Endone.

So early June, she went back in and the first operation to remove the adhesions on the Monday was quite lengthy. They couldn't put the gel in at that time because the operation went about 4 hours. She had that and they ended up giving her an ileostomy again at that time. They said they would put the gel in on the Friday. After that she was on high levels of Morphine for the pain and she was really off with the fairies. That was quite difficult.

On the Friday she had the other procedure. Dad and I always go down, and while she's having the operation, we'd sit and wait somewhere. The surgeon always comes out and lets us know what's happened. He seemed happy with the procedure- there was good coverage and everything seemed fine. Again she was on high levels of pain medication for the next few days. That was the Friday, then Saturday, Sunday. By Monday it was decided that she just wasn't getting any better; they were saying that they suspected infection. On Tuesday they decided they'd better go in and have a look. That wasn't so difficult because I suppose we were reflecting back on last time when this sort of thing happened before so we weren't overly concerned.

While we were waiting in pre-op, Mum was very sleepy because she was high on the morphine, but the last thing Mum said was, she didn't want to have another operation. But she went into the operation and we waited until she came out. The surgeon, Dr X came out and said, 'Yes there was infection'. He said he'd flushed the abdominal cavity out with 6 - 8 litres of water or something to get rid of all the infection and he said he was pleased with the gel, that that still seemed to be in place. He said that she would be in ICU overnight. This was what happened last time too.

She was in ICU overnight so that they could monitor her and we thought, 'that's happened before and she's fine'. So we thought we'd go and have some tea before we went home; this is getting to about 8 o'clock at night. […] Then we thought we'd go back and see her before we go. So we went back to ICU and were waiting outside. We were waiting for quite a while before they brought us into see her. The doctor came out and said, "She's a really sick lady." The things that I can remember that sticks out in my mind were: that she'd aspirated stomach acid into her lungs; that's the main thing. That was the initial thing that stuck in my mind because my aunty reminded me of it when I was talking of it later- but I don't remember much of what the doctor said at that time. [He told us] also that the infection had spread (avoidable suffering related to earlier limited or inaccurate information from surgeon).

I was thinking, "This is a lot more serious". The way Dr X had come out of surgery before it was just like "Yeah this has all happened before, it's all alright." Then this was all a huge shock for us to hear that she was actually a lot, lot worse than the surgeon had said. So I suppose initially, I suppose it was shock. I suppose that you just deal with it, you think of too many other things that you need to do so that the emotional side things just doesn't come into it in that very initial half hour or so. And then it was after the doctor had gone that Dad and I said, "We're going to have to start calling people". […] The first person I called was Dad's second eldest sister, who's probably a bit more of an organiser. Anyway I rang her to let her know. My cousin answered the phone; I was fine talking to him […]. As soon as I spoke to my aunt I couldn't say anything, I just broke down – burst into tears. And then she was in tears; she knew Mum was going to have the surgery. It was when I had to actually tell someone else. I was fine listening to someone telling us what was happening – you could sort of take that in, but when I had to actually tell it to someone else, it really hit home probably about how serious Mum was. That was really hard. I don't remember too much after that.

We did go in and see her that night - the doctor explained everything very fully. He was a very nice fellow - an anaesthetist. He ended up being the doctor that Dad had the most respect for. I suppose it comes with age- he was in his mid- fifties. He had a manner, and an ability to explain things. I remember him asking what level of knowledge we had. He didn't ask me in those specific words but he did work out what we wanted to know and what detail we wanted to go into. Dad reckoned he was quite possibly up to his third year of medical degree with all the 'going's on' with Mum (*chuckle*). So he told us exactly what was going on, didn't hide anything or try to tone it down. When we walked in, I think because we were forewarned about some of what was going on, it was easier. She was fully on a ventilator and heart monitor and numerous - I was pretty “taken aback”. I don’t really remember a lot about that night so I’m trying to picture what happened later on. What I saw initially there, we also saw for the next few days. My initial reactions, sort of were probably shock – yeah shock.

Any way the next morning, my aunts and grandmother and sister were all at the hospital at 9 o’clock. That was great to get them all there in that short a time. I arrived back in Brisbane soon after them (*Harry had been home to tend to the dogs*) - it was probably only about 9.30 or 10 and they’d all gone off to get coffee or something like that. Apparently Dad was looking for me about then. I struck him coming out of ICU and he said, “I’ve just got to go and make some phone calls.” So we went out to the front of the hospital and he was on the phone. My father who is very… it’s not right to say he doesn’t show his emotions, just keeps them inside. Dad was phoning his boss and he just said, “Look, I’m going to have to talk to you later.” That was difficult (*pause & sobbing here*) cause that’s the first time I ever saw my father break down. We were just out the front on the bench near the entry, our arms round each other – that’s what was really hard for me. But it was really nice, a lot of people in the office just behind where we were sitting came out and said, “Are you OK?” and “There’s a room where you can go to if you would like.” They were really good.

Then the days just sort of ran into one another. After the operation on the Tuesday night we were told she had an infection that just kept going – Necrotising Fasciitis. They were saying that the problem was the toxins that get into the system, the kidneys, the liver and everything working overtime. We were told initially that if she gets through the first 72 hours her chances would increase greatly – at each point the doctor spoke to us in percentages. He explained the reasons, how they worked out the percentages. It must have been the Wednesday, that’s when things started shutting down – the kidneys, the liver, and she had the damage to the lungs – so they said she had 25% chance ‘cause each of those systems counted as 25%. On the Wednesday they put her on dialysis and they also had some sort of new machine that they put her on which was some sort of heart monitor, I think – one that they hadn’t used before. Thinking back on it - I think possibly [they used the percentages] to give us an idea of what was happening with her and I think - it was a way of saying the chances are more against than for and it was possibly better for them to talk in percentages rather than saying, "it odds on she's going to die."

We'd take it in turns going in and being with her. They allowed us to go in whenever we liked – there was only a couple of occasions when we had to go out cause they were changing her or whatever, but the whole lot of the time we were there the doctors and the nurses just worked around us which was fantastic. At one point the priest did actually come and say the last rites for her – yeah – everything just starts hitting home then. You keep hoping that things; you've got this hope that nothing's real. The unit's on the third floor and it had big windows and you'd be holding Mum's hand and looking out the window, trying to detach yourself. I don't know if you can, just shake your head and tell yourself, "This is not happening."

I remember thinking earlier on, because I was watching the machines looking at the oxygen saturation and things like that "What else was going on?" The doctors had never spoken about the possibilities of brain damage or anything like that which I had thought of myself. One of my mother's sisters, she used to be on the board for the fund raising for the Victor Chang Foundation so she has a wide range of friends and one of them was a professor of intensive care from Sydney. On the Wednesday she rang him in the afternoon to seek his opinion [about Mum]. She did tell us that she was going to ring him, so she went off to use the mobile and as soon as […]she came back and I saw her face I knew that the news probably wasn't good. […]. He'd actually rung the doctors and got information directly from them and he said to my aunty, "Really you've got to prepare for the worst." So that was really difficult for her to put on her shoulders. I don't know whether the doctors thought if we tell them the chances that we've just worked out ourselves – what their results possibly would be or what.

Everything seemed to be improving. We took in every- every tiny bit that was a positive sign - I suppose we thought of it much greater than it really was. I had an exam due on the Friday morning. […] I'd seen the unit leader just to say that this had happened and to say that, "I don't know that I'll be able to attend the exam" […] The unit leader was good - he had said arrangements could be made either way […]. But Mum was slightly better [on Thursday night] and so I went home to do the exam Friday morning.

I didn't sleep well. Dad rang me on the Friday morning and he was quite encouraged. […] Things were finally at a point where - things were slightly better. So he just wanted to let me know before the exam. As soon as I arrived back, I just walked in the door and dad was coming out of ICU and straight into my arms in tears. That's when everything just started going downhill. After the surgery she'd had heart attack. That was about midday on the Friday – so we just kept up with still being with her all the time. But we still had this thing about the times – 'if she got through the 72 hours' that was still in our minds and then you have a big set back like that heart attack.

Then it was during that day that the intensivist came out and said that she was on the highest doses of Adrenaline- they were "just off the scale", that he'd ever seen – he'd never given anyone that much before. I think they were talking about down to 4% chance at that time but Dad was always – he said, "If that's all we've got to work with I still want to continue with the interventions". It was later that afternoon when Dad and I went into see Mum and we were talking to the guy who was the doctor in the hospital on-call, the registrar. He was a younger guy who Dad didn't particularly like; possibly because he didn't explain things in the way that the intensivist did, probably because he was a bit blunter. That's when I brought up: if she went into cardiac arrest what would you do? He said, "Well I'm glad you brought that up." Basically he said they didn't think she'd last through the night. He said he wasn't going to aggressively try to revive her. He said because her body was in such poor shape there wasn't a lot of hope of bringing her back. *(Long pause*) So [Dad said] he understood- that he was resigned to the fact that she was probably going to die that night and he just said that: Well, he understood that thinking that "they're not going to aggressively try to revive her".

None of us got much sleep over the whole time – I think Dad probably got the least. We were staying at a motel just across the road, so he went back with my grandmother and Mum's youngest sister to have a sleep while I stayed with Mum's two older sisters – they'd provided a room for us. It ended up it got to about 1am or late any way and as I was nodding off. Margaret (RN) came and said' "It's time- she's not going to last much longer." So we rang my father and he came over. We were all around Mum's bedside which was really difficult - it was good they came straight over - but and it's hard to say it's not going to be very long.

It was difficult watching all the machines - we watched the heart monitor - watching her BP going down - watching her going into asystole, it was really hard to watch – and you're watching a machine - everyone has their eyes on it. I thought at the time that it was an odd sort of feeling – standing at her bedside and all the focus is on the machine sort of thing. Constantly looking at Mum but then you're looking at things slowly drop. You're told she hasn't got much time and that – you've prepared yourself to watch – in a way what you're watching as it drops is an indicator of how much time she's got – it possibly was a bit of a detachment thing, I'm not sure. It was also weird that she'd have asystole and then the heart would have a few beats again. I suppose at that point you think, 'well, the inevitable is going to happen, when's it going to happen? Is it just going to be drawn out' It probably happened quickly – in minutes but it just seems so drawn out and longer.(avoidable suffering related to technological aspect of death)

In a sense it was almost a relief [when she died] because we'd just gone up and down from the shock and then hope that she was getting better and then I think once she'd had the heart attack on the Friday morning we had probably almost resigned ourselves that this was going to happen. It was actually 3 o'clock on the Saturday morning that she died. The nurses said, "We'll clean her up, take all the tubes out so you can see her." The nurses were absolutely fantastic – they were very comforting right the way through. So we went out to the lounge room and just sat down and – we'd called the local catholic priest and so he'd come in. Then we just said a prayer and basically walked back to the motel – I remember it was a beautiful night – it was almost a relief, I suppose we thought of it as a relief for Mum too that she wouldn't have been in any pain or suffering any more. Then we basically sat around and talked for a while which was really good – we didn't sleep – we couldn't sleep.

1.3 THE NURSES' VOICES

PETA

Peta has had broad critical care experience, having started in her specialty area soon after obtaining her baccalaureate. She has worked in a variety of metropolitan and regional units throughout the country for the last 12 years.

The one that sticks best in my mind was a gentleman who at the time was my own age. I would have been about 34, I suppose, and he had a sub-arachnoid haemorrhage. His daughter found him collapsed on the bathroom floor and called the ambulance. They took him into the nearest hospital. They 'tubed him, brought him into us, and he was basically brain dead when he arrived, but had had some muscle relaxants so we couldn't do anything until those had worn off. He had two daughters, the same age as my daughters. And his wife had died six months previously of bowel cancer. So the day that he came in the children weren't brought in. His mother and his wife's mother and several of his siblings were there and they came in and were basically told that, we were just waiting for these muscle relaxants to wear off. He'd had CT scans and there was nothing we could do. They discussed organ donation and decided, no, they didn't wish to go through with that. And so (*pause*) - I was on the late shift that day, and on early shift I was given the same patient – this man. At about ten in the morning they brought the children in.

They were six and nine at the time. I had a lot of trouble dealing with this, particularly because he was my age, and his two daughters were the same age as mine. No one had prepared them for what they were going to see; no one had, and no one was telling them that their father was about to die, and this sort of stuff. And so I met them at the door and told them exactly what they were going to see before they came in; described the tubes, the wires, the machines, all those other things, but I said, "Apart from that he just looks like he's asleep, you know? There's no need to be frightened, everything looks, I know it all looks awful, but he, just looks like he's asleep. So don't worry about the machines and things, just look at him". And so they came in and all the rest of it and, I mean everyone was in tears, myself included. And (*pause & deep breath*) when they were about to leave, the grandparents who were with these kids said, "Okay, well we'll go now". And nobody said to these children, "This is the last time you'll ever see your father". And (*pause & sigh*) I said to them, "You better give him a kiss, eh?" So they did that, and then they left.

Now I had a lot of trouble dealing with this from their point of view. I had major issues for myself as well, because as the only person in the unit in that situation, you know, with the kids the same age and all the rest, but I felt that perhaps I shouldn't have had that that patient two days running. But it was felt that I was the person who would deal best with the children, which was probably correct, so I don't know, six of one and half a dozen of the other. So yes, I had problems with that. I had problems with my colleagues who were, some were somewhat supportive, but in the main they were trying to cheer me up by telling me jokes and it was, you know, inappropriate in that situation (avoidable suffering related to level of support from nursing colleagues). So I had problems with a lot of things that were happening at the time, mainly with the fact that the children were not informed of what was going on, and I think in situations like that, even though they're not very old, they need to be included and told what is going on. Because if I hadn't said to them, if you want to give your Dad a kiss goodbye, in ten years' time those kids would be thinking, "I never even kissed him good bye" You know? And I was unable to say to them, you won't see him again, because the family had said, oh well, we're not telling them.

They purposely didn't tell the children because they didn't want to traumatise them. But from my point of view, it's more traumatising not telling them. And, I mean I've had no contact with the family of these children since, so I can't say whether what was done was the right thing or the wrong thing. But it just didn't sit well with me that, in that situation; these kids, were left in the dark. So that's probably the most traumatic life-ending situation of any. And they did the brain-dead test at half past two and said to me, okay, you can turn that ventilator off. And I just looked at them and said, "No. You can turn it off, I'm going home". And they just looked at me. And I said, "I've had enough, I can't cope, I'm going". So, you know, that would probably be the most traumatic experience I have had in an end of life situation. I've been involved in quite a lot of them, having worked in ICU mainly since finishing my training, and I find that a lot of your work with families in making decisions is very informal. And a lot of it is just listening to what they have to say and helping them crystallise what they want to do. By saying, you know, maybe we should do this, maybe we should do that, and they say well what do you think? And I say, " Well it's not my decision," you know, because it's not my father or whatever, you know, "What do you think this person would have wanted you to do?" and "How do you feel about that?" So yes, a lot of it is helping them make their own decisions. I don't think any of us have a right to make that decision for anyone else.

And I have my own beliefs, which would be diametrically opposed to many of the people in the beds and their family. But I don't have any right to tell anyone else, and I really don't even like to voice them to the people who I'm caring for, because it's not my role to impose things, and when people are in a situation where they're vulnerable, they might snatch at something I've said and do it, and then realise afterwards that isn't really what they wanted to do. So I think for a nurse it's very important that you don't put across your own beliefs, or your own feelings in the matter. You can discuss that with your colleagues, or your family, or whoever, wherever you need to get it off your chest, but you don't do it with the relatives, and you don't do it with the patients because that's not why you're there.

CAMILLE

Camille has specialist qualifications in critical care and a Masters in Nursing Management. She works in a moderately large metropolitan hospital where the event she describes took place. She had just come from a shift to this interview and was still angry about an episode in which a nursing colleague had acted unethically (in Camille's opinion) in sending a patient to the ward thirty minutes prior to the patient's death. She felt that the R.N. in question had done this because she was unable to handle the death of a client - a not uncommon phenomenon but one for which everyone develops individual coping mechanisms. She needed to talk about this and various related issues before we moved on to the discussion of her personal experience.

One of the latest events occurred a couple of months ago. It involved a lady who was in her early eighties. She came in with an M.I. and had streptokinase in the unit and then proceeded to arrest three times on the evening shift. We came that night shift and she'd been resuscitated three times quite quickly, each time within a time frame of a few minutes only. These were all V.F. (ventricular fibrillation) arrests. She certainly was with it mentally, quite alert and cooperative - she certainly didn't appear to have suffered any cerebral damage as a result of those first three arrests. She had been put on lignocaine, was arrhythmia free and fine for the rest of that night.

The second night she had had two more arrests on the day staff and a lengthy one on the evening shift and as a result of this she wasn't quite so with it. She'd open her eyes to voice but she wasn't verbalising. She'd look at you, was cooperative but certainly was not as able to move around and help, as she had been the night before. She was hypotensive, she had an I.D.C., which had been put in by the day staff but she had had no urine output for twelve hours, and she'd had no blood tests for twelve hours. They were sort of half treating her. I mean they weren't going all out yet we were supposed to go all out if she arrested again. [This was documented] in the chart: 'for full resus. in the event of an arrest'.

Anyway that was that night. She survived that night and then when I came on the third night she was still there. She still had no urine output; she had a Dopamine infusion up on a peripheral line; she had a Lasix infusion going and she still had a lignocaine infusion going because she was still having short runs of V.T. (ventricular tachycardia) and any other rhythm you care to name. She was unconscious, non-responsive, she was bloated (overloaded with interstitial fluid); she was dying. The niece was with her - apparently this lady had never married and her niece was very close to her. She spent the whole time there, slept with her head on the side of the bed; was very aware of what was going on and had been involved in the discussions with the doctors about her aunt and her treatment and she felt that they were going too far. She felt that her aunt had come to the end of her time and it was time to let her go at least with some dignity.

Then that evening the evening staff had heard her say to this niece, "Will you please stay with me, I'm dying and I don't want to be on my own but don't let them do any more to me." So she had been well aware of what was happening to her. These were actually the only words she spoke during her admission - she didn't speak at all until after about her fifth arrest and that was apparently to make sure that the niece wasn't going anywhere and then she became deeply unconscious not long after that. Now the niece made very sure that the medical staff was aware of what her aunt said and it had been overheard by one of the nursing staff so they were well aware of how the lady felt prior to losing consciousness. She was well aware that she was dying and happy to do so if she could be left alone to do it.

The fourth night I came on and she had died not long before I came on. The evening staff had been told she was not for resus but they had rung the doctor because she was deteriorating rapidly in that she was becoming bradycardic. She still had the dopamine and everything going and they wanted to clarify that order. He said "Oh yes, you must resuscitate her." [This was] a registrar who worked in the unit and who was more than "au fait" with what happened in the unit and also knew her history because this patient had been in the unit for four days while he'd been working there looking after other patients.

At this time when we'd been quite frantic - all beds full all the time. The registrar who had been looking after her had written quite detailed notes and that she felt that there was no further need for resuscitation in view of this patient's hypotension, anuria, age and mental state - and the niece had agreed with that. Now he came up just as she went asystolic and he worked on her for forty minutes [because]: "I'm not the doctor who normally looks after her and I don't feel that I can give that decision/ order." He had made the statement, "No one just dies in coronary care." You arrested, there was no such thing in his mind as a person just dying as a result of say cardiogenic shock. They arrested and regardless of their previous history they were actively resuscitated. He was very hard to deal with because of these fixed ideas - no matter what the patient history or your feelings and input no matter what you tried - there was no deviating him from these fixed beliefs of his.

In her case the problem was that he was actually there at her bedside when she went asystolic (avoidable suffering related to inexperience/ inappropriate management of care/ bad timing). Now if he hadn't been there at the time it could have been an entirely different story. They could have rung and said that she had died and there would have been nothing that he could have done about that, but the mere fact of his physical presence at the time altered that. He actually went and got the resus trolley himself because the girls stood there and looked at him in, I guess a bit of it had to be dismay - "You've got to be joking this lady has suffered enough - come on!" So he actually got the trolley and got the gear out himself. Then I guess they realised he was for real - had got over the disbelief - and of course he pressed the arrest buzzer and once it turned into a full-blown resus attempt and you get tied up in that its very hard to walk away from that sort of thing. I think it would be very hard not to try and physically stop him or say to his face that he was a bloody idiot - or something like its time you grew up and looked at your own moral and ethical values! Or perhaps I'd have said how would you feel if it was your mother or grandmother suffering through this? Sometimes they do listen to that. Some of them don't too - some come back with the reply "Well if it was my mother or grandmother I'd expect you to do everything possible."

The niece was really very distressed because to her the decision had already been made and confirmed when the aunt said what she did. She was aware that her aunt was dying and was quite accepting of it - especially in light of what her aunt had said the day before (avoidable suffering related to perceived breaking of trust). You feel like you should be able to physically stop them and say, "Hey what about giving this person some dignity" or, " Hasn't everything that can be done been done? - People do die in coronary care". He was one of the ones who were always very difficult in situations like this […] everyone was for resus (avoidable suffering related to sense of powerlessness). Now you and I both know that that is not always the case. If you've gone all out in every possible means beforehand and you've got no result then there is no need to do C.P.R. But he couldn't accept that. He felt that he had to intervene - but his intervention didn't get him anywhere because she'd been dying for two days so it wouldn't have mattered what he'd done. But what did matter was the indignity on her part; she was left no dignity at all after that. I mean there is a nicer way to die than to have some one jumping up and down on your chest as you do. I mean she was 'tubed the lot - no holes barred! You just wonder sometimes (avoidable suffering related to mismatch of aims/values and achievements).

I really get annoyed at times with the fact that they don't give you any credit for knowing anything, for being able to stand back and reason. I mean, I guess as nurses we probably make more moral/ ethical decisions than a lot of doctors do - as in we already accept things differently - for example you could see even two days beforehand that she was dying and that's what all of us had said and accepted, yet he was unable to accept this (avoidable suffering related to lack of recognition/ perception of being undervalued). […] He actually said that he would, "Do everything at all cost". He didn't seem to be able to look at all the facts in her notes what had happened in that four day period, look at her results, look at her notes and then logically say, "Hey she's had enough." Then going on the information in front of him, say she's obviously going through what is the normal dying process - he wasn't able to accept that at all. So then you get caught, you get trapped really because it doesn't matter what you as the nurse say or what the family's opinion is; in his eyes he was the one [with the responsibility] and he said, "It is my choice, my decision". He felt the onus was on him (sense of being trapped at the same time as feeling undervalued: avoidable suffering R/T non-inclusion in decision-making).

JILL

Jill is the charge nurse of a coronary care unit in a large metropolitan hospital. She trained in N.S.W., has over fifteen years experience in Coronary Care, a cardio-thoracic nursing certificate and is currently studying externally for her masters. Jill initially had difficulty selecting a single event "from the many" she had been involved in. Jill chose an event, which occurred eight years ago. Her memory of the event was vivid: rich in context as well as detail. Thus I decided to include this event and interview although the event falls outside the five-year guideline laid out in methodology.

[I was working in a] ten bed post-op cardio-thoracic I.C.U. We were reasonably busy - there was always a registrar working on the unit. They slept there overnight as well. This incident involved a patient who had been in coronary care with a big M.I. and was not recovering well at all. [This patient] was a doctor, his wife and sons were doctors. A fair percentage of his family and relatives were involved in the medical profession. He was in his late fifties to early sixties. His sons, I remember were about registrar stage/age. This was his very first presentation with an M.I. He had no real risk factors except stress - and I think he was a smoker who had given up a couple of year previously. Anyway the decision was made by the physicians to refer him for urgent coronary artery grafts. He had angiography, which showed he had only single vessel disease so they took him to theatre.

In theatre he was stable; he had only two grafts and he came back to the unit post-op and didn't wake up. We presumed he'd had a bleed (*cerebral*). He was scanned and this was confirmed. He then re-infarcted; basically wall-to-wall Q-waves on his E.C.G. (*indicative of a huge full thickness infarct)* and with that he went into cardio-genic shock. He ended up with a 'balloon' (*left-ventricular assistance*), the usual central lines, arterial lines, and he still had his chest drains in; he was only about day two - and he just kept deteriorating. It got to the stage where he was on 100% oxygen with the highest PEEP (*positive end-expiratory pressure*) we could give with blood gases that to me weren't compatible with anything that was living. He didn't react to voice, pain any sort of stimuli at all. It got to the stage where we had all his drips on pressure bags because we had no natural flow - there was still blood that was going in post-op *(replacing intra-operative loss)* the rest were on pumps. [This was because of] venous back-up (*pressure was now so high in his venous system from* right-sided *heart failure that it was impossible for his drips to flow without pressure behind them)*. It got to the stage where his limbs were stiff - he was blue and all of his pathology coming back was incompatible with life. We were basically ventilating a corpse. His arterial line was recording about 25 for a mean B.P. *(normal is 70 -105 mm Hg., Romanini & Daly, 1994).* This had happened very quickly, within two days.

I mean he was anuric, his mean B.P. was 25 mm Hg. I think the thing that upset everyone the most was that our medical staff wouldn't take the initiative to talk to his relatives who were all predominantly medically educated and basically say, "Hey we're ventilating a corpse here" (avoidable suffering related to frustration with incompatibility with nursing assessment of case and medical management). The family wouldn't accept that he was going to die, even though they could see his colour. They would come in and talk to him - all that sort of stuff. They were very much in denial. It got to the stage where we had just about pure inotrope through his central line. We were running Adrenaline and Isoprenaline via the burette in absolutely ridiculous proportions and we in fact had to get in Isoprenaline and Adrenaline in because we depleted the hospital's supplies.

Anyway I was on night duty on day two; it was a busy night - the usual first nighters were dropping their B.P.s all over the place and the usual sort of carry on. It got to the stage where I was just made up all these extra lines (I.V. lines) ready to change them over because they were going full pelt. It took me two hours until I actually stood back and looked at what I was doing and thought "This is ridiculous!" So I went and dragged […] registrar out of bed and said basically, "Look this man is dead" and he said "Oh, turn off the ventilator" and I said "No you turn it off". He wasn't very happy about that but I said basically," If you're not happy to turn it off, I'm not turning it off but I am not putting up any more of these drugs etc." So he did, he finally turned it off and I said "will you be calling the family?" and with bad grace he did.

We'd taken him off the ventilator by the time the relatives had arrived and we had removed most of the lines and just listening outside the screens I heard one of them say "Oh I just saw his eyelids move". They were still not accepting that this guy was dead. I didn't hear the exchange between our medico and them - but from what I was able to observe it didn't go very well - they were still denying that this guy was dead and probably had been for at least 12 hours. Our staff wasn't game to talk about it - they were treading on eggshells - for fear of being overheard - there were medical staff in and out all the time,

They knew they'd done wrong and the fact that we (the nursing staff) had made the move in the end to get something done only made it worse. I think they really realised that they were at fault for not getting in earlier and saying to the family, "Look your husband, father, uncle or what ever is not doing well and we need to look at being realistic and ceasing all these huge amounts of drugs". I think that they felt they hadn't done their job or played their role properly and I think that even though we hadn't voiced it till the end, I think they thought we were being very critical of them and which was a definite "No, No," - doctors don't get criticised by nurses. You got on well with most of them - we had a fairly good working relationship with most of the registrars and surgeons who came through the unit. You know we had social outings together the whole lot - but there was still that element there; the doctor was still God.

[I felt] anger, disbelief - I mean we were ventilating a corpse. I was also angry because we had a lot of students coming through that unit and I think it gave them the wrong impression of what it was all about. They probably viewed it a bit differently to staff in the unit who were seasoned - we didn't allow them to look after him because of his actual condition or lack of condition. I felt sorry for the guy himself. A bit of disgust really at the family because they were medically orientated and should have been more realistic about what was happening, but then again as I said it's different when it's a member of your own family. Those were the main feelings I'd say.

Also in the first place back in coronary care most other people would not have been considered for early coronary artery grafts. I think again that was because he was a doctor and with his family I think they thought - we'll jump the cue and get this all over and done with and I think that probably was the cause of his demise because his surgery actually could have been enough to cause him to re-infarct. Plus of course he had the cerebral bleed - but that could have happened anyway and anywhere - but there would be a very small percentage of people in that condition who would be considered for early angiography and early surgery and that was a bit more disgust as well - "why this select group of people?"

ELIZABETH

Elizabeth, 30years old, has extensive experience in critical care units in Q'ld and NSW. She completed her general training at a hospital in Brisbane and has since completed her degree and obtained qualifications in critical care nursing. Elizabeth learned of this project through a mutual friend and particularly wanted to share her experiences around one incident because: "I think it was a very important event in my nursing career - I nearly left nursing because of it."

We had an eighty- five-year-old woman with a pretty poor medical history admitted to the unit. She was just a sick eighty five year old […] she had terrible arthritis; she didn't have a very good quality of life to start with. She had C.O.P.D., diabetes, she'd had an infarct previously and now she had renal failure - she wasn't a very good candidate for intensive care. She was never ventilated and basically the story is she was in the unit and her husband was told, after they'd treated her for a couple of days, there was no improvement and the husband was told, "There's not much more we can do about it".

She was on antibiotics for sepsis and nearly 100% oxygen so basically we were still going for full treatment and then in the end it turned out that the husband had to wait four days for this woman to die simply because the doctor refused to take her off the 100% oxygen and kept the antibiotics going. I mean there was no point; the woman was going to die. The fact that she was eighty-five with a poor medical history - I don't think she should have been in I.C.U. to start with (avoidable suffering related to conflicted/divergent medical and nursing goals).

[But the rationale was] she was deteriorating, her renal figures were up and she had this infection - they thought they'd better fight it…she was never ventilated. Just the fact that after they'd told the husband, "There's nothing we can do for her." They just kept everything going instead of giving him the choice - that's what angered me. Instead of turning down the oxygen - maybe leaving the mask on just say 25% so that the husband could be comfortable but see "this is it - even with the oxygen". In my opinion it would have saved the husband a lot of pain and let her die with some dignity. Instead of doing that so that things could have progressed a lot quicker, they continued on and she took [a further] four days to die. The consultant who was on for the weekend told the husband that this lady's prognosis was poor. But the oxygen was kept on at 100% - the antibiotics were kept going - everything was kept on: inotropes, the lot (avoidable suffering related to conflicted/ divergent goals or poor interaction with consultant to clarify these goals).

[The husband] spoke to a lot of the nursing staff who were reinforcing that there was nothing more that could be done for her so he was prepared in that way but instead of getting it over with when it was obvious she was going to die, he was forced to wait fours days. And so of course he started to build up hope, you know, she’s lasted this long. Maybe she'll be all right. It shouldn't have gone on that long. And then the husband, after three days of waiting for her to die started saying things like, "What if we did a transplant or dialysis?" Things like that and this lady's blood pressure was low - it would never have coped - not even with dialysis. And the patient wasn't “there” - she was just moaning - she couldn't acknowledge that anyone was there - not even her husband (avoidable suffering: burden on nursing staff related to trajectory of death).

She basically stayed on everything until about ten o'clock the night before she died when the husband said, “I want everything stopped. I understand from talking to the nursing staff that the only reason she is alive is because of all this stuff”. [He meant] the drugs, the oxygen, the dopamine- and so he asked the consultant to stop everything and she died at 10 o'clock the next morning. I wasn't there when he asked the consultant but I know this doctor. He very rarely pulls out because of an incident in which he had to resus his own child. This baby had some weird and wonderful disease. The child arrested; he was on for the night and he had to go down and try and resuscitate his own child. Ever since then apparently he never "pulls out". He keeps up with full treatment to the bitter end.

[None of the] nursing staff talked to the consultant [about this decision]. In this unit you can't say too much - sure we talk amongst ourselves and to the residents and registrars and say things like, “Why is all this stuff kept going when there's obviously no hope, no chance of survival for this woman, why prolong the agony?” But when you've got a director of the unit who is dead set against terminal weans and anything like that, how can you expect the other consultants to say that's it? For example there was one consultant I worked with who, if there was no hope they'd terminally wean patients. We had such a patient and this consultant decided to wean her. The director of the unit came in that afternoon and because he doesn't believe in terminal weans he changed that order. That was due to another incident in which he was reported to the medical board after doing a terminal wean by a nurse who didn't know anything about - didn't understand what was happening. [So there was a lot of personal history behind this episode/ these episodes].

I was either in charge [of the shift] or looking after the lady in the bed beside her so I saw everything that happened and I watched the pain the husband went through - one time he went out in tears and the nurse who was looking after his wife couldn't leave her so I went out to him. He just wanted to know why this was happening and why it was taking so long. I was pretty darn angry. I mean if that had happened to my grandmother, as a nurse in that situation, I would have turned things off (no she wouldn’t). [I felt] empathy for the husband and the daughter who were just sitting there. You know feeling “I'd love to do something more for you but there's just nothing more I can do/ we can do as nurses”. We know or I knew myself that treatment should be stopped but I can't go and say that directly to the husband. It would have been undermining the doctor's authority. It's just not the done thing (avoidable suffering related to sense of powerlessness).

Her husband and daughter suffered, as they watched her die and yet were led to hope that maybe she wouldn't because it all took so long. She didn't seem to suffer any pain but then she had no dignity either. And as people, the nurses who cared for her and looked after her family, they suffered too! As a nurse you empathise for the patient and the family in that situation and feel like saying "I wish there was more I could do." but there's only so much you can do!

It makes you feel] very bloody angry and sad. I mean I.C.U. is for full on nursing and treatment. Why bring her to the unit in the first place when she could have been put in a single room down in the ward - surrounded by her family and maybe some flowers instead of machines and alarms and other relatives from other patients for the last few days of her life give her some dignity and privacy.

BERNADETTE

Bernadette is 26 years old and a mother. She has a Masters in Nursing and was studying externally for her coronary care certificate at the time of this incident. Bernadette contacted me after hearing about my research interests on "the grape-vine". She was clearly still affected by the issues in her story although it had happened more than a year earlier. Throughout our interview her body language was closed and she cried as her story unfolded. At the time of the incident she was working in the coronary care unit of a level two facility. The unit is resourced to care for six patients:

This incident happened about 14 months ago when I was working in coronary care. We had an aboriginal lady admitted - she was about 35. She had a history of C.V.A.'s and she'd had also had previous M.I.'s starting from when she was in her twenties. She was obese and had multiple risk factors. This time she'd had an extensive M.I.; arrested in the ambulance; arrested in A & E; arrested in the lift on the way up to C.C.U. So she got up to us and was quite unstable. She was still suffering; she was still having cardiac arrests.

[Before this lady turned up] I was feeling quite comfortable with the workload and staff to patient ratio. All of the other patients were unstable - We had one lady who we believed had had a C.V.A. of some sort - I don't know why she was in coronary care but she was; we a man with unstable angina who had a G.T.N. (glyceryl trinitrate) infusion running; we had a man who kept going in and out of S.V.T. (supra-ventricular tachycardia) and we had another lady who'd just had an M.I.; four potentially unstable patients. [We were staffed with] two RN's. [The other RN] had only been there for a few weeks. Of the two of us I had been there the longest and so I was senior. I was studying for my coronary care certificate at the time and I suppose I was probably the more experienced as far as the coronary care environment was concerned.

This other lady turned up about teatime-about five o'clock They brought her upstairs to us [with orders from the] consultant physician indicating that he had decided to put a central line in to measure her pressures just to see what was happening. I […] went to tea first because we knew this lady would be having a C.V. line put in soon and the other R.N. had never assisted with a central line. When I came back they were busy putting in the C.V. line [the physician had not waited]. [At that stage] she was still in sinus rhythm [but this kept deteriorating into] bradycardia or complete heart block - I don't know what happened [to her rhythm] down stairs [in A&E]. Her infarct from memory was extensive, huge-almost global.

They got the C.V. line in and started the Dobutamine. We'd been given a range to run it - to keep her heart rate at a certain […]. As time progressed, I kept increasing the dobutamine to keep her blood pressure up. Her pressures had been low - 60/40 from the start and it was becoming almost impossible to keep her pressures any higher than this. She was an aboriginal woman with a large family - they had all been visiting her in relays. Two visitors at a time is the maximum allowed in this unit because of the size of the unit and the patients' conditions. They were already into the mourning process and it was fairly obvious that this patient wasn't going to survive the night and the family had a lot of grieving to do; their good-byes to say basically. I was progressively titrating the dobutamine trying to keep her blood pressure up and all that was happening was that her heart rate was going up and her blood pressure was going down - we weren't getting anywhere. It was a classic picture. There just was no myocardium left to support cardiac output.

So at about eight o'clock, I rang up the registrar […] and said, "You're going to have to make a decision - are you going to turn the dobutamine off and let this family have their time with the patient - which is important - or are you going to persist with this line of treatment?" It wasn't accomplishing anything. To me the patient's infarct had been so extensive that nothing short of transplant was going to pull this lady through. I didn't see that this hospital had the staff or the equipment to deal with the problem that maybe a larger hospital might have had. Really this was a heart that was dying no matter what we did. So I was basically saying, "You're going to have to make a decision - are you going to let this lady go peacefully with her family there - which is important to them - or are you going to invade her body with all the things that you do**?"** And he said, "Well to be quite honest, I think we'll be jumping on her chest by midnight". Just then ... she arrested again. [She went into a] complete block and her resps. became really stertorous.

A general arrest was called, […] the consultant physician decided it was time to insert a pacemaker. The dobutamine wasn't doing any good so he thought a pace-maker might do the trick! (*Shouted this and laughed at the same time - with frequent emphatic shrugs of shoulders)* I think this was just a case of playing with toys for the sake of playing with toys! So there we were performing C.P.R., trying to intubate this patient and trying to insert a pacing wire at the same time. […] we actually got her heart going with a bit of adrenaline and could then stop [CPR] to put the wire in. We had the radiologist up with a student and all the image intensifier equipment. We had two doctors; the two of us and another nurse who came into help because […] some one was required to look after the other patients. While we were trying to put in the wire she arrested again and someone called a general arrest again. We had four more doctors turn up and we had the nurse manager. All up, and I did a head-count, we had twenty two people in that room including the patients (avoidable suffering R/T organisational chaos).

The physician eventually decided on his own [to stop]. I tried [to have more input to the decision-making]. At that point I don't think there was a great deal for me to contribute because things had gone beyond the extreme and it was then just a decision to stop medical treatment whereas earlier I was in the position to say, " …this woman's outlook isn't good, her family is with her and they need to be with her. Think about what you're doing". I think that earlier time was a time for input whereas by the time the decision was made to stop resuscitation ...(*tears*) it was all over by then anyway - what more could I say except "I told you so! - You should have let the family in before". (Avoidable suffering related to sense of powerlessness & inability to contribute to decision-making)

I thought the whole thing was a circus. Here were all these people just standing around watching. It was just bizarre - here I was doing chest compressions on this big woman - I had a consultant physician on the other side of the bed from me trying to put in a pacing wire and I head butted him. Poor old registrar trying to intubate this woman with the physician yelling at him, "Can't you see the chords? - Look there they are - get out of the way!" All these other doctors standing around watching and I felt like getting off the bed and shouting, "All right you lot, you do it - I'm sick of being yelled at!" It was the most bizarre thing I think I have ever seen - I thought, "This is a side show!"- It was incredible (avoidable suffering related to organisational chaos). Bizarre because doctors don't know when enough is enough, and they cross the line from saving lives to creating a situation, which is to me undignified, and this is bordering on abusing a body, which just has no more life (*since talking about the dignity of the person, B's voice became quieter and she curled up in her chair hugging her knees - prior to this she had appeared relaxed in posture despite occasional tears*). She was an aboriginal woman with a large family and I think once you learn about different cultures and their different views on death and dying, you learn that you've really infringed on an important area - and you've totally disregarded things that they value. A lot of cultures value the family's presence during that process-during the dying time, which was what prompted me to make the phone call initially. I wanted to say don't think enough's enough. But ah, we just kept going. It went on for most of the shift. It was possibly 10 P.M. by the time they let her be.

[I felt] sad because you know it happens so often - people are so insensitive to others' dignity and it can be something that can be very worthwhile-helping a patient and a family through the dying process-and fulfilling as a nurse and something that you really can do very well. People seem to be so afraid of it and they stuff it full of technology rather than saying "it's going to happen - let's just make it good for them." [I felt] frustrated and hopeless. I think that sometimes they're so obsessed with their toys, their need to keep going and with their inability to recognise that a body is viable no more. There comes a point where the body is worn out and no matter what you do its not going to achieve anything.

When there's a technical solution, sometimes the morals behind it don't seem to enter into it. I read a good quote somewhere – "there is a gap between the technical possibilities and the moral actualities". I mean she'd had an extensive M.I. - Jeez we could have been going through the night! But the reality of the situation is that for someone with that history and to have had so many problems at that age there was probably even something genetic causing all her problems. Nothing short of a transplant and maybe not even that would have helped her.

GEORGIA

Georgia trained at a Brisbane hospital. She has since completed her degree and obtained qualifications in critical care nursing. She has in excess of six years' experience in critical care - having worked in provincial and metropolitan critical care units in Queensland. This story occurred in a tertiary metropolitan unit. As her story unfolded it became clear that she was still angry about the issues she wished to discuss.

This incident involved a gentleman who was about 70. He'd come in for some major abdominal surgery and he'd initially come to I.C.U. for epidural anaesthesia and observation. He was electively ventilated because post-op he was very drowsy and wasn't tolerating physiotherapy. So they elected to ventilate him to let him get a good rest, help him clear his lungs etc (*a potential complication of abdominal surgery and epidural anaesthesia is atelectasis –collapsed lung- and pneumonia. With sedation and ventilation it would be possible to conduct more regular and thorough physiotherapy and to inflate his lungs a little more*.) Then he just got very sick. He ended up needing Dopamine, Dobutamine, and Adrenaline to keep him alive - very sensitive to the adrenaline. He eventually needed 100% oxygen on the ventilator.

He was well sedated so I don't know how conscious he was of what was going on around him. He never really woke up [even in] the last days when they decided to stop his morphine. He'd wince or stiffen up to pain but there was no sort of acknowledgement of when his wife was there or if any staff was there. He didn't follow you with his eyes or anything. And we battled on with him - he was given everything - he went into renal failure and he was given dialysis. Absolutely everything was done for this man *(said with an air of resignation and irony).* It just continued to drag on; there was no improvement, even with the dialysis he continued to deteriorate. He was needing more and more adrenaline to keep his blood pressure up, more oxygen, more PEEP.

[This all took] about a week - it then became evident that the doctors had been chatting and had agreed that there was not much more that we could do for this man (avoidable suffering related to absence of collaboration between parties caring for patient)**.** So they had a talk to the wife and told her this and she virtually said, "Well - yes I know that you've done everything that you can". It [the clinical picture] was basically the adrenaline that was keeping him alive. He then started having short runs of V.Tach. (*ventricular tachycardia*) which resolved spontaneously early on and then he was requiring lignocaine, but they still continued on with everything. I mean his heart was failing - they never did get to put a Swan-Ganz in (*measures left ventricular pressures*) just to see how badly it was failing but I think once he started having the V. Tach with the Adrenaline things were starting to look pretty grim then (*he was having so much Adrenaline to support his cardiac output that it was irritating his myocardium and producing the V.Tach.*).

But this is another one of those situations in which the doctors say, "We're not going to do anything more for this man". And they speak to the relative; tell them this and then it turns into a long drawn out saga. The wife was really good, she accepted the fact that he was going to die; it was just going to be within the next few days. Or SHE thought it was going to be within the next few days. Then they decided: we'll wean his oxygen but no less than 70%; the adrenaline - keep the adrenaline but titrate it to keep the B.P. (systolic) at about 100 - 110; keep the dopamine and dobutamine going. This was guy they were supposedly "pulling out" on. You know there WAS (G.'s emphasis) no more they could do. Then it got to further runs of V.Tach. So they decided to try an Amiodarone infusion. A lignocaine infusion had been going and that was stopped to put him on the Amiodarone (*an alternative anti-dysrhythmic with a different mode of action and many potential side-effects*). It’s like in my opinion, if there's no hope for somebody and I mean we (nurses*)* can see for ourselves when your looking at the progress of the patient and his results, his obs, just like the doctors, we're able to see for ourselves that there's no hope (avoidable suffering related to perceived absence of clear goals in clinical management of weaning process).

It just really makes me wild that they can't take - can't accept (it) - and say put him down (*wean the oxygen*) to 21% oxygen, take down the Amiodarone, Adrenaline, Dopamine and Dobutamine and let this guy go quickly and peacefully instead of dragging it out. It took this guy about a week and a half to die - it was just .... (*words seemed to escape Georgia here but her posture was slumped - fists clenched, as if she was carrying a weight on her shoulders perhaps).* I think it's unfair mainly for his wife. I mean even though she was a fairly strong woman and had accepted the fact that he was going to die, she was always there talking to him, talking to us, touching him - a loving wife. I think it would have been good if once she had had her cry, said her goodbyes and the family had said their goodbyes - why not let that be goodbye instead of - fair enough - you'd expect a day or two, but not a week and a half later because of the fact that he was just being kept alive by our interventions .

[I felt] angry in this particular situation. After about a week I actually spoke to the top guy and said "Why are we keeping going with all this treatment and the wife's expecting him to die? […] Why are you putting up Amiodarone when you've told the wife there's nothing more you can do ? Why is he still on 70% oxygen?" and he said "Oh, well maybe there is hope - maybe there is that one bit of hope that he might pull through" (avoidable suffering related to perceived confusion and hesitancy in medical). This is the doctor saying this. I mean if there is one bit of hope "Why aren't you still fully going on with the treatment of this patient?" I think it was in his mind that well maybe if we just keeping going a bit, this patient might come round, although its darn well obvious to the nursing staff - and residents and registrars that there' no hope for this patient. I think it was just a way of him saying well I'm not going to be the one who makes the decision to put him on 21% oxygen, and stop the drugs.

I guess I've seen two sides of the story - a unit where the director believed in terminal weans and one who didn't - but to come to a unit like this where there is no clear direction about anything especially in this sort of situation is just so frustrating. Sometimes I just want to punch them in the head or something or say something like, "You're the doctor - you're having trouble with this patient's life - do something! Help them to live or let them die" It can't be half- hearted - its got to be one thing or the other. I'm all in for doing the best you can and giving the patient a good chance -

but if they're not getting better or if they're deteriorating then - accept the fact - you can't live for ever. […] I believe we need a director in the unit with clear ideas on this sort of thing - you know clear policies on terminal weans, admission to the unit and save the relatives and patients from suffering. Because you know yourself after a short time these relatives start to develop false hope and so they get let down even harder when the patient does eventually die.

1.4 THE DOCTORS' VOICES

GAVIN

Gavin is now a specialist obstetrician who contacted me as a result of my overtures to the doctors' reform society. He told me a story from his experiences with end-of-life decision-making when he was in the position of registrar. Gavin would have been three years+ into his post-graduate experience, in a position with increasing responsibility.

I was working in Sydney in a big teaching hospital as the obstetric registrar and I got called to a miscarriage. It was supposed to be nineteen weeks gestation. And I mean the baby was on the way out when I got there. I guess there were a couple of things related to that. The first was that the babe was 19 weeks - probably more like about 23 or so and it took a couple of breaths and died. I didn't do anything to call the paediatric people. At that stage ah, I think the world record for the youngest surviving baby was about 24 weeks. It probably wouldn't have done too much but I guess I felt a bit uncomfortable with the sort of things that go on with the very, very premature babies anyway.

I get a bit worried about the degree of technology and intervention that gets brought to bear. I mean almost invariably, in fact invariably at that age they die anyway, and there is something a bit funny about the world where all the kiddies in the third world are dying for lack of very simple interventions; then people play... play with their toys. Well in some cases. I mean obviously there's a role for that in some cases. When they're really very, very premature, well, I haven't noticed it being helpful. I mean for this kiddie, even if it was born now - I mean we're talking about 10 years ago now, even now I don't think there would have been much chance. But yes that was a kind of issue for me. It was born alive but it died within the first two breaths. I felt a bit of a dilemma about should I be rushing around? Should the paediatric people be rushing in here with their trolleys and stuff or not? (avoidable suffering related to absence of support in decision-making)

I mean I had a dilemma over whether I was overstepping my authority in making the decision not to do anything. And of course, I'd just run up there and gotten in there. I hadn't talked to the Mother or anything to find out what she wanted. I mean, I had no idea about she wanted (avoidable suffering related to absence of direction re patient preference-compounded by urgency of event). I did [talk to her] a little bit afterwards. It was all right afterwards, but there hadn't been an opportunity to do that before the birth [because everything happened so fast].

Asked about the role and reaction from the midwife working with him, Gavin replied:

Well, in fact the midwife there basically thanked me for my role and said, "that was good". [We were comfortable with the decision but] it was a responsibility. There was just one other issue there. This wasn't really a life or death issue-it's just something I was a little bit uncomfortable about. I told a fib on the report because if a baby takes a breath you are legally required to have a funeral. It's a legal thing really - you don't get a choice whether or not you want to. So I told a fib and said the bub hadn't taken a breath. The mother hadn't seen a thing - she was in a different sort of position. She was lying down and it was all over very quickly. So I guess I wasn't quite sure whether that was the right thing to do either but that was how it worked out at the time (avoidable suffering related to absence of senior clinical support mechanism). My rationale there was to make things more comfortable for the mother. I figured she could have a funeral if she wanted to have one but, I hadn't really had a chance to talk to her and see what she wanted. [I did talk to her] just briefly later. Obviously she was pretty upset about what had happened. But she didn't seem to have any unusual kind of issues about things.

Ah, yes well, again [the key to this decision] was the timing. The thing I'd really like to do, if I had [more] time, would be to try to get the mother a bit more involved and find out what she was wanting in terms of people descending down on this infant or letting nature take its course. When I was called down I think there was this assumption that infant was 19 weeks. I think in that sort of situation it would be a little more helpful if it were possible for women in late miscarriage/ premature labour to clarify how active or otherwise they want treatment to be for the infant when it comes out. I would have had a look at her notes, I don't recall but I think she would have had an ultrasound at some stage to confirm-I guess they [obstetric team] were a month out (avoidable suffering related to obscurity of clinical data).

MAX

Max specialises in emergency medicine. As his story unfolded it became clear that the issues he was most upset about/plagued by, related to lack of support in the working environment…

[This case involved] an elderly man, 77 years old, who came here on Wednesday from a private hospital. [He had been] admitted for two days, inadequately resuscitated by any stretch of the imagination. He'd originally he'd fallen over and broken his rib. [This man had a previous history, which apparently included an underlying bone malignancy]. He had a collapsed consolidation of his right lung, was subsequently was admitted by his GP for "Pain in the abdomen". He had a C/T, which showed a ruptured spleen and fibrosis. Thereafter he didn't have anything done for another eight hours. Finally he had an anaesthetic [and surgical repair of his spleen]. He had a post-haemoglobin of five, a pre-haemoglobin of fifteen - wasn't transfused. The first medical notes were [recorded] six hours later in the high dependency unit. […] he remained anuric for the next 24 hours. I get phoned at nine o'clock on Wednesday, will I take him to Intensive care?

[I was feeling] really pissed off about this because I was going to have to monitor the dying process of somebody who could easily have been adequately resuscitated. Everyone dies, let's be honest about that. Either don't give him an operation and say he's going to die because he's got an underlying bone malignancy, or at least give him the best shot! This idea of: "Oh, we'll cop out at the end and let someone else pick up the pieces" I find offensive. And I find it more offensive that the nurses here know that, but they're the ones picking up the pieces as well as [supporting] the family [...]. So he came across here, having a blood pressure of 70; he had O^2 sats. of 80; he looked like a cadaver. So he got intubated, ventilated, an adrenalin infusion, a lasix infusion. I elected not to dialyze him and he died 36 hours later.

The private doctors involved had at no time spoken to the family about his mortality. So I spent the next six hours telling them that in fact he had a malignancy [...] in spite of him having had this for a long time. We're trying as best possible not to blame the doctors, not to drop them in the shit, about their inadequate work. The bottom line, though, is if a registrar did work like that, you'd shoot him! And yet [...] people are paying for the privilege. And their parting comment was, 'you know he's got the full private cover, so you know, you'll be able to charge for this'. To which one of my few brave comments was; I was proud of this: 'I think he can die for free don't you?'

I get angry that there's absolutely no support for my staff or me. Like take the fellow on Wednesday night: was an hour of adrenalin enough, that's where I draw the line. Have I killed him? Probably. Has he reason to die? Sure. Have I hastened it? Sure. Could I have I dialyzed him? Yes. Is not dialyzing the right answer? I don't know. I chose not to. But I don't know if it was the right answer. Is the right answer? If it was my grandfather I wouldn't do anything. I mean if it was my grandfather I wouldn't have ventilated. If it were my wife, I wouldn't have ventilated. So by not dialyzing a 77 year old who has been anuric for 36 hours, who has got respiratory failure, well he's dead by any stretch of the imagination. Dialyzing him to me is just making him more miserable. I'm not going to put a vascath in as well as everything else for someone who's ready for the high jump (avoidable suffering related to dissonance between clinical imperative and personal values). But, I've still got to make my peace with my maker eventually. No one talks to us about it, ever. We get zero debriefing (avoidable suffering related to absent professional support). It's got to be meaningful. It can't be pretend. I think the underlying thing is that we, as a group, get very sick of anything pretend. So if you want to debrief, it has to be someone that's got our respect. Very often it's people who blow in, blow out, we don't know who they are, forget it. I mean you know, new people, we don't trust them. I'd like another specialist. That's what I want, someone who understands, someone I can talk to (avoidable suffering related to absence of specialist professional support).

In response to my observation that Max seemed to assume the burdens of responsibilities for everyone in his department, Max described an interesting perspective on dynamics within his emergency department: Oh yes, we fight as a team here. We plan it. And I think that that's actually, in a sense, both good and bad. It's good in that what goes on here just stays in here. It's bad in that you've got to perhaps overlook things that shouldn't have been overlooked, because what goes on stays here. So in a sense, I can understand now why, or how a Ward 11 is created in Townsville. How a police culture exists, because the only person effectively who will cover my back are my staff. I'd get no support from anyone else. So you become very clannish. So unless you've got a meaningful support system, with meaningful debriefing by people who are respected, and proper confidentiality, you're not going to get anybody to open up to anybody. It just doesn't happen. We don't trust you. We just don't trust. That went out years ago (avoidable suffering related to isolation of unit).

As to what you tell relatives? I firmly still believe though that it's my role to withdraw treatment, it's not the family's decision. Because at the end of the day I'm the one that's paid to make the decision. I don't believe they should have to make it. The problem with my way of doing it is that you do it for long enough, it starts to erode a bit (avoidable suffering related to perception of ultimate & unsupported responsibility).

And it becomes apparent that you're not just making it for the family, you're making it for your staff. And that's one of the problems we [have]. In one sense we do not have much of a staff turnover here, so you know the values of all those [you work with]. But with the chopping and changing of staff, that sometimes can happen [then problems develop]. It's very difficult because the decision that is right and is made -

often is more difficult when you don't know the staff there. It's very much easier to say to someone [you know], this is a non-survivable head; here is why, that's why we're doing it [withholding/withdrawing treatment]. If you don't know the nurse, or on this particular day one of the nurses in question would have a student here, it would be a very difficult thing to do. I don't their values, I don't know what she's taught, I don't know. It's a gray area; it's a legal minefield, as to how much of it's withdrawal of treatment and how much of it is euthanasia. It's a very, very grey area. And that's what you pay specialists for, unfortunately. Every one of them gets tired and burnt out (avoidable suffering related to perception of {or actual?} unsupported burden of responsibility).

GORDON

Gordon is a specialist anaesthetist with extensive experience, both within Australia and abroad. He spoke to me at length about his experiences related to end-of-life decision-making. As he explored these stories, Gordon focused on the clinical imperative and the weight of its related responsibilities. He also elaborated on his views in relation to the decision-making process.

[I was caring for a] young fellow who had driven a friend's car home and ended up in a ditch. He had water intoxication and possible hypoxia. His C/T scan showed diffuse brain swelling. Our policy in those cases then was 2 days of ventilation and rest; wake [them] up. If they show signs then of coning etc. we will put them back to sleep [with sedatives, muscle relaxants & ventilation] for five days. During those five days the boy's father came to me and said, he didn't allow animals on his farm to suffer. He didn't intimate anything but you knew what he was asking. At the end of the five days I think I did actually say that I was hoping the guy would just cone and die but he didn't and (*long pause*) ... and he lived in a (*sigh*) persistent vegetative state. It's a terrible to say a guy's a vegetable – it's a vegetating existence - he really did need a lot of care […] and the father actually again said: "On the farm I don't do this sort of thing to animals". I could feel for the father in terms of what his son was then and what his son was now. I also had a lot of difficulty knowing I could have ended it but felt obliged to carry on. You have to. Now this is what I didn't say. You have to actually say to yourself: "For what ?" I mean if you've got this young fellow who you believe is not going to have any meaningful existence why don't you switch it off? Now the debate goes on - what is a meaningful existence? And people can always come along and say to his parents, his mother, brother: "Somebody learns something from his vegetative existence" - so therefore he has meaning and it's a personal judgement at the time as to what is a meaningful existence. Does Stephen Hawkings have a meaningful existence? - he's in a wheelchair all the time - but he's brilliant (suffering R/T internal moral dissonance – not avoidable, but may be ameliorated).

I was actually very sad that that fellow breathed because the father was very upset and when I think of it later the mother was just holding onto T.V. miracle-type situations whereas his Dad could see clearly that this was not going to come out well. He was trying hard because he was even thinking of getting a computer set-up so he could get his son to communicate. But he realised that it wasn't going to work on any long term basis (*long pause*). Not after we'd passed the "window" [*5 day's grace on ventilator*] - just a warning, "Look guys - on the farm we don't let animals suffer - are we going to let him suffer" and if so, shouldn't you do something about it NOW! (*Gordon's emphasis*) Afterwards it was almost a thing of saying, "I told you so". And [it felt] that we'd almost let him down but then there's the debate that we may have let him down in his expectations for his son but his wife probably hadn't worked through something [grieving process] yet (avoidable suffering related to sense of sole personal responsibility). So a more prolonged death and a later death may have been more beneficial for her. [But] - that's not up to me to decide and I actually feel that you've almost got to follow a protocol - you just have to do it and make the decisions later on.

So there's a big debate there and I feel that contrary to my own thoughts and possibly wishes if I was in that person's place, I feel obliged by teaching, history or whatever is expected of me to "do the right thing". And it's almost as if you're following orders even if you don't like the orders. Where are the orders come from? The orders come not from the medical fraternity but the medical establishment -you have to do it

You have to have those things. You have those brakes because if I was to become the judge and the sort of thing happen where you have a certain number of beds and an enormous demand for those beds and people actually have to weigh up the chances of the ventilated patients against the [hypothetical] young chap down in A&E needing a ventilator. And if you think about that case of the young girl where I learnt a heck of a lot and considered her recovery nothing short of miraculous [*where a senior physician had said wait and Gordon could not see why and in 24 hrs she had recovered*]. If I'd have been making the decision with someone with like her - I considered her recovery nothing short of miraculous - and I would have switched the ventilator off. So therefore, I now cannot make that decision and I have to say this particular person is on the ventilator and bad luck to you because you've come later.

This person on the ventilator has priority, meanwhile, bad luck, let's try and do something with you [chap in A&E], and do the best we can but you can't kick that person off the ventilator unless we can almost prove greater need. This is where a consensus decision must be reached because if it's up to me, I am manipulated by my prior experiences and I would possibly hang onto somebody who should possibly be switched off [because of prior experience] and so I think at that stage we'd have to have a big 'pow wow' with much input. I think, in that situation an experienced ICU nurse should have far more input than a registrar because a registrar just hasn't got the [relevant] experience. And that input has to be taken in as serious a light as say, my input. And if I say switch off and they say don't switch off then that means that there is an impasse and somebody with equal or more experience must be called in to break that impasse. I would say that the nursing input from an experienced ICU nurse is as equivalent and if they say we should switch off it should be listened to with as much weight. That's because they've got experiences from other situations: their experience from those situations is as good bad or ugly as mine and must be taken into account. But both parties must justify their reasoning. The reasoning at that point is not a physiological thing, it's a - I've done biochemistry, and chemical pathology. It's not at that level – it's at a level of: "look we've got experience showing us that this sort of thing doesn't really work" and if I say "Oh no I've got one case which showed... " you know, then you have to bring other people in to give another opinion and say "hey let's go for that" and the more people you bring in and the bigger consensus you get, the better, because two out of three is not as good as three out of five.

PAUL

Paul is an Intensivist with international experience. His story and discussion illustrated his approach to the issues around communication with family members regarding decision-making.

One case that comes to mind was a thirty-year old diver in another city who was diving at a major industrial facility and he was doing an underwater tank inspection when someone turned on the vacuum extraction for that tank and he was sucked down. His mate grabbed him. The force of the suction was such that it ripped off all his SCUBA gear. To find somebody to hit off the emergency switch, get him to the surface, then do the resuscitation, there was about a 15 minute down time. When he arrived in my - well in the emergency room-I was helping run intensive care then-he had a pulse of 40 and no recordable blood pressure.

Early resuscitation attempts got him back very quickly but by then it had been about 25 minutes since the original event had occurred. So he obviously was very unwell for a long period of time. He was brought in by the paramedics, intubated and given a couple of doses of adrenaline but not much response. I suspect it (*the adrenaline*) was still stuck in peripheral circulation somewhere (*because poor cardiac output would not have facilitated its circulation*). When he had a blood pressure, I took him across to the C/T scanner straight away. [While there he] gave a cough on the ‘tube and I had to paralyse him, which surprised me to see some basic brain function (*still had a cough reflex, indicating brain stem function*). I thought my hospital wasn’t the best place for him, we only had a very small intensive care with no neuro-surgeon and so I arranged for the same ambulance that brought him in to take him straight across to a major teaching hospital. They heard ‘25minutes of down time’ and said, “Oh well there’s no possible of hope of neurological survival.” Waited till the relaxants wore off, [extubated him] he took a few breaths, they put him out to the ward, and he died that afternoon.

Certainly, the neurological outcome from the history was obviously going to be very poor, but it was always in the back of your mind that we didn’t give him time to find out if the history was wrong. We didn’t give him time to find out if nature was going to try and perform some miracle in this one? My approach had always been up until then and certainly since then, to try and give everybody 24 hrs and see what happens then. Often, as you know as a nurse, things develop by then and it becomes blatantly obvious. And I think that’s the important thing when your thinking of withdrawing life support-that it takes time for everybody to come to terms with the fact that you’re not doing anything more for this patient by actually keeping them ventilated and on inotropic support and everything else. I think that’s the biggest issue with intensive care. Everybody else here is about providing hope. When you’re no longer providing hope what you’re doing really is extending a very miserable existence. However every staff member and family member and every doctor in every unit in some ways is just a little bit different in how long it takes to come to the decision that we’re no longer providing the hope, that we’re only providing a miserable existence and we should pull out and it’s there where most of the conflicts, I think, come in.

Every case is just that little bit different, you have to consider the feelings of everybody involved and some families just need some extra time to come to terms with things- that’s fine, they need that extra time. It’s interesting, I’ve never ever been faced by a situation where I’ve been told by a family “Please, you must do everything, keep, going, keep going!” I’ve never been faced with that. It’s never been an issue at all. I don’t know the reason for that. Maybe it’s just an individual thing with me. I’ll bring issues up early: I’ll say, “This is looking very hopeless.” I think they should be prepared. I don’t think you should go along saying, “We can save,” and, “We can save,” and, “We can save,” then all of a sudden say “No we can’t - we’re going to extubate him this afternoon and let him die!” ‘Henry’ (a colleague) is a perfect example of this - he’s very up front and discusses all issues with the family and I try and do the same.

Henry

Henry is an intensivist with international experience. His stories illustrated his approach to the issues around withdrawal of treatment. In particular he was able to illustrate how he related to both the relatives and the nursing staff in relation to these issues ….

All the ones I've been involved in, I've been comfortable with the decision to withdraw, but I tend to (*pause*) apart from brain stem dead patients, I would not turn a respirator off. The way I get round it is to "draw lines in the sand". I'd make the decision not to dialyse for instance, or I'd put a cap on the inotropes; or I'd put a cap on the oxygen level. Now, I do this with the support of the nursing staff - I ask them if they're comfortable, and I also get the support of the relatives. Now I actually give the relatives an option for me to go onto the nth degree with this. I certainly wouldn't go against the relatives' wishes. Now it might be a majority wish because I might actually have somebody who's not very comfortable with drawing lines in the sand, but usually we talk, the relatives and I, we talk this individual member around. It's usually the spouse. I find the spouse is maybe on occasion willing, or wants to go the nth degree. But the way I get round that is by saying, what does the husband or wife think, "If they were conscious, what would they want us to do?" This is the patient, what would the patient want to do. So that way I feel that I'm comfortable with the decision. I do tend to look at a patient on a very personal level and I wouldn't do anything to a patient that I wouldn't want done to myself, or a member of my family, and I have experienced the death of my father [to reflect on]. So, basically I take it very personally. That's the only way I can survive, doing this. And I would want the support of the nursing staff and the nurses.

Well basically I usually measure their [nursing staff]concerns, and I just ask them am I right? What I would say is, "This patient's been on inotropes on 10 mls. an hour or 15 mls. an hour, should we cap it here? Are you happy with that?" And I just ask them, "Am I right?" I think I know them sufficiently well that I know when they're unhappy about it, but generally they're not unhappy about it because we've been treating the patient over a period of hours or days, they're professionals and they know that the prognosis is not worth it. And they're usually happy with lines in the sand. I haven't had an occasion where they've disagreed. And I think they can talk to me, I mean I don't sort of lord it over them or anything like that. I think that's, we're a team. I think that's the main thing.

In response to my observation that it seemed like a pretty much a collaborative process, Henry replied: That's right. I mean we've got a patient at the moment; he's a 60'ish guy who's had an out of hospital arrest. He's probably had two down times. He's certainly had one down time that was of at least eight minutes. He's very sedated at the moment and currently we're lightening him to see what his mental state is like, and the nurse is involved. She's with the patient the whole time, so come tomorrow morning, she can give me a lot of information […]. Maybe he'd been making purposeful movements for instance, which is quite unlikely. But she's told me that he's got cogwheel (*jerky*) movement of his limbs and that in itself is probably a bad sign. I won't make a decision on whether to turn it [life-support] off tomorrow; […] we'll probably give him another 24 hours and see what he does. He's maintaining his blood pressure at the moment so, unless he has another heart attack in the meantime […] we may be able to get him off the ventilator. He is on inotropes at the moment, but by lowering him off sedation, we may actually be able to lower the inotropes (*a side-effect of sedation is hypotension; with reduced sedation, less inotropic support will be necessary*). Now this is not [likely to be] a wean situation. It [decide to withdraw treatment] might be able to be done with a patient who's severely handicapped, but […] we haven't turned anybody off. It may come to the fact that he may not breathe. So that's a difficult one, that's a difficult one (. But there again, you see, we will reduce, get him off all the sedation, all the inotropes and we may find, "Well, he's not breathing". We'll go to the relatives, say he's not breathing, not waking up, don't think he's going to wake up. […] We may be able to enlist the help of the relatives. (Some avoidable suffering related to dissonance here between personal values, empathy for patient and /professional values)

Henry outlined his probable interactions with this patients' family:

Well, first of all, when I talk to relatives, I usually ask them whom they've talked to, because they've probably talked to other doctors, and I don't want to say anything different to what they've been told. And it may only be slightly different, from relative to relative, but they may pick up on this. So usually what I say, is whom have you talked to, what do you understand by it, and I get them to talk to me first and then I will lead in. […] And so I will build on that and, I don't tell patients outright that there's no hope, but I sort of lead into it. The sort of things I will talk about is, "Well, so and so is on life support. That means they're on a ventilator, they're on inotropes." And then I'll go into, if they're on a ventilator, how much oxygen they need. I say, "We all we need 21%, but so and so is on 80%". And then I tend to talk about organ failure, usually I start off that if you've got one organ that's failed, you've probably got 50, 60, 70% mortality rate. If you've got two organ failure, you're up to 100% or thereabouts. I still put this forward as a sort of figure, to work on. I mean there's wide disagreement at these figures, but I usually put it forwards as a figure to work on. Then, if I think that the situation's not completely hopeless, I give them a little bit of ray or light, or hope. But if I think the prognosis is completely hopeless, I will say so: ' The chances of survival are very small'. And then I'll probably have, another talk after a few hours, or maybe the next day […] so I'll lead them into it gradually. Because I think, it's rather like being hit with a sledgehammer to tell them well, "That's it. Dad's going to die". […] I think it's most important is to keep them on side, and not to give the impression that you've sort of given up and that's it. Usually the relatives will actually come on side and, the other thing I would say is, is 'We're very good at keeping patients alive'; And, " Do you want us to prolong the act of dying?" This what they have to decide So, try to make them think about the patients, perhaps, rather than thinking about themselves, but actually think of the patient. What would Dad have wanted? That sort of phrase. I get them on side. I think that's the point.

Asked how he dealt with those relatives who had troubled accepting the prognosis of brain death because of life support measures, Henry replied:

They come along and say the patient, or Dad's pink. And his heart's going, and good blood pressure, and I say, "Well look, you know, that's fine. But, he's on life support. He's only pink because we're ventilating him. His blood pressure's only 130 odd because he's on inotropes, he's on drugs that are flogging his heart to produce that blood pressure. And I just tell them, candidly, if I switch all this off, he won't last two or three minutes. He'll die very, very quick. And it's only this that's keeping him going. But you've got to think about the brain. […] And I will use the word vegetable. Yes, I just tell them they won't be the same person; that Dad would have gone. Usually I think people are so well educated nowadays, that they know. They watch programs on television. They watch ER. People aren't stupid, they know. And usually in a group of relatives, you will always get one very sensible person and I sort of get a rapport with that person and get them to explain to the rest of the family what's going on, because usually they'll bring the rest of the family round. And usually they're sensible enough. So relatives today are well informed. It makes my job easier.

MURRAY

Murray is a neurophysician with wide experience. He chatted to me for a couple of hours about his experiences related to end-of-life decision-making. Murray is now in private practice with visiting rights to the tertiary teaching hospital and two private hospitals in the large rural city where he now practices. His experience and expertise meant that he was often called upon to offer an opinion related to brain death and so two of his most salient stories related to this issue.

The case that sticks in my mind is of a lad who was only twelve years old, and who had been knocked down as a pedestrian and suffered grievous head injuries. About a week after the accident, he was still showing no signs of recovering. [In this case I was one of the three physicians pronouncing brain death] They're procedures, which I might add that in more recent years I've had more and more reservations about. But I'd never say, yes I authorise turning off the life support.

I was called in because I was not in any way involved in the management of this case, and because I had no involvement in any organ transplantation possible through his death. But I reflect on his case from time to time, because in the years since, I've seen a number of patients who have survived, as far as I can tell, equally grave head injuries, after very, very lengthy treatment and painstaking rehabilitation. And they had survived because the relatives had not given permission for life support to be turned off. And I guess I've seen perhaps a dozen of these patients. Now three or four of them have actually become moderately ambulant again. All have learnt how to communicate at varying levels. Some have remained totally dependant on others for all of their personal needs. And so the spectrum is very variable.

But the common feature of all is that they, they regained the ability to communicate, to feel, respond, and in all cases, according to their parents or relatives, that told me years later when I became involved, there'd been a discussion at the time about turning off life support, which they have not wanted. Now the interesting thing is, of course, that I'm only seeing those patients who have survived that experience. In that particular context, obviously I'm not seeing those patients who did have life support sustained and sustained and sustained and eventually turned off. I've never seen a patient, of the kind that we read about occasionally, who's been in a so-called coma for several years, and then started to recover. I really don't know how possible that is. My hunch is that they may have been the kind of patient that had actually not been in coma. But through just maintaining care, maintaining devoted stimulation, they'd gradually shown signs that they can actually respond.

Because that's another feature of some of these survivor patients I've just mentioned, that, for a long time, they need tending. Medical and nursing staff have no inkling patients have actually taken things in. It's almost a syndrome that the relative, commonly it's the mother, will say, my son or my daughter actually knows I'm there. So its the relative that starts communicating. I've heard a paper prepared and read at an international medico-legal conference on this reporting the dozen or so patients with whom I've been involved. You see, the issues become very complex about whether we maintain or don't maintain the life support systems. I've already alluded in passing to the question of organ donors. […] And what makes me uncomfortable is that there are certain financial vested interests that become involved whether or not the person is nurtured long enough to recover, to the extent of being able to experience some of the experiences of life again. But, one thing I'm sure about, these people who do survive, are glad they've survived. I ask them, are you glad you're alive, and they always say yes. Even though they might be bed-ridden [they're happy with their quality of life.]

Asked whether he had interacted with the family of the twelve-year old whose condition had required that he act as one of the three independent physicians deciding on brain-death, Murray replied:

No, I didn't. But there has been another occasion, quite recently, where I gave the third opinion, where I did [talk to the family]. And that was a very moving experience. I remember concentrating very hard on being mindful that I have to keep this as simple as possible. Because I didn't think they'd take in the various parts of what I had to say, which is what I did. It was a desperately sad situation because the patient's illness, in itself, had been terribly complicated; caused dreadful stress in the family, disintegration of the family. The family members were there, and I was mindful of their background, so I was aware of keeping it as simple as possible.

The child had had epilepsy, which had been extremely difficult to control. He'd been very well looked after by a colleague, who had decided to resort to the use of another anti-epileptic drug. And this is one of those rare instances where the patient then suffered devastating, full-blown complications with the drug, and eventually had to have a liver transplant. […] The patient became better stabilized on the other medications. I mean the anti-convulsant that was causing it was discontinued; other things were tried. And, then he suddenly deteriorated and became comatose and couldn't be resuscitated. Well he could, enough to be brought into ICU, but not to the point of regaining consciousness.

[When speaking to the family] I was mindful that part of the grief reaction often entails blame seeking. No doubt you've encountered it yourself. And so I was very careful to define exactly what the problem was, to define that all that can possibly be done had been done. I can only go on impressions of other members of the family, but it seemed to me that they were all accepting, which is as much as one could hope for. Sometimes they aren't accepting, but I see my professional role in that situation as making things a little less unbearable, and trying at all costs not to add to the burden. I mean, often there's nothing you can really do. And I think this is where we find the ultimate professional demands being laid on us. We do what we know has to be done, without looking for a particular reaction.

In one way this becomes a responsibility, but if you know that you are doing what has to be done, and part of that obligation is making it as simple as possible for the relatives of the patient, then everything else will fall into whatever place it's going to find. By contrast, I don't feel you can specifically aim at getting a response of thanks. Thanks will come when one's done one's job. But you can't go into it from that point of view. You have to go into it as professionally as you can. People outside the medical and nursing profession, I think ambulance attendants are exposed to this too, and police. People who are not confronted with life or death situations, can't begin to imagine what the professional boundaries are, what the professional objectives have to be, how simple they must be. And the older that those of us become who work in these professions, the more we know. But you've got to keep it simple, and keeping it simple is one of the most compassionate things you can do. And you must only do what has to be done.

I'm always affected by the pressures [of these responsibilities] and it comes into other areas whenever I am dealing with a patient who has a fatal disease, and I have to break the news. I always then give myself time, ten minutes, quarter of an hour, no matter how packed or busy the day is, to give myself a bit of time to recover my composure. I allow myself to feel emotions, that I do feel, because just from my own personal lifetime experiences, those sorts of things do arouse feelings, and I have found that if I've had to do that sort of thing or become involved in one of these life or death crises, then I do think of those loved ones who I have lost. It helps me to cherish the memory of them, and I deliberately do that rather than push them away. I like to remind myself: Yes, I have this special feeling (avoidable suffering related to absence of counselling/ support facility).

1.5 CONCLUSION

This section of the dissertation has presented all the decision-makers' stories and their own reflections on the most important issues related to their end-of-life decision-making experiences. While each actor's story is unique, common threads and similarities can be seen to be running through them. Potential avoidable suffering has been identified in each story as the first step in analysis. The reader has probably noticed much suffering that was not remarked upon in each story. This highlights the fact that there is much inherent suffering in the critical care environment. This dissertation has not sought to address the unavoidable suffering inherent in critical care. Chapters five, six and seven have focussed on analysis of the interactions around the key decision making moments in each of these stories. Strategies to ameliorate the avoidable suffering identified in these stories have been identified in analysis and discussed in conclusions. Hopefully adoption of these recommendations will help ‘buffer’ the impact of the inherent suffering of the critical care environment.

APPENDIX II : ADVERTISEMENT FOR FAMILY MEMBER PARTICIPANTS

"Frequently family members are confronted with heart-rending decisions about the treatment for their loved ones: should Mum, Dad, or a child have or continue complex medical or technological treatment which may or may not work? Should we give permission to donate organs now we have been told their brain is dead?" These are questions asked by Deborah Sundin-Huard a Nursing PhD research candidate at the University of Southern Queensland.

"These decisions often have to be made in foreign, frightening surroundings, under an overload of complex information and conflicting emotional challenges. If we could understand all these issues more clearly from the perspective of the family members, then perhaps we could do something to reduce the suffering associated with this difficult time," Ms Sundin-Huard said.

As part of her PhD study, Deborah is interested in talking to people who have had to make decisions about life-saving treatment for their loved ones in critical situations just like these. "What issues are important to the families and how can we make the decision-making process better, and reduce the suffering? Essentially this is what I am hoping to find out," she said.

If you are willing to participate in research which aims to improve the way health care professionals deal with these situations Deborah Sundin-Huard can be contacted on email: sundinhuard@primus.com.au or phone 46312938.

APPENDIX III: INFORMATION SHEETS:

FAMILIES, NURSES AND DOCOTORS

INFORMATION SHEET (FAMILIES):

I am interested in the issues surrounding the decision-making process that occurs when a patient's illness or injury results in the need for decisions regarding the continuance or withdrawal of life-saving care. My aim in pursuing this line of inquiry is the reduction of unnecessary suffering for all the stakeholders affected by this process. I am therefor interested in talking to the families of patients who have unfortunately been the centre of such decisions. My project will gather information from unstructured interviews. During the interview you will be invited to describe your experiences, actions (if any) and emotions in relation to the situation you nominate to discuss. These interviews will occur in the setting in which you feel most comfortable - I offer my home as a possible venue, but will be happy to come to yours if this is more convenient and comfortable.

Any and all identifying information related to yourself, your family member and the institution in which the experience occurred will be altered to protect all these parties. Some of the information you give me may still be able to be linked to individuals or institutions and yet be vital to my research for examination purposes. In this event these sections will be withheld from publication and only be made available to my examiners. Any information you provide me with will remain confidential. The interviews you participate in will be taped and transcribed. You will be given a copy of these transcipts and have the right to withhold any of the information from being in the thesis. The tapes and transcipts from the interviews will be kept in a locked filing cabinet in my home to ensure its safety. The computer I will use for the processing of the information gained during this project is not linked to a modem and is therefore not potentially available to unauthorised access.

You have the right to withdraw from this project at any time. This project may expose emotional challenges for you during the interview process. Through my nursing experience and knowledge I am able to deal with emotional crises. Further to this, provision has been made for referral to ongoing counselling if this is desired.

I have read this information sheet and am happy to take part in the research project as explained to me by DeborahSundin-Huard.

Signed:-
Date:
Witness:-
Date

APPENDIX IV: EVOLUTION OF THE CRITERIA FOR THE DIAGNOSIS OF BRAIN DEATH

While doubts are emerging about the validity of this concept it is important to understand the background to what currently remains “established practice”. The following section outlines the evolution of the criteria for the diagnosis of brain death. I will conclude this section with a summary of the contemporary position with respect to the diagnosis of death in Australia today.

Brain death was first described in 1959 in the French neurological literature as *coma dépassé*, literally ‘a state beyond coma’ by two Parisian Neurologists, Mollaret and Goulon. They introduced the earliest criteria for recognition of this condition in their description of 23 cases of comatose patients who had lost brain stem reflexes, as well as the capacity to breath and who had flat electroencephalograms (Pallis, 1987); (Wijdicks, 2001). The French neurological literature was not widely read in Britain and America and brain death did not gain an international profile until almost a decade later (Pallis, 1987). Evolution of the criteria then progressed upon relatively parallel lines in both the United States of America and Britain.

United States

In 1968, the ad hoc committee of the Harvard Medical School, chaired by Professor Beecher, re-examined the definition of brain death. The committee’s report stated that any deeply comatose patient (not under the influence of hypothermia or drugs) who remained unreceptive, unresponsive and apnoeic for a period of 24 hours, and who in addition had absent brain-stem reflexes, should be considered to be in a state of irreversible coma. The committee’s report and definition effectively equated ‘irreversible coma’ with death. A flat electroencephalogram (EEG) was stated to be ‘of great confirmatory value’ (Pallis, 1987). This report went onto to agree that: “…life support could be withdrawn from patients diagnosed with ‘irreversible coma or brain death’ (terms they used interchangeably) and that, with appropriate consent, their organs could be removed for transplantation”(Hoffenberg 2001, p.1480). Conjoined legal opinion offered at the time of the report advised that patients satisfying the criteria for brain death be pronounced dead before organ removal was attempted (Hoffenberg, 2001). The recommendations of this report were welcomed and adopted by specialists and authorities who had been battling with the challenges of terminating life support for the preceding decade - ever since it had become possible to maintain cardio-respiratory function and homeostasis almost indefinitely (Pallis, 1987); (Capron, 2001); (Hoffenberg, 2001).

In 1971 refinements were added to the Harvard committee's definition by two neurosurgeons from Minneapolis (Mouhandas & Chou). These specialists published a paper identifying irreversible loss of brain-stem function as the 'point of no return' with respect to brain damaged individuals. Their first refinement was that there had to be a known cause for the coma – this cause had to be an irreparable intracranial lesion. In the development of this criterion, Mouhandas and Chou were calling attention to the importance of meeting preconditions before a clinical diagnosis of brain-stem death could be contemplated. They also called for the witnessed absence of spontaneous motor movements for a period of 12 hours; that apnoea persist for at least four minutes following disconnection from the ventilator and that no brainstem reflexes were present. As these two specialists were monitoring brainstem function, they argued that the EEG (generated in the cerebral cortex and therefore not really relevant to brain stem function) was not mandatory in this respect (Pallis, 1987). Their refinements, dubbed the Minnesota Criteria, were to have an important impact on the development of the UK Code.

The issue was revisited in United States, in 1981 by the President's Commission for the Study of Ethical problems in Medicine and Biomedical and Behavioural Research (Wijdicks, 2001). The commission was ambivalent in their definition of death declaring, "…an individual death depended on either irreversible cessation of circulation and respiratory function or irreversible functions of the entire brain". Further to this, they recommended the use of confirmatory testing to reduce the requisite period of observation but still recommended a period of 24 hours for patients with anoxic damage. I find this a curious recommendation as most brain injuries have some element of anoxia or hypoxia in their history somewhere. More recently, the American Academy of Neurology (1995) published their report and recommendations following a review of practices related to the determination of brain death. This report specifically addressed the validity of confirmatory testing and provided practical guidelines for apnoea testing. These will be discussed shortly.

Following this commission, a Uniform Determination of Death Act, which insisted upon "whole brain death" as a *sin qua non* of brain death was enacted into law and accepted in most states. There is some suggestion in the literature that this insistence upon "whole brain" death as a criteria for death is a flawed concept and raises as many problems as it seeks to solve (Capron, 2001); (Hoffenberg, 2001). As Hoffenberg, points out, if taken literally, the detection of any residual electrical or neurohormonal activity in any part of the brain at all would preclude the diagnosis of brain death. Indeed, there have been reports of residual electrical or neurohormonal activity in subjects who would other wise have met the criteria of brain death, and some authors are arguing that the concept is flawed. Moreover, these authors are calling for a return to the traditional cardio-pulmonary criteria for death or a change in the terminology (Truog, 1997); (Shewmon, 1998) (Capron, 2001); (Evans, 2002).

Increasingly, research is lending an enhanced understanding to the pathophysiology of increased ICP and its impact on blood supply to the whole brain and/or infratentorial regions (Coimbra, 1999); (Hypothermia after Cardiac Arrest Study Group, 2002); (Safar & Kochanek, 2002). It has been hypothesised that this impaired blood supply, which may last hours or up to three days reduces the patient to a state of "ischaemic penumbra" producing the coma and cerebral areflexia currently considered diagnostic of brain death (Coimbra, 2002). As it is during this three-day period that testing for brain death is carried out, it is conceivable that some misdiagnoses have occurred through the years.

United Kingdom:

The development of the criteria for the diagnosis for brain death was significantly influenced by publication by Mohandas and Chou in 1971, who identified damage to the brain stem as the crucial component and linked it to profound irreversible coma. In 1976, the Conference of Medical Royal Colleges and their Faculties in the United Kingdom published its statement on the definition of and guidelines for the diagnosis of brain death. This statement defined brain death as the complete and irreversible loss of brain stem function and offered both a refinement of apnoea testing and the requirement that two doctors carry out the specific testing on two separate occasions (Conference of Medical Colleges and their Faculties, 1976). Hoffenberg suggests that this early acknowledgement of the significance of brain stem death saved Britain much of the controversy related to definition of death that has troubled the U.S. This definition of brain death: that without a functioning brain stem, life does not exist, was argued to be robust. A meta-analysis of 1300 cases who met the criteria for brain stem death showed that asystole ensued within 48-72 hours despite ventilatory support in every case(Pallis, 1987). This study has been challenged in light of enhanced knowledge related to acute brain injury and the pathophysiology of raised intracranial pressure. The imminence of asystole despite maximal therapy was assessed in a recent and wide-ranging meta-analysis of cases of survival following formal diagnosis of brain-stem death (12,200 sources surveyed to yield 175 applicable cases) (Shewmon, 1998). This review found that although survival probability decreased exponentially, dropping initially at around two- three months and then a one year, some patients survived up to 14 years. Further, the authors of this study found that the tendency to asystole was transient only and attributable to systemic failures rather than the absence of brain stem function per se. It is important to acknowledge that all the subjects who met the criteria for inclusion in this review were on “maximal therapy” rather than just ventilation. They also had the benefit of 22 more years’ research and insight into the pathophysiology of brain injuries and the possible measures used to support the failing systems of the body.

Table IV.1 Summary: Evolution of Criteria for Brain Stem Death:

Author/s & year	**Significant events**	**Characteristics**
Mollaret & Goulon **1959**	First Definition *(coma dépassé)*	▪ Loss of brain stem reflexes ▪ Loss of capacity to breath spontaneously (apnoea) ▪ Absence of tendon reflexes in limbs (spinal cord function had also ceased) ▪ ECG was 'flat'
Harvard ad hoc committee **1968**	Linked irreversible coma with death	▪ Unresponsive/ unreceptive & apnoeic for period of 24 hrs +Absent brain stem reflexes
Mohandas & Chou **1971**	Minnesota Criteria (identified importance of preconditions i.e. irreparable intracranial cause of coma)	Called for: No observed spon. m'ment For 12 hrs rather than 24 At least 4 minutes' apnoea No brain stem reflexes
Conference of Medical Royal Colleges & their faculties **1976**	**Publication of UK Code** Reviewed without alteration 1995 & again in 1998 (DoH) with links to organ donation protocols	Identification of coma Clinical evidence of cause Exclusion of drugs & hypothermia Absent motor response Absent brain stem reflexes Apnoea
President's Commission for study of Ethical Problems in Medicine **1981** **Uniform determination of Death Act**	US Code Published Reviewed 1995 – Recommendations: Confirmatory testing& Practical guide to apnoea testing	Follows same criteria as UK Code

(Conference of Medical Royal Colleges and their Faculties in the United Kingdom, 1976); (Pallis, 1987);(Black et al., 1998); (Jennett, 1999); (Wijdicks, 2001);

The validity of the concept of brain death and its diagnosis was brought under close public scrutiny in the United Kingdom following the airing of a programme on *Panorama* in 1981, suggesting that the diagnosis of brain death could be uncertain. This assertion was swiftly and specifically rebutted in a later programme made by two specialists nominated by the College (Jennett, 1999). A review of the code of practice related to diagnosis established a minimum period of observed coma of 6hours, but found no other need to alter the criteria developed in 1976 (Evans, 2002). A 1995 review by the Conference of Medical Royal Colleges preferred the term 'brain stem' death but otherwise found no need to modify their original diagnostic criteria. While a further review in 1998 linked the process to procurement of organs, it was of a similar confident view regarding the original diagnostic criteria for brain stem death (Black et al., 1998). These US and British documents have informed medical practice in most English speaking western countries ever since (National Health & Medical Research Council, 2002).

Australia

In 1977 the Australian Law Reform Commission recommended that the definition of death include not just brain stem death but also the "…irreversible cessation of all functions of the brain of the person". These recommendations have been enacted into legislation in all states and territories apart from WA and so under Australian law death is generally defined as irreversible cessation of circulation of blood in the body of the person or irreversible cessation of all functions of the brain of the person (National Health & Medical Research Council, 2002). Brain death is defined as the absence of all brain function as demonstrated by profound coma, apnoea and absence of all brain stem reflexes (the definition first posited by the gentlemen of the Harvard ad hoc committee in 1968).

APPENDIX V : DETERMINING BRAIN DEATH

Clinical neurological examination remains the standard for determination of brain death and has been adopted as such in most countries. To be accurate however, it must be complete and performed with precision. (Chaloner, 1996); (Sullivan et al., 1999); (Hoffenberg, 2001); (Lazar et al., 2001); (Wijdicks, 2001). The declaration of brain death involves the combination of a series of neurological tests with the establishment of the cause of the coma, the ascertainment of irreversibility, the resolution of any misleading neurologic signs, the recognition of possible confounding factors, the interpretation of findings on neuroimaging, and the performance of any confirmatory laboratory tests deemed necessary (Crippen, 1991); (Black et al., 1998); (Sullivan et al., 1999); (Sahni, 2000); (Lazar et al., 2001); (Wijdicks, 2001). Just who performs the clinical neurological examinations leading to the determination of brain death depends upon each hospital's protocols and upon its locality and resources. It has been convincingly argued that because of their expertise, only neurophysicians and neurosurgeons should perform these examinations and make the related determination (Wijdicks, 2001); (Baumgartner & Gerstenbrand, 2002), but in practice there is a wide variation in the experience and qualifications of the doctors involved in diagnosing brain death. As the current NH&MRC discussion paper on "…the diagnosis and certification of death with respect to brain function criteria" acknowledges, the procedure varies from hospital to hospital. The authors of this paper felt that the practices have however, become 'fairly standardised', being guided by codes of professional conduct and the statutory definition of death (where applicable) (National Health & Medical Research Council, 2002). This statement may well be true in Australia. It is by no means, reflective of practice around the world as a meta-analysis of practice guidelines for brain death diagnosis within 80 countries indicated. This study found agreement with the neurologic criteria used for testing (apart from apnoea testing), but major differences in the standards and procedures used in diagnosis of brain death (Wijdicks, 2002).

Prerequisites

Before the clinical neurological examination of the patient in whom brain death is suspected can proceed, certain initial prerequisites must be met. These are perhaps best conceptualised as essential preconditions and necessary exclusions:

Essential Preconditions:

Typically, the individual for whom such a diagnosis is being considered will present with clinical or neuro-imaging evidence of an acute, catastrophic cerebral event.
Most importantly the cause for patient's presentation and coma must be established as irremediable and this cannot be done on theoretical grounds. All attempts to correct potentially treatable problems must have been undertaken, eg if a blood clot is the problem this must be drained; if hypotension and therefore hypoperfusion of the brain is a possible cause this must be corrected; if hypoxia or CO^2 retention might be in play, this must also be corrected before assessment for brain stem death is contemplated (Pallis, 1987); (Crippen, 1991).

Necessary Exclusions:

Prior to testing to determine the level of damage caused by this event it is initially necessary to establish that there are no confounding or extraneous influences on the patient's condition. Thus, in discussion of this process all the references that I was able to access were in agreement with respect to the initial requirements for the clinical determination of brain death:

- The exclusion of conditions that may confound the assessment (e.g. any extremes of metabolic or endocrine disturbance that might mask or potentiate responses to testing).
- Drugs (i.e. sedatives, muscle relaxants) or poisoning must be excluded as possible explanations for the patient's condition.
- The patient must not be severely hypothermic, i.e. must have a core temperature ≥ 32° C

(Pallis, 1987); (Hudak et al., 1990); (Dorr, 1997); (Black et al., 1998); (Sullivan et al., 1999); (Lazar et al., 2001); (Wijdicks, 2001).

The **cardinal** findings in brain death include coma or unresponsiveness, absence of cerebral motor responses to pain in all extremities, absence of brain stem reflexes and apnoea %%401(Sullivan et al., 1999)%% The clinical examination and thus determination of brain death is essentially a three step process involving examination and documentation that the patient meets these criteria:

Determination of the depth of the coma,

Includes assessment of motor response to pain

1. Clinical assessment of brain stem reflexes,
2. Apnoea testing

Coma

Coma has been defined as

> "…deep sustained unconsciousness that results from dysfunction of the ascending reticular activating system in either the brain stem or both cerebral hemispheres. The eyes remain closed, and the patient cannot be aroused. To be distinguished from syncope, concussion, or other states of transient unconsciousness, coma must persist for at least one hour." (The Multi-Society Task Force on PVS, 1994 p1452)

Characteristically, such patients will have been in a comatose state as a result of their injury for a prolonged period or what some authors euphemistically call an "… appropriate period of observation" (Hudak et al., 1990). This period of observed unconscious was set at 6 hours minimum in the 1983 review of the UK Code of Practice (Evans, 2002). In most patients with brain death, the reason for this prolonged period of unresponsiveness will have been established with neuro-imaging, as injuries consistent with the loss of brain or brain stem function will have been imaged (Dorr, 1997); (Sullivan et al., 1999); (Schubert et al., 2001). In rare cases of brain death due to ischaemic-anoxic cerebral injury, the patient may have normal neuro-imaging studies (Sullivan et al., 1999); (Wijdicks, 2001). In such cases, where the patient's coma is of indeterminate origin, determining brain death remains difficult and presents increased difficulties for the patient's family (Evans, 1995). Diagnosis, however, can be achieved through prolonged observation and confirmation that the patient's condition fits the clinical and diagnostic criteria for brain death.

Motor Responses to Pain

The depth of the individual's coma is assessed through the documentation of the assessment of the cerebral motor responses to pain. These are elicited through the use of "standardized" painful stimuli such as pressure applied to the finger nail beds, supraorbital nerves or to the temporomandibular joints. Purposive or cerebrally modulated motor responses to painful stimuli will be absent in all peripheries in brain death. (Black et al., 1998); (Sullivan et al., 1999); (Lazar et al., 2001); (Wijdicks, 2001). It is noted that spontaneous motor responses (eg twitching, small arm or leg movements) may occur during apnoea testing as a result of hypoxia or hypotension. These movements are considered to be due to spinal cord reflexes and noted to be a potential source of concern for relatives and inexperienced staff (Black et al., 1998); (Sullivan et al., 1999). They do not include attempts to breath or voluntary purposeful movements. Once the absence of motor responses has been documented, the examination should proceed to the assessment of brain stem reflexes.

Functions of the Brain Stem

In order to fully understand the criteria and procedures for determining brain stem death it is necessary to understand the functions of the brain stem. The following section outlines and briefly discusses these functions. The brain stem is responsible for or mediates all essential life functions. Through the respiratory centre located in the medulla oblongata, the brain stem is responsible for respiratory drive. It is in large measure (but not exclusively) the controller of blood pressure through the vasomotor centre and the cardiac centre in the medulla oblongata. Apart from vision and smell all sensory traffic reaches the brain via the brain stem and all motor output from the brain leaves via the brain stem. The brain stem also mediates all the cranial nerve reflexes. Importantly, although the cardiac centre is lodged in the brain stem and to a certain extent controls heart rate and blood pressure, the heart can be 'paced' or driven completely independently of the brain stem (Guyton, 1987); (Brown & O'Toole, 1992). As Pallis (1987) demonstrated, this capacity of the heart can continue for up to 72 hours without innervation from the brainstem. He reviewed 1300 cases of clinically diagnosed brainstem death for whom ventilation was continued "…either because doctors did not initially accept that a non-functioning brainstem inevitably implied asystole or at the request of relatives." (p.91). This review indicated that asystole will occur within 48-72 hours of brainstem death (Pallis, 1987).

The brain stem is also thought to mediate and integrate consciousness. A properly functioning paramedian tegmental area of the upper brain stem is a precondition for full consciousness and allows the cerebral hemispheres to work in an integrated manner and so alteration in consciousness may be one of the first signs of increased pressure in these areas (Pallis, 1987); (Romanini & Daly, 1994) (Hanley, 1998).

In effect, without a functioning brain stem, an individual cannot survive. The assessment for brain death is an assessment of these functions, by testing for function and reflex in an orderly manner.

Assessment of Brain Stem Reflexes

The assessment of brain stem reflexes is the assessment of the lower brain's ability to sustain basic life. For example, such functions as the ability to cough, gag, withdraw from noxious stimuli and especially the breathing reflex are the supported by the brain stem. All brain stem reflexes will be absent in brain death (Conference of Medical Royal Colleges & their Faculties in the United Kingdom, 1976); (Jennett, 1981); (Pallis, 1987); (Sullivan et al., 1999); (Lazar et al., 2001); (Wijdicks, 2001). If brain stem reflexes are absent then the examination should result in the doctor documenting:

Pupillary signs:

The pupillary reflex in response to sudden bright light shone into eyes will always be absent in brain death. Round, oval or irregularly shaped pupils are all compatible with brain death and midsize with respect to dilatation (4-6mm). Dilated pupils are a poor prognostic sign, though it is possible that constricted pupils may still occur in brain death because of intact sympathetic cervical dilator pathways to the pupillary dilator muscle. However, even in that case, the pupillary response to sudden bright light shone into eyes will be absent.

Facial Sensory and Motor Responses:

There must be no grimacing, eye opening or any form of purposive response to pain such as withdrawal for brain death to be diagnosed. This pain response, if present, may be elicited by applying deep pressure bilaterally to the temporomandibular joints. A similar effect might be tested by gently touching the edge of the cornea with a cotton-tipped swab. The corneal response will be absent in brain death.

Clear visualisation of either the pupillary response, eye opening or facial response to pain is difficult to assess and interpret in the case of traumatic head and facial injuries and the swelling and bruising accompanying such cases. Accurate assessment of these responses therefore becomes problematic in these situations.

Ocular Movements:

Both the ocular-cephalic reflex (doll’s eye) and oculo-vestibular reflex (caloric test) are absent in brain death.

Ocular-cephalic reflex (doll’s eye) The details of testing and normal response can be found in glossary – appendix v. This test is recognised as difficult to interpret %%348(Crippen, 1991); 497(Lazar et al., 2001); 488(Wijdicks, 2001)%%, and therefore it is not a very reliable test. Furthermore, as it requires the rapid turning of the patient's neck from side to side, it is not possible to perform this test safely when a person has an unstable cervical spine.

Oculo-vestibular reflex (cold caloric test) The absence of provoked eye movements should be confirmed in such situations by cold caloric stimulation of the tympanic membrane (see glossary for details). Trauma to the head involving the auditory canal and petrous bone will both inhibit these reflexes and render their examination problematic as this test involves injection of cold sterile fluid down the ear canal. This is a reasonably common occurrence in brain death diagnosis.

Pharyngeal and Tracheal Reflexes:

Both the pharyngeal (gag) and tracheal (cough) reflexes are absent in brain death (see glossary for details). The results of stimulating this reflex can be difficult to assess in the orally intubated patient who will be sedated and chemically paralysed to facilitate oral intubation and optimal mechanical ventilation (Black et al., 1998); (Sullivan et al., 1999); (Lazar et al., 2001); (Wijdicks, 2001).

Table V.1 Summary- Brain stem reflexes

(Sullivan et al., 1999); (Wijdicks, 2001)

Brain Stem Reflexes assessed	Findings in Brain Death	Cranial Nerves Tested	Reliability in massive Brain Injury
Pupillary reflexes	Absent response to bright light (pupils at midpoint with respect to dilatation 4-6mm)	II and III	Dependant amount of swelling and access to eyes
Facial sensory & motor responses	Absence of grimacing or eye opening in response to pain, eg deep pressure on temporomandibular joints	Afferent V & Efferent VII	Problematic in presence of facial swelling
Corneal Reflexes	Absence of grimace/ pain response when edge of cornea	V and VII	Dependant on access to eyes

	is touched		
Oculo-Cephalic reflex (problematic)	Absence of deviation of eyes to opposite side following rapid head turning 90° (doll's eye phenomenon)	III, VI and VIII	Problematic in presence of unstable cervical spine – not recognised as reliable
Oculo-Vestibular reflex (caloric test)	Absence of response (deviation of eyes towards side of cold stimulus provided by introduction of ice water)	III, VI and VIII	Problematic in presence of facial/jaw/temporal area trauma
Pharyngeal (gag) reflex	Absent – elicited by stimulating rear of pharynx with tongue depressor	IX and X	Difficult to assess in the orally intubated patient (often the case in the first 24-48 hrs with head injuries).
Tracheal (cough) reflex	Absent – elicited by inserting a suction catheter deep within the trachea.	IX and X	Most reliable

Apnoea Testing

Once the absence of other brain stem reflexes has been documented, formal apnoea testing follows according to the current criteria. This step is regarded as essential component of determination of brain death as loss of brain stem function definitively results in the loss of centrally controlled breathing due to damage to the medulla oblongata, resulting in apnoea (Black et al., 1998); (Sullivan et al., 1999); (Wijdicks, 2001). A discussion of the pathophysiological control of the mechanism of respiration and the consequent development of criteria for apnoea testing can be found in the glossary.

Apnoea testing to date has called for the induction of hypercarbia to such a level that it would be expected to stimulate the patient's chemoreceptors in the medulla and therefore trigger inspiration in the otherwise healthy individual (see glossary for details). If inspiration does not occur, the inference drawn is that irreparable damage has been done to the patient's brain stem. Research and refinement has instituted such safeguards as apnoea diffusion oxygenation and streamlining of the process by raising the patient's $PaCO^2$ to 40mmHg before disconnection from the ventilator (Roper & Zisfein, 1990; Benzel et al., 1992). Nonetheless, apnoea testing requires disconnection from the ventilator for a period long enough to satisfy the testing physician that the patient is not going to breathe spontaneously and to allow the patient's PCO^2 to rise to 60mm Hg. To satisfy the current criteria for brain death this process is repeated by a second medical officer.

If apnoea testing is to proceed, then of equal or prime importance at this stage is the insurance that the exclusion from the patient's system of drugs that might interfere with assessment of this step, i.e. muscle relaxants and sedatives, has been assiduously maintained. One might assume that this would happen as a matter of course prior to apnoea testing but the discourse in the literature suggests otherwise as the issue of double-effect is raised in relation to the maintenance or even initiation of muscle relaxants and sedation as the patient is extubated (Swinburn et al., 1999); (Truog et al., 2000); (Street et al., 2001).

While the criteria for the determination of brain death have been well researched and documented, it cannot be said that they are always uniformly and rigorously followed (Jenkins et al., 1997); (Sahni, 2000). As this review and discussion has illustrated, neither are they without their problems. As Wijdicks acknowledged, there are concerns about the use of 'adequate' precautions when apnoea testing and there have been no recent audits of the competence of physicians in the determination of brain death (Goudreau et al in Wijdicks, 2001). It would seem therefore that: the only really reliable test of brain death is whether the person breathes when the ventilator is turned off. In situations where components of the clinical evaluation for brain death cannot be reliably evaluated then the physician may have to turn to confirmatory testing.

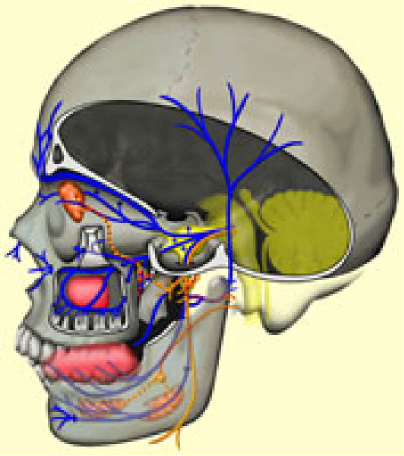
Confirmatory testing

The use of confirmatory tests to augment the clinical determination of brain stem death is mandated by law in several European, Central and South American and Asian countries (Wijdicks, 2001). Conversely, confirmatory testing is perceived and discussed as 'optional' corroboration of the diagnostic process in the literature emanating from the United States and Britain where the use of such tests is left to the discretion of the physician (Litscher, 1999); (Sullivan et al., 1999); (Swinburn et al., 1999); (Wijdicks, 2001). As the diagnosis of brain death is intimately linked to the procurement of organs for transplantation, some of the discourse related to confirmatory testing centres on how this might facilitate the 'speeding up' of the whole process so that 'fresher' organs might be obtained for harvest and transplantation or indeed how the charges for care might be minimised if the process of determination of death were shortened. For example one study suggested the entire process could be speeded up using just one clinical examination together with a nuclear medicine brain flow scan (Jenkins et al., 1997).

The Jenkins study reported improvements with respect to the numbers of organs procured per patient, reduction in costs for care, and reduction in complications while these patients were being cared for. There was, however, no discussion of the relative accuracy rendered by this alternative 'speedier' method of determination of brain death. As this method depends on one clinical examination only, the validity of the diagnosis of brain death depends upon one physician's expertise and opinion. Although this examination is supported with a recognised confirmatory test, this testing method is seriously flawed in that it does not allow for the passage of time for the patient's condition to alter or for the value of a second opinion. Although costs are a concern both to the consumer and the health care system, one would presume accuracy in diagnosis to be the prime consideration in light of the impact of a finding of brain death upon the loved ones left behind (Evans, 1995); (Inwald et al., 2000); (Pugh et al., 2000).

The confirmatory tests discussed in the literature include Electroencephalography, Cerebral Angiography, Transcranial Doppler Ultrasonography, Somatosensory-evoked Potentials, and Cerebral Scintigraphy (Nuclear imaging) all of which of have relative use and accuracy depending on the clinical scenario (Pallis, 1987); (Bates, 1997); (Jenkins et al., 1997); (Zandbergen et al., 1998); (Litscher, 1999); (Carter & Butt, 2001); (Wijdicks, 2001); (Hankey, 2002). For example there has been on-going debate about the usefulness and applicability of the electroencephalogram in the diagnosis of brain death and in some cases, eg MRI or Cerebral Scintigraphy, the sheer logistics of moving the patient and their equipment to radiology for testing becomes a consideration. The details of the performance of these confirmatory tests are discussed at length in the glossary.

APPENDIX VI: RAISED ICP (AS APPLIED TO GRANT'S CASE)



According to Gray's Anatomy, the fifth or trigeminal nerve is the largest cranial nerve. Also called the trifacial, this nerve resembles a spinal nerve in arising from two roots; in function – it is a compound nerve; and in having a ganglion on its posterior root. This nerve serves as the great sensory nerve of the head and face, and the motor nerve of the muscles of mastication. It emerges from the side of the pons, near its upper border, by a small *motor* and a large *sensory root*—the former being situated in front of and medial to the latter p725(Pick & Howden, 1977).

There remains some debate over the actual pathophysiology of pain production in trigeminal neuralgia. One theory suggests that peripheral injury or disease of the trigeminal nerve increases afferent firing in the nerve; failure of central inhibitory mechanisms may be involved as well. In most cases, no precipitating cause can be identified and the aetiology is labelled idiopathic by default. But in some cases, abnormal vessels, aneurysms, tumours, chronic meningeal inflammation, or other lesions may irritate trigeminal nerve roots along the pons. This would appear to have been so in Grant's case. Previous investigations (probably an MRI) would have identified the offending lesion and its location.

As previously identified, the root of this nerve arises along the pons, a section of the brain stem lying deep within the brain. Thus, surgical release of lesions causing irritation or inflammation to this nerve involves handling, movement and possible dissection of vital brain tissue. This intervention has the inevitable side effect of triggering off the body's inflammatory response. The most worrisome manifestation of this in Grant's case is the accompanying production of oedema during and following surgery (vasogenic oedema). The adult cranial cavity is a rigid case with a finite capacity. If there is an increase in volume of any one of the intra-cranial components (brain tissue, CSF or blood), there must be a corresponding decrease in one of the other components otherwise intracranial pressure will rise. The body can achieve this for a brief time through the process of autoregulation whereby intracerebral arterioles are constricted to temporarily reduce cerebral blood volume. Autoregulation can only compensate for a very small volume increase, however – volume increases of 10mls or more can have dramatic effects on intra-cranial pressure p602-606(Romanini & Daly, 1994). Past this point, elevations in intra-cranial pressure (ICP) will have dramatic effects on the brain as ICP approaches arterial blood pressure and blood supply to the brain is compromised. The patient loses consciousness, may exhibit abnormal respiratory patterns, an elevation in blood pressure with a widening pulse pressure and cardiac dysrhythmias. If ICP continues to rise, then eventually ICP equals arterial pressure and blood supply, oxygen and nutrients to the brain are lost resulting in brain death (Romanini & Daly, 1994); (Sullivan et al., 1999).

Concurrent with and compounding this loss of blood supply is the syndrome of tentorial herniation. The intra-cranial cavity is divided anatomically into compartments by overlapping, rigid projections of the dura mater. As ICP rises, this pressure may cause sections of the cerebrum, basal ganglia, diencephalon and midbrain to displace side-ways or downwards. This displacement causes damage to the tissue itself, but more importantly, it causes, obstruction of the flow of CSF, which further exacerbates the pressure problems within the cranium. Signs and symptoms of impending intracranial herniation include:

- Decreased level of consciousness (coma)
- Pupillary abnormalities
- Motor dysfunction (hemiplegia, decortication or decerebration)
- Impaired brain stem reflexes (corneal, gag, swallowing)
- Alterations in vital signs, including respiratory irregularities

(Hickey, 1981 cited in Romanini & Daly, 1994, p 607)

As Sandra describes, Grant clearly developed a number of these symptoms. On his way back from the C/T scanner to theatre she noted that he was having a “nice sleep” which she later recognised to be a coma. She also noted the “snoring” quality of his breathing which is the stertorous breathing typical of an unconscious individual unable to maintain their own airway (Brown & O'Toole, 1992). Sandra also refers to Grant’s decorticate gesturing and her difficulties in dealing with its significance. Other changes – pupillary abnormalities, impaired or absent brain stem reflexes – would have been picked up by the health professionals caring for Grant and would have formed part of the eventual assessment for brain death (Sullivan et al., 1999).

Factors that may effect intracranial pressure include intra-thoracic pressure, intra-abdominal pressure, intravascular oncotic pressure and blood gases (specifically acidosis or hypoxemia) (Hanley, 1998); (Romanini & Daly, 1994). With this in mind, efforts to reduce vasogenic oedema as a result of surgery focus on the management and minimisation of these factors. Intra-operatively, it is the anaesthetist who will be primarily responsible for this management – monitoring systolic BP and arterial blood gases through the use of an arterial line placed in the patient’s wrist. Aware of the impact of raised intra-thoracic pressures on ICP, the anaesthetic would aim to ventilate the patient with lower pressures and higher volumes intra-operatively(Schubert et al., 2001). The aim here would be to achieve an appropriate SaO2 without raising intra-thoracic pressures and therefore ICP. At the same time, the anaesthetist would be aware that high oncotic pressures within the intra-vascular volume will encourage removal of oedema fluid from inflamed brain tissue. Accordingly, intra-operatively, he or she would administer an intravenous solution with a high sugar concentration which will increase the intra-vascular oncotic pressures, eg Mannitol (Romanini & Daly, 1994). All these measures would normally be implemented to keep the production of vasogenic oedema to a minimum (Hanley, 1998); (Romanini & Daly, 1994). As I was not present at Grant’s operation, I was not able to observe whether such practices were followed intra-operatively in his case.

APPENDIX VII GENERATING THE APACHE II SCORE

Overview: The APACHE II score is a general measure of disease severity based on current physiologic measurements age and previous health condition. The score can help in the assessment of patients to determine the level and degree of diagnostic and therapeutic intervention.

Components:

(1) acute physiology score (APS)

(2) age points

(3) chronic health points

Data collection:

- The data for the acute physiology is collected during the initial 24 hour period after ICU admission.
- The worst (most deranged) physiologic value is selected for grading.

Acute Physiology Score (APS)

PARAMETER	**FINDING**	**POINTS**	**-1**	**1**	**2**	**3**	**4**	**5**
rectal temp in C°	>= 41	+4						
	39-40.9	+3						
	38.5-38.9	+1						
	36-38.4	0						
	34-35.9	+1						
	32-33.9	+2						
	30-31.9	+3						
	<= 29.9	+4						
mean arterial pressure mm Hg	>= 160	+4						
	130-159	+3						
	110-129	+2						
	70-109	0						

	50-69	+2						
	<= 49	+4						
heart rate in beats/minute	>= 180	+4						
	140-179	+3						
	110-139	+2						
	70-109	0						
	55-69	+2						
	40-54	+3						
	<= 39	+4						
respiratory rate in breaths/min	>=50	+4						
	35-49	+3						
	25-34	+1						
	12-24	0						
	10-11	+1						
	6-9	+2						
	<= 5	+4						
oxygenation	A-aDO2 >= 500 and FIO2 >= 0.5	+4						
	A-aDO2 350-499 and FIO2 >= 0.5	+3						
	A-aDO2 200-349 and FIO2 >= 0.5	+2						
	A-aDO2 < 200 and FIO2 >= 0.5	0						
	PaO2 > 70 and FIO2 < 0.5	0						
	PaO2 61-70 and FIO2 < 0.5	+1						
	PaO2 55-60 and FIO2 < 0.5	+3						
	PaO2 < 55 and FIO2 < 0.5	+4						
arterial pH	>= 7.7	+4						

	7.6-7.69	+3						
	7.5-7.59	+1						
	7.33-7.49	0						
	7.25-7.32	+2						
	7.15-7.24	+3						
	< 7.15	+4						
serum sodium	>= 180	+4						
	160-179	+3						
	155-159	+2						
	150-154	+1						
	130-149	0						
	120-129	+2						
	111-119	+3						
	<= 110	+4						
serum potassium	>= 7.0	+4						
	6.0-6.9	+3						
	5.5-5.9	+1						
	3.5-5.4	0						
	3.0-3.4	+1						
	2.5-2.9	+2						
	< 2.5	+4						
serum creatinine in mg/dL	>= 3.5 and not acute renal failure	+4						
	2.0-3.4 and not acute renal failure	+3						
	1.5-1.9 and not acute renal failure	+2						
	0.6-1.4 and not acute renal failure	0						
	< 0.6 and not acute renal failure	+2						

	>= 3.5 and acute renal failure	+8						
	2.0-3.4 and acute renal failure	+6						
	1.5-1.9 and acute renal failure	+4						
	0.6-1.4 and acute renal failure	0						
	< 0.6 and acute renal failure	+4						
hematocrit in percent	>= 60	+4						
	50-59.9	+2						
	46-49.9	+1						
	30-45.9	0						
	20-29.9	+2						
	< 20	+4						
WBC count in thousands	>= 40	+4						
	20-39.9	+2						
	15-19.9	+1						
	3-14.9	0						
	1-2.9	+2						
	< 1	+4						
Glasgow Coma Score		15 - (Glasgow Coma Score)						

where:

- The score for serum creatinine is doubled if the patient has acute renal failure.
- mean arterial pressure = ((systolic blood pressure)+ (2 * (diastolic pressure))) / 2

If no blood gas data is available then the serum bicarbonate can be used (assume in place of the arterial pH):

PARAMETER	**FINDING**	**POINTS**	**-1**	**1**	**2**	**3**	**4**	**5**
serum bicarbonate in	>= 52.0	+4						

mmol/L								
	41.0 – 51.9	+3						
	32.0 – 40.9	+1						
	22.0 – 31.9	0						
	18.0 – 21.9	+2						
	15.0 – 17.9	+3						
	< 15.0	+4						

Age Points

Age	Points
<= 44	0
45-54	2
55-64	3
65-74	5
>= 75	6

Chronic Health Points

Operative Status	HEALTH STATUS	Points
nonoperative patient	history of severe organ insufficiency OR immunocompromised	5
	no history of severe organ insufficiency AND immunocompotent	0
emergency postoperative patient	history of severe organ insufficiency OR immunocompromised	5
	no history of severe organ insufficiency AND immunocompotent	0
elective postoperative patient	history of severe organ insufficiency OR immunocompromised	2
	no history of severe organ insufficiency AND immunocompotent	0

here:

- organ insufficiency or immunocompromised state must have preceded the current admission

- immunocompromised if: (1) receiving therapy reducing host defenses (immunosuppression chemotherapy radiation therapy long term steroid use high dose steroid therapy) or (2) has a disease severe enough to interfere with immune function such as malignant lymphoma leukemia or AIDS
- liver insufficiency if: (1) biopsy proven cirrhosis (2) portal hypertension (3) episodes of upper GI bleeding due to portal hypertension (4) prior episodes of hepatic failure coma or encephalopathy
- cardiovascular insufficiency if: New York Heart Association Class IV
- respiratory insufficiency if: (1) severe exercise restriction due to chronic restrictive obstructive or vascular disease (2) documented chronic hypoxia hypercapnia secondary polycythemia severe pulmonary hypertension (3) respirator dependency
- renal insufficiency if: on chronic dialysis

APACHE II score = (acute physiology score) + (age points) + (chronic health points)

Interpretation:

- minimum score: 0
- maximum score: 71
- An increasing score is associated with an increasing risk of hospital death.

Knaus WA Draper EA et al. APACHE II: A severity of disease classification system. *Critical Care Medicine* (1985) 13, 828-829.

APPENDIX VIII – GLOSSARY OF TERMS AND PROCEDURES

Algorithm: by definition a logical progression programme for a computer. In critical care a logical progression of steps to be taken in a given and usually urgent situation e.g. Ventricular Fibrillation (OToole, 1992; Romanini& Daly, 1994).

Admission Criteria for ICU:

Decisions about acceptance for admission to intensive care in Australia and the United States are guided in the most part by the framework developed by the Society of Critical Care Medicine (SCCM) and the American College of Critical Care Medicine (ACCM) and set out in the document, "Guidelines for ICU Admission, Discharge and Triage" (Society of Critical Care Medicine, 1999). Rather than a 'strict set of criteria', this document proffers "…minimum admission standards which serve as a general framework for an intensivist-led multi-professional team to improve the outcome of critically ill patients as measured by mortality, length of stay, and resource consumption" (Wasiak, 1999, p. 4).

This framework incorporates clinical judgement and the use of the predictive tools Acute Physiology and Chronic Health Evaluation (APACHE) II and III and the Therapeutic Intervention Scoring System as indicators of prognosis and therefore possible benefit of intensive care and monitoring, although these tools are yet to be validated as pre-admission screening tools (Wasiak, 1999).

The ICU admission decision within this framework – as stated by the SCCM – is based upon three models:

Prioritization:

The prioritization model defines those patients who may benefit from ICU. Patients are given are priority ranking which correlates to the degree of intensive treatment and monitoring.

Diagnosis:

The diagnosis model uses specific conditions or diseases to determine the appropriateness of ICU admission. This is based upon the APACHE II or III tool

Objective Parameters:

The objective parameter model lists a number of physiological parameters (again, found within the APACHE tool) that are to assist those referring clinicians in admitting a patient into ICU. The criteria listed, while arrived at by consensus, are by necessity arbitrary and require the admitting physician/ intensivist to adapt the depending upon local circumstances.

Surprisingly, this framework did not include other predictors such as ICU bed census and availability, nursing and economic resources, unit-specific capabilities. Not surprisingly, ethical and moral considerations were not included (Society of Critical Care Medicine, 1999; Wasiak, 1999).

APACHE II &III

The APACHE II score developed in 1985 (Knaus et al.) is a general measure of disease severity based on current physiologic measurements age and previous health condition. The score can help in the assessment of patients to determine the level and degree of diagnostic and therapeutic intervention needed. This was refined in 1991 (Knaus et al.) with the development of the APACHE III scoring system. This was a two armed or two-option system offering prediction of ‘initial’ risk for severely ill hospitalised patients within defined specific patient groups and a predictive equation for hospital mortality for ICU admissions which combined the APACHE III score + reference data on major disease categories + treatment location immediately prior to ICU admission.

APACHE II score = (acute physiology score) + (age points) + (chronic health points)

Interpretation:

- minimum score: 0

- maximum score: 71
- An increasing score is associated with an increasing risk of hospital death.

Apnoea Testing

The aim of this process is to test for brain death, not to induce it. Cardiac dysrhythmias and hypotension may occur during apnoea testing due to respiratory acidosis and hypercarbia if the appropriate precautions are not taken. To reduce the risks to the patient (and their organs), research has recommended the use of "apnoeic diffusion oxygenation" to maintain the patient's oxygenation throughout the test (Roper & Zisfein, 1990), and advocates starting the test at a Pa CO_2 of 40mmHg to streamline the process (Benzel et al., 1992).

Prior to commencing this test, the patient should have a core temperature of 36.5º C or higher and their systolic blood pressure should be 90 mm Hg or higher. The patient should be pre-oxygenated with 100% oxygen for 10minutes prior to the test as this eliminates stores of respiratory nitrogen and accelerates the transport of oxygen via a catheter to the carina at a rate of 6L/min during the test (apnoeic diffusion oxygenation). The patient must be disconnected from the ventilator during the test and abdominal and chest wall movements assessed as the mechanical ventilator may give false readings. This disconnection from the ventilator should occur once the Pa O_2 reaches 200mm Hg or higher or if the Pa CO_2 reaches 40 mm Hg. The physician should then observe the chest and abdominal wall for respiratory movements for eight to ten minutes and should concurrently monitor the patient for changes in vital functions. At this stage arterial blood is drawn. If there is a partial pressure of carbon dioxide of 60mm Hg or higher (or 20 mm Hg than the patient's normal baseline value) and no respiratory excursions have been observed to this point, apnoea is confirmed (Sullivan et al., 1999; Lazar et al., 2001; Wijdicks, 2001).

Cardiogenic Shock: Inadequate oxygen delivery to met cellular demand, brought about by the heart's failure to function adequately as a pump. The most common causes for cardiogenic shock include extensive myocardial infarction, mechanical failure (eg wall or papillary muscle rupture), end stage cardiomyopathies. Clinical signs of cardiogenic shock will vary depending upon which ventricles are involved (it is possible to have only the right, only the left, or both ventricles of the heart involved) (Kidd & Wagner, 2001).

Cerebral Angiography:

Conventional selective four-vessel angiography may be performed to ascertain the level of intracerebral filling (or otherwise). This is test is not without its perils as the radio opaque dye must be injected under pressure to ensure filling of the intracranial arteries, and this in a head that is already under some form of stress. In patients with brain death, there will be no intracerebral filling of cerebral circulation beyond the entry of the carotid or the vertebral arteries to the skull, while the external carotid circulation should still be patent (Sullivan et al., 1999; Wijdicks, 2001).

Cerebral Scintigraphy:

The scanning of the patient's head to assess the uptake of a radio-isotope eg Technetium Tc 99, or Xenon 133 will result in the "hollow skull phenomenon" in the brain dead individual (Sullivan et al., 1999). This result should be confirmed by a scan of the liver to ensure that the dye has been correctly injected and to confirm uptake of the dye (Wijdicks, 2001). As this test requires the use of a scintillation camera coupled to a computer, the patient needs to be moved to the radiology department but not off their bed (Jenkins et al., 1997; Hankey, 2002). Nonetheless, moving a ventilated, critically ill patient to radiology is not without its challenges and dangers both for the patient and the health professionals caring for them and considering the use of this confirmatory test.

Electroencephalography:

16 or 18 channel electroencephalographs (EEG's) are mentioned as being 'useful' in the determination of brain death-no electrical activity should be seen for a period of at least 30minutes of recording to confirm brain death (Sullivan et al., 1999). As the EEG measures cortical output only, one can understand the disagreement with this opinion over the years, particularly with the advocates of "brain-stem" death as death, who argue that as the EEG measures only cortical output, an EEG will be of little confirmatory value (Mohandas& Chou in Pallis, 1987). Most recently, the use of electroencephalography has been linked to somatosensory-evoked potentials as a confirmatory testing tool. This has been applied with some success in the prediction of outcomes for the severely brain injured (Zandbergen et al., 1998; Carter & Butt, 2001)

Functions of the Brain Stem

The brain stem is responsible for or mediates all essential life functions. Through the respiratory centre located in the medulla oblongata, the brain stem is responsible for respiratory drive. It is in large measure (but not exclusively) the controller of blood pressure through the vasomotor centre and the cardiac centre in the medulla oblongata. Apart from vision and smell all sensory traffic reaches the brain via the brain stem and all motor output from the brain leaves via the brain stem. The brain stem also mediates all the cranial nerve reflexes. Importantly, although the cardiac centre is lodged in the brain stem and to a certain extent controls heart rate and blood pressure, the heart can be 'paced' or driven completely independently of the brain stem (Guyton, 1987; Brown & O'Toole, 1992). As Pallis (1987) demonstrated, this capacity of the heart can continue for up to 72 hours without innervation from the brainstem. He reviewed 1300 cases of clinically diagnosed brainstem death for whom ventilation was continued "…either because doctors did not initially accept that a non-functioning brainstem inevitably implied asystole or at the request of relatives." (p.91). This review indicated that asystole will occur within 48-72 hours of brainstem death (Pallis, 1987).

The brain stem is also thought to mediate and integrate consciousness. A properly functioning paramedian tegmental area of the upper brain stem is a precondition for full consciousness and allows the cerebral hemispheres to work in an integrated manner and so alteration in consciousness may be one of the first signs of increased pressure in these areas (Pallis, 1987; Romanini & Daly, 1994; Hanley, 1998).

In effect, without a functioning brain stem, an individual cannot survive. The assessment for brain death is an assessment of these functions, by testing for function and reflex in an orderly manner.

Guillain-Barré Syndrome

A relatively rare disease affecting the peripheral nervous system, especially spinal nerves, but also the cranial nerves. The syndrome results in progressive paralysis as a result of demyelination, inflammation, and nerve root compression. Aetiology is unclear though onset usually follows a febrile illness such as a respiratory infection or gastroenteritis within 10-21 days. Onset is characterised by generalised malaise, muscle weakness and 'tingling' sensations rather than loss of sensation. Paralysis tends to sweep upwards from the lower extremities, reach its maximum point, plateau for days or weeks and then, spontaneously, start to improve by 'leaving the body' in the reverse order to its earlier establishment. Paralysis is not accompanied by loss of sensation. Instead patients experience episodes of abnormal numbness and tingling. Recovery may take weeks, or rarely months. The prognosis for full recovery is good but tends to reflect the timeframe of the earlier 'establishment' period of the syndrome (Brown & O'Toole, 1992).

Heart Block more correctly named atrio-ventricular block, this condition refers to several dysrhythmias in which conduction from the S-A (sino-atria) node in the atria of the heart is 'selectively' blocked through the A-V (atrio-ventricular) node on their passage to the ventricles. This 'blockage' in conduction may be the result if disease, chemical induction (poisons or drugs) but is most often the results of hypoxic irritation or scarring following hypoxic irritation and infarcts (Conover, 1988). In the case of the patient in Georgia's story, this heart block extended to episodes 'complete' heart block: periods in which the A-V node was not conducting any impulses from atria to ventricles. This was a result of the major ischaemic damage to her cardiac septum as a result of her 'global' infarct .

Hypoxia

Deprived of oxygen for more than three minutes, significant ischaemia occurs in the human brain and then in other major organs (Kidd & Wagner, 1997). Permanent neurologic damage occurs if circulation or effective CPR is not established in a patient within four minutes (Dougherty, 2001; Safar & Kochanek, 2002).

Inotropes/ Inotropic support

Drugs used to stimulate/strengthen contractility of the myocardium in an effort to enhance cardiac output and thus blood supply the tissue in the event of cardiac disease or shock. The body uses the hormone Adrenaline in times of stress to trigger the sympathetic nervous system to prepare the body for action (increased heart rate, vaso-dilation, increased contractility of the myocardium). Mimicking that effect, the inotropic drugs stimulate the β1 & β2 receptors in the body to varying degrees with differing impact on contractility, heart rate and urinary out put. The most popular of these are synthetic Adrenaline (Epinephrine), Isoprenaline, Dopamine and Dobutamine (Brown & O'Toole, 1992; Kidd & Wagner, 1997).

Ocular-cephalic reflex (doll's eye):

Examination of the ocular-cephalic reflex requires the rapid turning of the patient's head through 90° to one side and the interpretation of movement of the eyes in response to that movement. The 'normal' response in the undamaged individual being "conjugate" movement of the eyes turning together to the side opposite to the turn. In brain death, the eyes may not move as the head is turned or may not move together- i.e. in a conjugate manner (Sullivan et al., 1999).

Oculo-vestibular reflex (cold caloric test):

Once it has been ascertained that the ear canals are clear of clotted blood and cerumen and that both tympana are intact, the head is tilted 30° and the Oculo-vestibular reflex is elicited by irrigating the tympanum with 50mls iced water or saline. There should be no tonic deviation of the eyes towards the cold stimulus in brain death (Lazar et al., 2001; Wijdicks, 2001). It is recommended that the patient be observed for one minute after the irrigation of the tympanum and that five minutes be allowed to elapse between testing of each tympanum (Sullivan et al., 1999).

Oesophageal varices

These are dilations or engorgements of veins commencing at the base of the oesophagus and as it meets the stomach then running along the length of the oesophagus. The engorgement is a result of 'back-up' from hypertension in the portal system secondary to disease (cancer), abuse (long-term drug use), or obstruction (tumour). The varices can 'leak' slowly but tend with increasing pressure to rupture 'spectacularly' causing massive loss of blood volume up the oesophagus. Emergency treatment requires intubation to maintain the patient's airway and passage of a 'Senstaken' tube – a short-term only intervention which applies pressure to the bleeding areas until more effective long-term treatment can be started (Romanini & Daly, 1994; Kidd & Wagner, 2001; Kasper, Braunwald, Hauser, Fauci, Longo & Jameson, 2004).

Pharyngeal and Tracheal Reflexes:

The pharyngeal (gag) reflex can be examined by stimulating the back of the palate with a tongue depressor but the results of this stimulation can be difficult to evaluate in the orally intubated patient. The tracheal (cough) reflex is best examined using a suction catheter to stimulate the cough reflex. The results of stimulating this reflex are difficult to assess in the orally intubated patient. (Black et al., 1998; Sullivan et al., 1999; Lazar et al., 2001; Wijdicks, 2001).

Physiological Mechanisms of Respiratory Control and Apnoea Testing

Respiration is controlled by chemoreceptors lodged in the brain stem and bathed by cerebro-spinal fluid (CSF). These receptors respond to changes in concentration of $PaCO_2$ and Ph of the CSF, which in turn reflects plasma Ph and $PaCO_2$. In the majority of individuals, respiration is stimulated by a rising concentration of carbon dioxide in the plasma (Hudak et al., 1990; Schubert et al., 2001). Wijdicks (2001) states that, "The threshold of maximal stimulation of the respiratory centres within the medulla oblongata has been arbitrarily set in the United States at a partial pressure of arterial carbon dioxide of 60 mm Hg or 20 mmHg higher than the normal baseline" (p1216). These figures are far from "arbitrarily" set as Sullivan et al. (1999) acknowledge. They are the product instead of experience, clinical observation and research into the area of apnoea testing in brain death. The UK criteria set the threshold to be reached at 6.65 kPa (50 mmHg) 562(Jennett, 1996). This criterion was not altered in the review by the Working Party of the Royal College of Physicians on behalf of the Academy of Medical Royal Colleges 501(Black et al., 1998).

Transcranial Doppler Ultrasonography:

Using sonography, transcranial arteries are isonated bilaterally either through temporal bone above the zygomatic arch, or through the suboccipital transcranial 'window' to access the vertebrobasilar arteries in the 10% of patients who may not have a temporal isonation 'window'. Findings consist with brain death include a lack of diastolic flow (or a reverberation during diastole), and small peaks indicating weak flow during early systole. The complete absence of flow may not be a reliable finding due to the problems with inadequate transtemporal isonation windows in some individuals (Sullivan et al., 1999; Wijdicks, 2001)