

Critical Care Nurses' Influence on End-of-Life Decision Making

A Grounded Theory Study

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Attestation of Authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.



Signature:

Date: ...28/08/2015.....

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Abstract

In critical care end-of-life care is a process that occurs in stages, which can vary in duration. It is the domain of nurses, while involvement in decision-making is less defined and based more on the individual nurse and the choices they make. The aim of this study was to examine the influence critical care nurses have on end-of-life decision making and care in New Zealand, using the grounded theory methodology of Corbin and Strauss. Nine critical care nurses working in a large tertiary hospital were interviewed and asked about their role in the process of decision-making. The research found that critical care nurses are vital to the joint processes of end-of-life decision-making and end-of-life care. In terms of their role, balancing the needs of both the patient and their family featured strongly, along with recognition that a patient was dying, transitioning from cure to comfort, utilising strategies to stay engaged and facilitating a good death. Participants described changing the environment once end-of-life care began. Moving into a side room marked a different approach to care, one that involved fewer interventions and greater access for family and friends. Seeing death as a failure was rejected in favour of letting go, that courage means negotiating dying with dignity, and not losing a battle with fear.

The grounded theory of Corbin and Strauss, underpinned by symbolic interactionism supported the researcher in formulating an explanatory theory of '*Experienced Understanding*', which is composed of five major sub categories: Raising the Subject, Working the Problem, Making the Transition, Time/Timing – Getting it Right and A Good Death is Dying Well. It is proposed the outcomes of this research have the potential to inform current practice regarding end-of-life decision-making and care in critical care, including how nurse's skills and experience can be utilised to facilitate both these processes.

A significant reason for this potential is the nurse's constant and consistent bedside presence. Consequently the nurse is the immediate health professional available to the patient and their family and acts as a conduit between these parties and the multidisciplinary team. To be effective, the skills required for this nursing population during challenging life events are diverse. The ability to empathise, by tapping into previous experiences of dealing with death, either professionally or personally, is important, along with understanding that care will not just include the patient but their wider family/whanau.

Chapter One: Introduction

In this chapter I discuss the focus of this study, and the thesis structure and terminology related to the subject area. Both personal and professional experiences have led me to undertake this study, and I will feature my own experience within a critical care unit where a family member received care. In addition, the background to the study is covered, which includes my professional interests behind completing this research, the context within which this research took place, and outlines how a number of influences; nursing levels of practice, palliative care in New Zealand and The Treaty of Waitangi inform end-of-life decision-making and care in the critical care environment.

The Focus of the Study

The focus of this thesis is on critical care nurses' involvement in end-of-life decision-making processes, and care. While research has been undertaken in this area at varying times, it is by no means complete, with regard to understanding nurses' perspectives. This thesis has the potential to add to the body of knowledge in New Zealand critical care units.

In 2009 the Critical Care Nurses Section (CCNS) of the New Zealand Nurses Organisation (NZNO) defined critical care nursing as "the provision of nursing care for patients and their families/whanau within critical care, intensive care, combined intensive/high dependency/coronary care, or high dependency care units" (p.1). Workman (2007) reported that Canadian ethicists "identified conflict over treatment decisions at the end of life as the most important ethical challenge facing society" (p.791). While intensive care units are the pinnacle of technologically advanced care, mandated to treat and reverse life threatening illnesses and injuries, the very nature of their patient population, means they are also areas that deal with many deaths. A range of authors suggest that nurse's lack of involvement in this decision-making process is a cause for concern, particularly as they often hold unique information regarding patients, gathered during their constant bedside presence (Carlet et al., 2004; Halcomb, Daly, Kackson & Davidson, 2004; Hov, Hedelin & Athlin, 2007). Over the duration of a 12-hour shift, nurses spend more time with patients than other health professionals (Zamperetti, Bellomo & Ronco, 2008). The development of a therapeutic relationship is further facilitated in New Zealand intensive care units by a 1:1 nurse patient ratio. For individuals experiencing reversible critical illness, an admission to intensive care may prove to be lifesaving, however substantial suffering can result from medical intervention with minimal to no gain (Australian and New Zealand Intensive Care Society (ANZICS): College of Intensive Care Medicine of Australia and New Zealand, 2010). Internationally the nurse's input into end-of-life decision-making when working in the speciality of intensive care is varied, or non-existent, despite the fact that in the United States alone, 20% of in hospital deaths occur in intensive care.

End-of-life decision-making occurs when a patient, their families/whanau and the multidisciplinary team work through the process of deciding what treatment interventions would be used, when treating a life threatening illness (Thelen, 2005). Thelen suggests a variety of options exist when it comes to this process, including not for resuscitation (NFR) orders, advance directives and withholding or withdrawal of treatments. The research reported in this thesis specifically involved withdrawal of life sustaining treatments, and the nurse's role in how this occurs. Examples of life sustaining therapies range from vasopressors and nutritional and fluid administration, to mechanical ventilation and dialysis. The discontinuation of any one of these interventions could result in the patient's death; with the decision to withdraw treatment simultaneously linked to a transition to end-of-life care (Thelen, 2005).

Terminology and Structure of the Thesis

A range of terms will be used interchangeably throughout this thesis, for example the terms critical care and intensive care unit (ICU) are used interchangeably. Throughout the world hospitals have devised different names for this specialised unit, concerned with caring for the critically unwell patient. These include, but are not limited to the two mentioned above and in addition; the department of critical care medicine and intensive treatment unit. There are also other specialities and disciplines where ICUs exist; listing their interpretations will serve little purpose and have not been included in this thesis. Registered Nurse (RN) refers to the professional title held by the participants in my study, and is used interchangeably with nurse and nurses within this thesis. The employment designations of Staff Nurse or Critical Care Nurse require their holders to be RNs in the first instance, and are not to be confused with Enrolled Nurse's (ENs) who were not included in the study. Pseudonyms have been used for participants. The use of family/whanau as it is written here, appears throughout the thesis, with whanau being the Maori word for family.

In this thesis various terms will be used interchangeably. End-of-life decision-making and end-of-life care will often be referred to as end-of-life processes, which I perceive aptly describes their interconnectedness. The descriptors doctor and physician are used interchangeably, as are the terms end-of-life care, comfort care and palliative care. In the ICU context an intensivist and a consultant refer to the same role, that of a senior doctor who is a specialist in intensive care medicine.

Throughout this thesis many examples of participants' words have been used to provide context and depth. However, spoken words transcribed verbatim can be difficult to read, and it is for this reason, where necessary, incomplete sentences have been completed, and words added, subtracted or replaced for clarity. Additions and replacements are indicated in square brackets. The use of medical terminology by participants throughout their interviews was not always correctly transcribed. Therefore corrections have been made when such words feature in excerpts.

In the interest of avoiding confusion I am going to explain here my choice to include literature relevant to my study, in the background section of the thesis, rather than waiting till the literature review. In describing the context in which this study was undertaken, providing examples from the literature that support the focus of inquiry was relevant, before a more in depth literature critique was completed in chapter two.

This thesis has been organised in the following way. Chapter one focuses on providing a background to the study. Chapter two is a critical review of the literature relevant to this area of inquiry. In chapter three I present the research methodology and methods utilised in this research study. Chapter four reports the research findings, and chapter five presents the explanatory theory of '*Experienced Understanding*'. Chapter six focuses on discussing and critiquing the research findings, implications for practice, future recommendations, significance of the study and conclusion.

A Personal Experience

The loss of someone with whom we have shared our lives, is a journey experienced by most of us. A hospital admission for an infected tooth saw my mother-in-law spend four weeks in ICU, intubated and fighting to survive. After several weeks had passed, my mother-in-law was able to return home, while ever present were the lasting reminders of her time in ICU. Two years on, my mother-in-law died in hospital after becoming increasingly unwell in the rest home where she was a resident. Complications from diabetes and congestive heart failure were significant contributing factors. Her death was difficult. Sixty-five and old before her time, and to an extent, had drawn a short straw with regards to her health.

I recognised that as a family we had to decide, whether we were able care for our mother in her own home, or whether a rest home was our best option. An intense and emotional discussion ensued around hiring a hospital bed; home help, district nursing, hospice and a roster of family members who could assist providing a 24-hour home presence. However, none of these combinations were a solid fit, with option after option being discounted. Keeping our mother's preferences front and centre became increasingly difficult. She wanted to be able to leave hospital and return home. We were unable to achieve this.

During my mother-in-law's ICU admission, one nurse stays present in my mind as being both an informational resource and a compassionate sounding board, while the family worked through the decision making process. I was reminded of how much a nurse can offer those seeking to find the best solution for a loved one who is no longer able to look after themselves. A key part of this nursing role was providing information on the services that were available to help keep our mother at home. Trying to make an informed decision in the absence of accurate, clear information would be close to impossible, narrowing the spectrum of options significantly. With the help of this particular nurse I felt I was able to glean a clearer picture of the limited services we would be able to access.

The decision to place my mother-in-law into a rest home was extremely difficult. I personally faced a gauntlet of emotions ranging from guilt and denial to feeling boxed in and selfish,

with nowhere to turn. Despite my background as a nurse I felt completely unprepared to deal with such a decision in relation to my own family.

Death and dying are intensely personal, messy and heartbreaking, even if the consensus of all those involved state that nothing more can be done to avert its inevitability. Taking charge of the path you are on however does provide some semblance of control over how a journey of death could play out and on whose terms (or by who's rules) this will be achieved.

I became aware that facing the prospect of a family member whose condition is no longer responding to treatment in the intensive care environment, levels a unique challenge to those nurses who specialise in this area. In the past I had always felt that my own personal experiences of assisting and caring for patients or family members who had passed on had helped me to offer guidance to others when caring for someone in the same situation. Being able to draw on more than intellectual or philosophical opinion I believe made me a better nurse, and as I write this, my point of view has not changed.

Background to the Study

In this section I will discuss the background, context and setting within the New Zealand healthcare system, in which critical care nurses interact with end-of-life processes, and the fundamental factors guiding their practice. A discussion relating to the Liverpool Care Pathway (LCP) and its application in end-of-life decision-making will be presented. Levels of nursing practice feature in conjunction with the Nursing Council of New Zealand's (NCNZ) Code of Conduct, both of which underpin nursing practice in this country. Hospice New Zealand's (Hospice NZ) palliative care standards are detailed along with the Ministry of Health's (MoH) palliative care strategy, which are both designed to provide support and guidance to healthcare professionals caring for people at the end of their life. The Code of Patient Rights has also been included; specifically those that the researcher considers are applicable to this study. The Treaty of Waitangi (The Treaty) and cultural safety are integral aspects of practicing nursing in New Zealand, and key elements around the integration of these into everyday clinical encounters have been outlined. I also introduce international literature as part of contextualising end-of-life processes in New Zealand.

Critical Care and End-of-Life Processes

I am a registered nurse and other than a six-week placement as a third year student nurse, I have not worked in intensive care. For the past six years I have been working in clinical education as a Resuscitation Education Facilitator. Part of my role involves teaching various strategies to other health professionals on how to manage deteriorating, or collapsed people primarily in the acute hospital setting. Simulation is one of the teaching methodologies my colleagues and I utilise to create situations that are representative of actual clinical conditions. These cases require participants to work as a team, identify priorities such as starting chest compressions, sending for help, defibrillation and airway management, in conjunction with role allocation, effective communication, the maintenance of situational awareness and making decisions under stressful circumstances.

Through this broad palette of work I have developed a keen interest in how nurses make decisions, particularly in high stress, high stakes situations. I therefore decided to examine this interest further for my Master of Health Science by conducting a grounded theory study in a hospital in-patient setting, which manages and cares for the needs of the critically unwell.

As a discipline "critical care nursing faces unique ethical challenges due to the acute and complex health needs and treatments of the critically ill patient" (CCNS, NZNO, 2014, p. 1). Two of these unique challenges involve end-of-life decision-making and end-of-life care.

Conquering death has traditionally been a central focus of the medical model, where dying is perceived as a failure, and allowing a person to die almost impossible (Freund & McGuire, 1995). Freund and McGuire suggest that the side effects such a perspective creates is that the ability to reduce suffering, hear the patients voice and improve quality of life at the end of life, are all compromised. Death is an event that is not readily spoken about in Western

culture, with preparation for its occurrence addressed in the most superficial of ways. Freund and McGuire indicate that hospitals to a degree have perpetuated the segregation of the dying, while choosing to focus on those who are deemed likely to benefit from curative treatments. In contrast to this traditional view, contemporary perspectives related to death and dying are that while care at the end of life can be upsetting, those who deliver such care can believe it embodies a sense of purpose (Pattison et al., 2013). Research with critical care nurses conducted by Beckstrand, Callister and Kirchhoff (2006), reported one participant's view that "death is the most critical point of illness and we must learn to treat it with the dignity and respect it deserves" (p. 40). Such a position aptly demonstrates how death is recognised as a milestone and that nothing is achieved by not engaging with this process. This is congruent with the hospice and palliative care movements, which have shone a light on how moving away from a cure focused approach, to one that acknowledges death as an outcome is necessary in providing a good death (Ellershaw & Ward, 2003). Ellershaw and Ward indicated that healthcare professionals have a significant and influential role in bringing about this cultural shift and in providing palliative care that meets the patients' needs.

A striking characteristic of contemporary critical care units, is the central part nurses play, and their equal footing alongside medical colleagues, regarding certain aspects of care (Seymour, 2001). A relatively simplistic overview of decision-making in intensive care, involves an intensivist mandating a course of action regarding treatment, and a nurse putting this into action (Seymour, 2001). ICU nurses have a different relationship to death, in comparison with other health professionals. A number of papers discuss that ICU nurses generally feel comfortable once the decision to withdraw treatment is made; however many believe that this decision takes too long to come about (Bertolini, 1994; Jensen, Ammentorp, Johannessen & Ording, 2013; Meltzer & Huckabay, 2004; Morgan, 2008). The allocation of one patient per nurse and technology that, to a degree allows for death to be postponed, creates a unique environment in which to provide palliative care.

As Norton and Bowers (2001) observe end-of-life decision-making is a multifaceted process with those involved often having differing perspectives on treatment options, and their appropriateness. Alternatively, Zamperetti et al. (2008) suggests that the notion of curing diseases should be the focus of healthcare systems globally is not only misguided, but also unsafe and unacceptable. Therefore, they assert that the healthcare sector's duty needs to be centred on caring for people who are unwell, in partnership with their wish and interests.

The Setting

Florence Nightingale, a British nurse, is customarily considered to be the first person to have utilised an ICU (Grenvik, & Pinsky, 2009). These authors' suggest that critical care nurses continue to be the most essential group of people who work in this specialised area, and over the years they have developed their own unique insights and procedures. The critical care complex where RN participants were recruited for this study is a major tertiary hospital, located in a large New Zealand city. It comprises two closed units, the ICU and the High

Dependency Unit (HDU). In New Zealand and Australia most ICUs are closed units, meaning that their primary care physicians are intensivists, and while these specialists consult with other doctors regarding patient care, they ultimately take responsibility for treatment decisions over the duration of a patient's ICU admission (Judson & Fisher, 2006). Patients are admitted to ICU on a case-by-case basis by either an intensivist or a delegated medical registrar. Judson and Fisher emphasise that the philosophical underpinning behind decisions concerning patients in critical care across New Zealand and Australia is that senior clinicians, and not trainees make decisions.

Intensivists generally do not admit patients if they are unlikely to benefit from a stay in ICU, and as such, apply admission criteria for the units. A patient's autonomy has a minimal bearing on circumstances where interventions within an ICU are not medically indicated (Judson & Fisher, 2006). Criteria for admission is based on whether a patient has a life threatening condition that has the potential to be reversed through the application of intensive care. As Judson and Fisher state "the intensivist needs knowledge, technical skill, interpersonal skills, and the ability to work on a team" (p. 417).

Intensive care nurses are members of this team and collaborate closely with their physician colleagues. In Australasian ICUs the accepted nurse to ventilated patient ratio is one to one, while in high dependency units this ratio increases to 1:2. In practical terms this means that even if a unit has beds available, admissions are constrained by the availability of nursing staff (Judson & Fisher, 2006).

In New Zealand there are 28 adult ICUs and one paediatric intensive care unit (PICU), providing a total of 259 ICU beds (ANZICS, 2013). ANZICS reported that in 2010/11 a total of 27,781 people were admitted to ICUs across New Zealand, with a mortality rate of 7.5% for the same period.

For patient's, an admission to intensive care can either mean a return to full recovery, a semblance of their pre hospitalisation health status, or an irreversible situation where death becomes the only outcome. How nurses involve themselves in the process of end-of-life decision-making, along with the subsequent end-of-life care is the focus of this study.

The 130 plus nursing team in the critical care unit the study took place, are employed in a variety of roles ranging from new graduate, to senior associate charge nurse managers. To support the nurses caring for the patients, float one and two nursing roles have been created to provide advice and decision support, assistance with complex care, and cover for the bedside RN to attend family meetings. Two nurse educator roles provide an additional layer of support. In this ICU it is an expectation that a postgraduate certificate in critical care nursing is completed. Nurses are also expected to achieve competent practice within 12 months of employment. The stated aim for all nurses in ICU is to achieve proficient practice as described later on (p. 11).

The New Zealand Context

The availability of literature on New Zealand critical care nurses involvement in end-of-life decision-making is not exhaustive, I have chosen to present it here to provide a clear link to the New Zealand setting. The critical care unit, in which this study took place, serves a unique community comprised of multiple ethnic groups and ages, including paediatric patients. It is a closed unit with the majority of bed spaces existing in an open plan setting, partitioned by curtains, with the exception of a side room for patients who are dying.

The remainder of this section examines research undertaken in New Zealand ICUs. A comparison of Auckland Hospital's ICU to an American ICU, where Cassell (2005) explored the involvement of intensivists in end-of-life decisions, and noted that in four New Zealand ICUs, families were not expected to have the final say on withdrawing active treatment and moving to comfort care, with this being the domain of the intensivist. No explicit discussion regarding nurses' roles in this process took place, although nurses' were interviewed as part of this research.

In 2010 McLennan, Celi, Gillett, Penney and Foss published their findings from a small study conducted with 16 nurses of varying experience working in older people's health and intensive care. The aim of the study was to investigate how end-of-life decision-making at Dunedin Hospital could be improved. The researchers employed a qualitative research method known as "immersion/crystallisation", which is referenced to the work of Borkan (1999). Data was gathered via semi-structured face-to-face interviews, with participants receiving interview prompts in the following four areas: resuscitation, communication, quality of life decision-making and withdrawal of treatment. The results were presented under the interview prompts expressed above. All the nurses who participated were of the opinion that discussing end-of-life concerns with patients was important. Some did find these conversations difficult, however the majority stated they were comfortable talking about these issues. There were differing perspectives regarding the person to instigate these discussions. Many of those working in ICU reported that both medical and nursing staff should undertake this, while those employed in older person's health perceived the instigation of end of life discussions to be the domain of medical staff.

On the subject of resuscitation, McLennan et al. (2010) presented a number of perspectives. Some nurses reported that cardiopulmonary resuscitation (CPR) was performed too often in futile circumstances, and needed to be utilised more selectively. All 16 nurses were agreed that patients must be provided with the opportunity to discuss CPR, what it entails and the likely outcomes. All participants agreed on treatment withdrawal where the likelihood of recovery was low. The consensus was CPR was being employed appropriately, and underscored the need for discussion to occur, particularly with family members. Quality of life decision-making engendered three perspectives regarding the decision maker for acceptable quality of life when end of life decisions were taking place. Eight nurses considered such a decision needed to be discussed between the patient, if able, their family/Whanau, medical staff and nurses. Others perceived the patient as the decision maker, and

if they were not deemed to have sufficient capacity, the family needed to take on this role. Lastly, three nurses took the stance that if the individuals were not able to decide for themselves, then the decision rested with the doctor.

Overall the researchers reported that a partnership model was clearly favoured by nurses, when undertaking difficult aspects of clinical decision-making, along with the importance of collaboration between nurses, doctors and families (McLennan et al., 2010). The work undertaken by this group highlights the importance in healthcare of people working together, to achieve a common goal; keeping patients the central focus around which all care is layered. This is no less important when stepping back from active treatment and commencing end-of-life care.

The involvement of ICU nurses in end-of-life decisions is a key aspect of effective collaboration, and the research undertaken by Ho, English and Bell (2005) in New Zealand, across 35 ICUs aimed to add further information to this subject. The authors employed a self-report survey research design. The return rates for the surveys were estimated as being between 43 and 81 percent with a total of 611. Seventy-eight percent of the nurses who responded stated they were actively involved in end-of-life decisions, particularly those practicing at a senior level (four or expert), and those who identified themselves as European. Ho et al. found sixty-eight percent of respondents would favour more involvement in this process, as they considered such decisions to be delayed. Interestingly, these findings reported that, sixty-five percent were of the opinion that active involvement would lead to increased job satisfaction.

The significant percentage of study participants who identified as being actively involved in decision-making at the end-of-life, was consistent with the opinion of ICU directors in New Zealand, as per the findings of a study conducted by Ho and Liang (2004). This involvement of New Zealand ICU nurses differs from reported international findings, which demonstrated ICU nurses were rarely involved in end of life decisions. The researchers indicate that their finding pertaining to senior and European nurses having greater involvement in end-of-life decision-making has not previously been reported. They attribute senior nurse involvement to their experience, and are therefore more likely to engage in this process (Ho et al., 2005). Differing levels of engagement related to ethnicity and country of practice are supported by other researchers findings, which demonstrate both these factors are determinants of overall levels of involvement in care and decision-making at the end-of-life.

As in the McLennan et al. (2010) study, Ho et al. (2005) found delayed communication and decisions, as significant. They cited effective communication as a key indicator of quality end-of-life care, and suggest there is some likelihood that nurses are better communicators than doctors. Hence doctors engaging in discussions with their nursing colleagues to outline rationale pertaining to their clinical decisions may reduce feelings of exclusion and assumption formation (Ho et al.). Ho et al. also suggested that RNs who wanted input into decision making were prompted by a sense that end-of-life decisions are frequently made too late, and that their input may positively influence this. It would have been interesting to

see this study followed up with qualitative research that could have further examined survey findings. The authors themselves identified this as a limitation to their research, recommending the use of qualitative methodologies to further examine this topic.

Nursing Levels of Practice

The nurses who took part in this research represented a cross section of four levels based on their skills and experience. A brief explanation of these levels will be provided. Furthermore, due to the exclusion criteria I employed for this study, new graduate nurses were not eligible to participate; hence an explanation of this practice level will be excluded. The levels explained are as follows: Competent, proficient, expert and senior.

In 1984, nursing theorist Patricia Benner presented the Dreyfus model of skill acquisition as applied to nursing. Benner separated levels of nursing experience into five stages with the following designations: Novice, advanced beginner, competent, proficient and expert. The levels of practice outlined below have clearly drawn on Benner's work when being formulated, although the author may not have intended that they be used for this purpose. Since the publication of her work, Benner has faced both criticism and support, choosing at times to respond to her detractors herself. In 1996 she published a response to a critique from Cash (1995) who held that among a number of transgressions, Benner underestimated the sway of power gradients when negotiating clinical knowledge. Benner conceded that her primary focus had not been on power relationships, but on clarifying what power dialogues were being discussed, and how to achieve the best interpretation within a clinical situation, thus affording the best outcome for the patient. At other times in her response, Benner highlighted how she and Cash were in agreement, in particular regarding how expertise in practical situations is determined; that the notion of expertise is not just based on personal attributes, but being able to demonstrate these skills against an evaluation tool.

Hargreaves and Lane (2001) contest that much of the critique levelled at Benner's work is focused on semantics and deconstructing her theoretical concepts. These authors discussion paper aimed to take a case study and use it to critique "Benner's concept of context in the development of expert nursing practice" (p. 389). Hargreaves and Lane put forward that while context is a significant aspect of Benner's work, as a concept it has not undergone any in depth scrutiny. They suggest however, that while this does not make Benner's work flawed, it does caution against the unconditional acceptance of a single research finding, no matter what its calibre, to fulfil the role of informing practice development. In drawing this analysis to a close, the perspective of Darbyshire (1994) is of note: "I propose that Benner's work is among the most sustained, thoughtful, deliberative, challenging, empowering, influential, empirical (in true sense of being based on data) and research-based bodies of nursing scholarship that has been produced in the last 20 years" (p. 760). Therefore, Benner provides an important starting point.

According to the New Zealand National Professional Development & Recognition Programmes Working Party (NPDRP Working Party) (2004) a competent nurse is confident

when dealing with familiar situations, can prioritise and manage their assigned clients and workload, form partnerships and encourage participation that implement the principles of The Treaty and effectively apply the skills and knowledge required to hold their position.

In addition, to the above, the proficient nurse demonstrates the responsibility of a resource person and role model, actively participates in quality improvement initiatives and change processes, initiates clinical learning opportunities for colleagues and is able to practice collaboratively and autonomously from an evidenced based foundation (NPDRP Working Party, 2004). Further the expert nurse is expected to embody the above qualities while also undertaking postgraduate study, demonstrating specialist knowledge, leading others to apply safe cultural practice, acting as a leader and role model for others and is recognised as an expert in their area of practice (NPDRP Working Party, 2004). In New Zealand these levels apply to all nurses working for District Health Boards (DHBs).

These levels of practice act as a guide for nurses to achieve when building their skill levels; both technical and non-technical. As technology has become more pervasive in everyday practice, nurses face the challenge to not let the acquisition of technical skills and knowledge, negatively impact on the caring aspect of the profession (Pirret, 2011). Particular resonance exists here for nurses' working in environments, such as ICU where caring for some of the most unwell patient's in a hospital, takes place alongside sophisticated technology capable of sustaining and prolonging life.

End-of-life processes are one of the most complex responsibilities nurses encounter, as the loss of loved ones, for family and friends permanently alters lives (Condon, Grimsley, Kelley & Nissen, 2014). Condon et al. commented that over the duration of a nursing career and perhaps even before it commences, registered nurses and nursing students are likely to have been involved with caring for a dying person. And as these authors attest, this is an opportunity to understand that death is not a failure, nor is it ultimately preventable, it is a significant life transition and is as important as being born. Therefore they suggest, gaining the knowledge that resides innately within and perfecting it into an art needs to be actively encouraged within our society and within nursing. That dying continues to command such an atmosphere of mystery, despite the existence of palliative care, the hospice movement and individuals empowering themselves by writing down their wishes in preparation for the inevitable coming to pass, is powered by the finality that death means for us all (Florczak, 2014). The nursing levels of practice discussed above, are underpinned by the nursing code of conduct and the code of rights, which inform and guide nurses in their daily practice.

Nursing: Code of Conduct

In New Zealand the code of conduct is a document holding nurses to the standards formed by NCNZ which nurses are expected to abide by and uphold. It "complements the legal obligations that nurses have under the Health Practitioners Competence Assurance Act 2003 ('the Act'), the Health and Disability Commissioner (Code of Health and Disability Services Consumer's Rights) Regulations 1996 and the Health Information Privacy Code

1994" (NCNZ, 2012, p. 2). This section will focus on the areas of the code that I believe have relevance to this study.

The code of conduct is comprised of eight principles with accompanying standards that formulate the codes foundation and are to be interpreted as carrying equal weight. They are, Principle one: Respect the dignity and individuality of health consumers. Principle two: Respect the cultural needs and values of health consumers. Principle three: Work in partnership with health consumers to promote and protect their well-being. Principle four: Maintain health consumer trust by providing safe and competent care. Principle five: Respect health consumer's privacy and confidentiality. Principle six: Work respectfully with colleagues to best meet health consumers' needs. Principle seven: Act with integrity to justify health consumers' trust, and lastly principle eight: Maintain public trust and confidence in the nursing profession. These eight principles are underpinned by four overarching values: Respect, trust, partnership and integrity (NCNZ, 2012).

While equal importance is given to each principle, in the context of this study standards within principles one, three and seven are the most evident, and are as follows: Taking steps to ensure the physical environment facilitates health consumers to maintain their privacy and dignity, and listening to health consumers, asking for and respecting their views about their health, and responding to their concerns and preferences where practicable, are important aspects of palliative care. Working in partnership with the family/Whanau of the patient where appropriate and being respectful of their role in the care of loved ones, was found to be essential in this study. These three standards have particular resonance for family/whanau and the patients who are dying and have had or are in the process of having invasive treatments withdrawn (NCNZ, 2012).

Principal three of the NZNC code of conduct incorporates four standards that impact upon good end-of-life processes. The explanation and sharing of information with patients, delivered in a way they will understand is a key part of preparing patients and their families about end of life care. Respecting patient's rights to participate in decisions about their care and involve them and their families/Whanau where appropriate in planning care. Understanding concerns, priorities and needs of the patient and their family/Whanau, along with supporting and respecting the contribution they make to their own care and well-being are important for ICU nurses to demonstrate. Nurses must ensure that the care they give is in the best interests of the patient and that they have taken reasonable steps to ascertain their views, which is particularly important if the patient is sedated, intubated and ventilated (NCNZ, 2012).

Code of health and disability services consumers' rights

Running parallel to communication and a holistic approach to end-of-life processes is the nurses skill at respecting diverse opinions and points of view, recognising that this aids collaboration for an agreed way forward, while keeping the patient and their family/ Whanau front and centre (NZNO, 2010). Integral to a patient's ability to guide their own care

decisions, is the right they hold to make informed choices regarding the options they have available. These health consumer rights are presided over by the Health & Disability Commissioner Code of Health and Disability Services Consumer Rights Regulations 1996, and interpreted in conjunction with the individual's own values, beliefs and culture. While there are ten consumer rights, NZNOs position statement cites the particular importance of rights six and seven, which relate to informed choice and consent (The Code of Rights, 1996). In addition, as per the code, I suggest that the foundation for sound end-of-life decisions, is strengthened by nurses awareness of rights one and three; namely respectful treatment and the right to dignity and independence. As Milton (2014) observes, for individuals at the end of their lives, choosing to form engaging relationships can give meaning to the time they have left. The author postulates that for nurses possessing an understanding of what others hold as important, in a particular moment must be perceived as integral to their practice and by not honouring the provision of respectful attention, they are jeopardising the potential to walk alongside the dying person, as they grapple with accepting the ultimate life transition. The Code of Health and Disability Services Consumers' Rights is an important tool and guiding regulation for health professionals, in the pursuit of care excellence.

The nursing levels of practice, the code of conduct and the code of rights are interlinked, and their inclusion here was to underscore the wider context in which ICU nurses in New Zealand practice. For nurses to progress up the practice levels, they need to demonstrate how they incorporate knowledge of these codes into their patient interactions. This awareness strengthens their advocacy skills and their ability to improve patient care (Bunch, 2002).

Withholding and Withdrawing Treatment

In 2003 ANZICS released a statement on withholding and withdrawing treatment in the intensive care unit. ANZICS asserted that while treatment provided in intensive care may save the lives of people experiencing critical illness, it is important to remember that treatment interventions can be unpleasant, causing suffering and discomfort for both patients and family members with little, to no avail. Benefits associated with the treatment that can be provided in intensive care include the minimisation of disability and the prolongation of life. These advantages therefore need to be contrasted against suffering, pain and lost dignity. This statement discussed that finding the balance between benefits and burden is based upon probability as opposed to certainty. ANZICS goes on to recommend when making the decision to withhold or withdraw treatment, it is important that the patient's views, if they are known, are taken into consideration, as they relate to what the individual deems a satisfactory quality of life and that the treatment outcomes justify any consequent loss of self. Raising the subject in relation to limitation or withdrawal of specific treatments can be initiated by the patient themselves, healthcare professionals, or the patient's family and friends. ANZICS suggest before such a decision is ratified the critical care team and any other medical or surgical teams involved in the patients care, need to be in agreement.

Once the decision has been reached to transition, a plan for palliative, comfort or end-of-life care must be initiated. In addition the plan requires focus on symptom control, maintaining dignity, and pain management, including the prescription and administration of medication to achieve the goal, even if this may shorten the patient's life.

In 2014 'The Last Days of Life Working Group' was established, under the Palliative Care Council of New Zealand. While mandated to examine the provision of care to all people in the last days and hours of life, across all care settings, there are a number of provisional observations that critical care would benefit from either adopting or refining, if not already in place. An editorial published in 2013 by Ellershaw and Lakhani was the key source document for the above working group, and mirrored the work of Ellershaw and Ward (2003) who suggested that it is easy to underestimate the impact that death has on our society. Their clinical review paper aimed to take learning from a hospice setting and examine how acknowledged best practice could be transferred to other clinical environments and benefit patients dying from causes other than cancer. Ellershaw and Ward intimate that a strong motivator behind this work was the finding that too high a proportion of patients in the United Kingdom were experiencing undignified deaths, with poorly controlled symptoms, and that healthcare systems globally face this challenge, which stems from an inability to accept that dying as a diagnosis must be acknowledged as a legitimate option, so that barriers to caring for patients who are dying can be overcome.

The New Zealand nurses organisations position on end-of-life decision-making and care

Due to the complex nature of end-of-life processes and to assist nurses in better understanding their role, NZNO articulated their stance on this issue in their 2010 position statement. The statement stated that end-of-life decision-making commences as soon as a person's clinical condition becomes such that death is the only likely outcome. NZNO contends that ethical nursing practice is underpinned by a group of core values that include beneficence, autonomy, justice and non-maleficence, veracity, confidentiality, fidelity and professionalism. NZNOs position supported that dying with one's dignity intact can be achieved through the use of these values, and that additionally the use of these core values will facilitate all New Zealanders to have access to a fair and equitable health system, in partnership with Te Tiriti o Waitangi.

In addition to equitable access, effective communication is recognised as being an essential component in supporting responsive and individualised care at the end of life (NZNO, 2010). The authors stress that a holistic approach needs to be adopted when planning care for the dying person, and necessitates "establishing the person's priorities, values and choices in all aspects of the management and provision of care to meet their taha tiana (physical health), taha wairua (spiritual health), taha Whanau (family health) and taha hinengaro (mental health) needs" (p.2). The central guideline for nurses in this position statement is that the dying process, as with other health conditions has specific physical requirements, which need to be managed, along with a wider network of needs that must not be overlooked.

Palliative care in New Zealand

Hospice NZ (2012) reiterated their working definition of palliative care in New Zealand, originally published in 2007. Hospice NZ states their aim is to “optimise an individual's quality of life until death by addressing the person's physical, psychosocial, spiritual and cultural needs... supporting the individual's family, Whanau, and other carers where needed, through the illness and after death” (p. 10). They published their third edition of standards for palliative care, with the intention that everyone in New Zealand should have equitable access to the highest standard of care available, as they move towards the end of their life. Hospice NZ recommended that if healthcare professionals are to make a difference to the benchmark of palliative care quality, which people receive every day, then the national standards must be relevant to all environments. The 14 standards set out by Hospice NZ pertain to adults who are nearing the end of their life, the people caring for them and their family/Whanau, and are summarised as follows: Values based care, ensuring equitable access, coordinating care, and the provision of a whole person assessment. Meeting the cultural needs of diverse family and Whanau, while providing person centred care planning, ensuring ongoing assessment and planning, and caring for patients who are dying, along with supporting reflective practice and self-care. For nurses working in any clinical setting, including intensive care, these standards are a valuable resource for comprehensive and well-rounded approach to end-of-life care.

The New Zealand palliative care strategy (2001) published by the MoH complements Hospice NZ's stance on how end-of-life care can be delivered, to a standard accessible by everyone. The MoH define palliative care as “the total care of people who are dying from active, progressive diseases or other conditions when curative or disease-modifying treatment has come to an end” (p. 2). The palliative care principles that underpin this definition focus on dying as a normal process, and that hastening or postponing death is not a central goal, whereas relieving suffering and distressing symptoms is, along with providing support to carers and family/whanau during the death and dying process. The MoH emphasises the integration of social (whanau), physical (tinana), spiritual (wairua) and emotional (hinengaro) aspects of care to assist the dying person and their family/Whanau achieve an acceptable quality of life. The common denominator between NZNO, Hospice NZ and MoH is the focus on providing strong support for nurses caring for dying patients, and that patients and their family/whanau are acknowledged as an integral element in the provision of relevant, holistic end-of-life decisions and care. The aim therefore is to offer an “alternative to the medicalised death, in which the dying person is reduced to a set of physical symptoms and their social, psychological and spiritual needs are overlooked” (Lloyd, White & Sutton, 2011, p. 389).

The Liverpool care pathway

The LCP is internationally recognised as being a best practice strategy when it comes to end-of-life care provision (DH, 2008). It is not the intention of this section to provide an exhaustive review of the literature pertaining to LCPs, but rather to provide some

explanatory background on this tool. Prior to the commencement of this study the critical care unit where the research took place was in the process of introducing an amended LCP that had been adapted to suit the specific cultural needs, unique to the regional demographic this hospital provides services. A more in depth discussion pertaining to the introduction of this modified LCP, features on page 121. The LCP is an “evidence-based framework of care for the dying patient and provides guidance on comfort measures, discontinuation of inappropriate interventions, anticipatory prescribing, holistic care and care of the family after death” (Jack, Gambles, Murphy & Ellershaw, 2003 as cited in Walker & Read, 2010, p. 267). Originally developed in the United Kingdom by the Royal Liverpool University Trust and The Marie Curie Centre Liverpool, it was designed to replicate hospice based model of care into other clinical care settings and is a multidisciplinary decision support-strategy (Jack et al.). The LCP, a relatively new addition to the intensive care settings tool kit, has undergone adaptations prior to its introduction (Walker & Read, 2010).

In 2012 Anderson and Chojnacka conducted a literature review examining the benefits of using the LCP in end-of-life care. Their findings centred around three prevailing themes, where a positive impact was indicated. These themes were, symptom management, documentation and communication. They reported that the LCP promoted symptom management processes that have transferability across the healthcare sector, thereby empowering healthcare professionals to provide a high standard of palliative care without being experts in this field. Documentation is positively influenced by use of a LCP; firstly as it is a one-stop shop for documentation to take place, replacing the need for multiple forms. Secondly, due to its employment of in built prompts the use of LCP improves the quality of documentation. According to Anderson and Chojnacka, communication results were mixed regarding overall application, particularly from relatives’ perspectives.

Since its inception critique of the LCP has been widespread, despite its many positive features and ubiquitous integration into end-of-life care, particularly in the United Kingdom (UK). Chan and Webster (2013) updated their 2010 Cochrane review that examined end-of-life care pathways, and observed that their introduction into practice had gone ahead in spite of ambivalent evidence supporting their effectiveness. Watts (2012) directly addressed this observation, and suggested that this observation needed to be taken in context with regard to the overall hierarchy of evidence, where the gold standard for assessing any interventions usefulness remains the randomised controlled trial. Watts contended that palliative care pathways are complex interventions and their efficacy may not be fully understood, if only investigated from a single perspective, particularly if the research question is not designed to elicit such complexity. Watts warns against relying solely on any systematic review process that privileges trials and quantitative methodologies over any other approaches.

The Treaty of Waitangi

This section discusses The Treaty, which is an integral component to the delivery of healthcare in New Zealand, including the provision of palliative care, as outlined in the previous section. The hospital in which this study was conducted, expects all its employees

to demonstrate an understanding of the three principles related to the Treaty (delineated below). Signed in 1840 between Maori chiefs and the Crown, the Treaty came about due to concerns that Maori people were experiencing both the malevolence of British settlement and the devastating health effects of colonisation (Durie, 1998). The original intentions behind the Treaty related to the protection of physical and human resources. It is important to note here that while The Treaty has a wide reaching influence on many facets of decision making in New Zealand society, in the context of this thesis, the material presented here will relate solely to health.

The Treaty comprises three principles, partnership, participation and protection and are defined by Durie as follows: "Partnership is strongest when it refers to an agreement between Iwi or hapu and the Crown, although it is sometimes used with limited justification to describe a working relationship between Maori and government agencies" (p. 85). However Durie goes on to emphasise that while partnership suggests an alliance of equals, it can more often pertain to a reassignment of government held influence to a tribal group under purposefully restricted guidelines. Durie discussed that while some tribes have demurred engaging in government-initiated partnerships, many have formed partnerships, for example with the MoH and DHBs, with the understanding that the two partners to the Treaty bound by constitutional symbolism, will work to attain mutually beneficial goals. The unique relationship that exists between patient and nurse strives to make the patient a partner in the healing process, but acknowledges the imbalance brought about by the ill persons inherent dependence and vulnerability (Campbell, Gillett & Jones, 2006).

The second principle participation refers to the involvement of Maori in a specific sector or activity that, in the context of healthcare, involves working with health professionals to better understand Maori health needs. However, a dependence on healthcare professionals has led to the marginalisation of Maori input, which has consequently led to a health revolution in New Zealand driven by Maori wanting greater involvement in decision making, health planning and healthcare delivery (Durie, 1998). The third principle protection, relates to State's policies and initiatives to assure Maori have the same 'privileges and rights' as other New Zealanders, and incorporates practical applications to both prevent illness and promote health with the ultimate goal of providing Maori with the same standard of healthcare as everyone else (Durie, 1998).

In New Zealand the Treaty plays an important role in the provision of health care services to Maori, who have unique cultural needs that must not be overlooked by a homogenous healthcare system. New Zealand's unique way of approaching the health needs of Maori, are based on four important foundations of health, drawn from the imagery of a constellation of stars known as Te Pae Mahutonga (Durie, 2004). He suggests these four foundations or central stars represent cultural identity, protection of the environment, well-being and complete involvement in wider society. Durie explains how Toiora or healthy lifestyles and well-being acknowledges that indigenous peoples possess their own perceptions of what constitutes health and well-being, with a commonly discussed Maori health perception being

a metaphor that compares good health with the four sides of a house. This involves striking a balance between intellect and emotions, spirituality, human relationships and the human body. From a traditional Maori perspective the inseparability of the spiritual and physical in sickness and death, is clear, whereby death is seen as both the end of a life lived and the reaffirmation of the identity of the person who has died (Campbell et al., 2006). The physical body is symbolic according to Campbell et al. of how the interconnectedness of the spiritual and physical rests at the centre of a holistic notion of life, meaning a person upon their death is placed in a meaningful context, and death is not interpreted as meaningless.

Cultural safety

Cultural safety or Kawa Whakaruruhau relates to a patient's experience when receiving nursing care and defines culture as including, "but not restricted to, age, or generation, gender; sexual orientation; occupation and socioeconomic status; ethnic origin... religious or spiritual belief; and disability" (NCNZ, 2011, p. 7). I have included it here as the ICU nurses who participated in this study reported patient's culture played a part in end-of-life processes. Cultural safety is a New Zealand term unique to nursing education, and "was born from the pain of the Maori experience of poor health care and evolved over ten years against a backdrop of bicultural development" (Wepa, 2003, p. 339). While there are correlations between the Treaty and cultural safety, the latter is broader in its application, while the former provides health care professionals with information regarding nursing practice and Maori health and the impact on Maori of colonisation, the latter (within the Maori context) acts as an intrinsic element of both nursing and Maori health, particularly in its contribution to the attainment of constructive health outcomes (Harding, 2013; NCNZ, 2011).

To provide guidance for nurses in the practical application of cultural safety to their everyday practice for all New Zealanders, NCNZ (2011) developed four principles. Principle one "aims to improve the health status of New Zealanders and applies to all relationships", while principle two strives "to enhance the delivery of health and disability services through a culturally safe nursing workforce" (p. 8-9). Principle three concerns the need for cultural safety to be comprehensive in its application, and principle four pertains to nurses understanding how to manage power imbalances within their professional relationships, and how to rectify "any tension between the cultures of nursing and the people using the services" (p. 10).

For nurses working in the critical care setting and caring for patients for whom end-of-life processes are either in discussion, or in play, integrating cultural safety and the Treaty into their practice will deepen its effectiveness and reception. It is also worth noting here that for nurses practicing in New Zealand, they are required as part of their annual PDRP submission, to provide evidence of how they integrate the Treaty into their practice and work in a culturally safe manner with all who require health care.

Summary

This chapter has provided the forum to discuss the context in which critical care nurses interact with end-of-life processes, and the fundamental factors guiding their practice. In New Zealand these specifically relate to levels of practice, which provide nurses with a framework to follow as they progress through their career. In the ICU this study took place there was a clear expectation all nurses would progress through these, in conjunction with undertaking post graduate education. The nursing code of conduct, the code of rights, The Treaty and cultural safety all act as touch stones for nurses in guiding what is expected during their day-to-day practice. The unique cultural environment in which healthcare is provided in New Zealand; through recognition of the specific health needs affecting Maori have ongoing relevance to the ICU setting and the dying patient. The tenets of palliative care were examined, along with the role of LCPs in supporting high quality end-of-life practices to be adhered to.

The key points addressed in this section were the uniqueness of the ICU environment, where nursing takes place with a one to one ratio, and additional senior nursing roles facilitate a nursing presence at the patient's bedside 24 hours a day. Nurses are therefore positioned to be key influencers regarding end-of-life decision-making, and to be the primary administrator of end-of-life care.

Chapter Two: Literature Review

Introduction

In this chapter I examine and discuss the literature relevant to the study presented in this thesis, beginning with the search strategy I employed and an overview of the role literature plays in a grounded theory study. A critique of the literature pertaining to both end-of-life decision-making and care was undertaken, specifically in relation to ICU nurses, and how they engage in these processes. Overall, the main areas examined are: End-of-life decision-making, medical and nursing professionals working together, effective communication, decision making, shared decision making, family involvement in shared decision-making, nurse's decision-making ability, the timing of decisions to make the transition and how an ICU's culture may influence decision-making processes.

Limited research into ICU RNs influence on end-of-life decision-making has been conducted in New Zealand, resulting in their input being under acknowledged. In addition, gaps exist internationally regarding how the information gleaned via research conducted in this area, can be utilised to overcome the barriers RNs reported exist, making their input the exception, rather than the rule. My aim is that the research I have undertaken and presented in this thesis will add to the body of knowledge being produced in New Zealand.

Search strategy

To access information relevant to the focus of my study, I searched PubMed, CINAHL, Ebsco, MEDLINE, Ovid Nursing database, Index New Zealand and ProQuest Health and Medical complete databases using the following search terms: Critical care nurses' and end-of-life decision-making, intensive care nurses' and end-of-life decision-making, critical care nurses' and decision-making along with the same, but substituting end-of-life decision-making for end-of-life care. In addition I used the same search phrases to find literature via AUT libraries search function, which provides access to a range of printed materials. Citations from the reference lists within relevant articles were also followed up, and acted as a valuable additional search approach. Since the commencement of this study in 2013, I have continued to regularly undertake searches as per the above, to capture new publications. The literature presented in this review was deliberately chosen for its topic relevance, including as far back as the 1980s. Ethical decision-making and ethical dilemmas as related to critical care nurses has sporadic relevance to the wider context in which this study sits. Therefore literature, which discussed these areas, will be critiqued as part of this review as and when I acknowledge their significance in the field of study.

The literature review in a grounded theory study

When using a grounded theory method the role and timing of the literature review can be contradictory and confusing. As Cutcliffe (2000) summarises many texts and articles advise

minimal literature use prior to the data collection and analysis processes. The rationale presented is that the emergent theory will be more likely to be grounded in the data. An alternate perspective is that a review of the literature in grounded theory actually needs to take place prior to data collection and analysis (Hutchinson, 1993). Hutchinson indicates that a literature review can uncover contemporary gaps in knowledge and assist with the provision of a rationale for the research.

The decision to use grounded theory to examine my research question made me acutely aware of how much was too much existing knowledge to bring to the field of inquiry. As I had already undertaken reading pertaining to end-of-life decision-making and care, I took renewed confidence from the work of McCallin (2003) who stated that few students commence a study without any prior knowledge of the topic whatsoever. McCallin posited that acquired knowledge couldn't easily be placed to one side so that the researcher begins with their mental slate wiped clean. Therefore, the author attests that prior knowledge takes on the role of being data that can be assimilated into a piece of research, through the use of constant comparative analysis and helps to hone emerging categories and concepts.

End-of-life Decision-Making

What is end-of-life decision making? In healthcare, it is a process which patients, their families and healthcare professionals work through to decide what interventions will or will not be employed in the treatment of a potentially fatal illness or injury (Thelen, 2005). Thelen (cited previously) focuses on end-of-life decision making in the ICU, defining this as "one aspect of end-of-life care" (p. 28). It provides a succinct reminder of how end-of-life decision-making is characterised throughout this thesis. Thelen examined several facets of the decision-making process, including who participates, the process itself, and the factors influencing the process, how healthcare providers perceive the process and what strategies facilitate these decisions being made. Over all, the author concludes that strong, effective communications between everyone involved are key components that will augment end-of-life decisions. In turn, stress and suffering should decrease, effectively creating a more hospitable place within critical care environment for the end of life.

End-of life-decision making is comprised of two phases; one, making the decision to withdraw or withhold treatment from a person and two, the transition to end-of-life care. Shifting from active treatment to a palliative care focus, if a patient is not responding to such treatments, or they are unlikely to be effective is a reality common to intensive care units (Ho & Liang, 2004). As Mann, Galler, Williams and Frost (2004) acknowledge, "the management of death is a major part of intensive care practice" (p. 1). It is a widely held belief however that ICUs are places where lives are saved, not lost. Therefore, these researchers proposed that moving into a realm where dying becomes an accepted outcome, the patient made comfortable and their family supported to understand the change of direction in approach is an important part of the nursing and medical staffs' responsibilities.

The decision to stop actively treating a patient and transition to comfort care follows a range of courses. How nurse's fit into the process is an area of research, which is gaining increased attention. Unlike working on a medical or surgical ward where the nurse/patient ratio could be as high as 1:7, in a critical care setting the ratio is 1:1 where the nurse is constantly present at the patient's bedside other than during meal breaks. The 1:1 ratio affords a unique perspective that if accessed during end-of-life decision-making, could yield valuable information. Cassell (2005) identified this strength in her work undertaken at Auckland City Hospital's Intensive Care Unit, where a 1:1 nurse/patient ratio enabled nurses to build a strong rapport with both the patient and their family over the course of a 12-hour shift. The author, an anthropologist working in collaboration with an American trauma surgeon conducted ethnographic research into end-of-life issues in ICU in the late 1990s. Data collection was via fieldwork in an American semi closed surgical intensive care unit (SICU), an open ICU and a closed medical surgical ICU in New Zealand. The motivation for the study was to compare practices and ideas between the three sites. A key finding reported by Cassell was that in the New Zealand ICU, intensivists had total responsibility for their patients, in contrast to their American counterparts, where in the SICU responsibility was shared between critical care specialists and surgeons. Differences arose between these two specialities around whether or not to persist with aggressive active treatments for an extremely unwell patient, with surgeons tending to convey more optimism than the intensivists. In the context of end-of-life decision-making Cassell found such a lack of consensus resulted in miscommunications and mixed messages being conveyed to family members. In New Zealand Cassell reported that intensivists placed more value on supporting quality of life and the alleviation of suffering at the end-of-life, as opposed to fighting death right to the end. As one intensivist articulated, "It's not technology that makes intensive care work, it's people who intensively care" (p. 105). ICU nurse's uninterrupted bedside presence means they are uniquely positioned to potentially be more directive in the decision-making process, and guide the ongoing acquisition of sound communication and collaborative skills (Pattison, 2014).

Cassell (2005) provided important insights into how ICUs in two different countries interpret decision-making and care at the end-of-life. There appear to be advantages to how closed units operate, in that amongst medical staff, inter speciality conflict is limited through intensivists having authority.

Working Together: Medical and Nursing Professionals

Malloy et al. (2009) examined nurses' insights into their working relationships with doctors, and observed that nurses were faster at comprehending the presence of futility, shifting focus to the quality of life left to live and the manner of dying. These authors conducted focus groups with 42 nurses across four countries; Canada, Ireland, Korea, and Australia. Data analysis using thematic content analysis yielded four themes namely, philosophy of health: care versus treatment, decision process: constrained obligation, silenced voice and professional respect. Malloy et al. highlight the complex interplay that exists between these

nurses and doctors, noting how difficult it can be for nurses to voice a differing viewpoint to that of a doctor regarding their perspective of a patient's problem.

Collaboration between nurses and doctors when engaging in end-of-life decision making is recognised as beneficial. Ferrand et al. (2003) used a closed-ended questionnaire in their study of 3156 nurses and 521 physicians, from 133 intensive care units across France. The researchers reported that over 90% of medical professionals believed decisions should be made collaboratively, however only 50% of doctors and 27% of nurses thought that nursing staff were actually included. Festic, Wilson, Gajic, Divertie and Rabatin (2012) conducted a cross sectional survey (n=331 nurses: 50 physicians). Analysis involved comparing survey responses with 12 fixed-response statements employing a five-point Likert scale. Results indicated that doctors have higher levels of satisfaction than their nursing colleagues when it came to decisions made at the end-of-life. The suggested reasons to the existence of such a satisfaction gap ranged from lack of decisional involvement by nurses through to poor communication and the dissemination of conflicting information.

Frick, Uehlinger and Zenklusen (2003) found that disparity between nurses and physicians was common in relation to their respective assessments about the futility of medical treatments, in relation to seriously unwell patients. Frick et al. employed a "prospective opinion survey of critical care providers; comparison with follow-up for survival, functional status, and quality of life" (p. 456). The setting was a six-bed MICU, located within a 1,000 bed, university tertiary care hospital, with participants comprised of all patients over 18 years of age admitted to the MICU for longer than 24 hours, over a one year period. The studies interventions involved nurses and doctors daily judgements regarding futility of medical interventions, pertaining to survival and quality of life. Additionally, telephone interviews were conducted with discharged patients, and focused on functional status and quality of life six months post admission. These researchers reported that nurses tended to be more pessimistic than their physician counterparts resulting in them correctly identifying more dying patients, however they also suggested withdrawing treatment in some patients who subsequently survived. Nurses and doctors working in the ICU where this research was completed openly discussed significant patient decisions and approaches to treatment as a matter of course.

The studies together paint a picture of two groups of health professionals who struggle to work alongside each other, with the common goal of delivering the highest care to their patients. The hierarchical divide that strongly dictates aspects of the doctor/nurse relationship lays down a challenge to those working in critical care; to rise above the ingrained behavioural response in order to see one another's perspective. Festic et al. (2012) did not only find differences between these two professional groups, but also observed areas of agreement. These ranged from a belief that in critical care, it was a privilege to care for families and patients' who were at the end-of-life and that death was not perceived as a failure. On a daily basis, nurses in critical care units, work with people who are dying (Beckstrand & Kirchhoff, 2005). It is an aspect of the role that can be both

rewarding and draining. Beckstrand and Kirchhoff conducted research that examined what critical care nurses believed were barriers to providing well rounded end-of-life care and strategies that can address this. A range of obstacles and supportive behaviours featured as part of the questionnaire, which was developed originally for a national survey conducted with members of the American Association of Critical-Care Nurses (AACN). This pre-test assisted in refining the survey items, prior to the commencement of this study. The researchers used an experimental, post-test-only, control-group design with 864 participants recruited from the AACN, from an original 1400 members, netting a response rate of 61% to the questionnaire.

Beckstrand and Kirchhoff (2005) suggested the most frequently cited impediments were families who did not comprehend what was meant by lifesaving measures, regular phone calls from family members seeking information on their loved ones, and doctors differing in their views regarding the course of a dying patients care. Supportive behaviours that received the highest rankings were, the provision of dignified and peaceful bedside scenes after death, facilitating adequate time for family members to spend with their loved one after death and educating families how to be around a dying loved one. These findings raise awareness for ICUs of areas where nursing staff can be supported, resulting in a higher standard of end-of-life care.

Further research by Cook, Rucker, Giacomini, Sinuff and Heyland (2006) examined attitudes toward care at the end-of-life and the impact these attitudes have on patient outcomes within the intensive care unit. The authors conducted a narrative literature review aimed to examine the unique challenges of the ICU setting in the delivery of the best possible end-of-life care. Cook et al. explored how four distinct research types can offer insights into better understanding withdrawal of life support, and put forward seven approaches that would alter prevailing attitudes towards life support withdrawal in the intensive care environment. These research types were: Qualitative research, observational studies, decision support tools and surveys, with multiple ways to effect attitudinal change identified and reviewed. These included promoting social change in a professional manner, establishing the needs of dying patients' families, role modelling high quality end-of-life processes for future health professionals and utilising narratives to dig beneath the surface of perceived challenges.

The role of technology

Part of Cook et al. (2006) approach in exploring this issue was to undertake their own qualitative research to investigate the rationales behind why life-sustaining technology is employed when caring for patients dying in the ICU, who were not able to make decisions for themselves. Cook et al. collected data from field observations during 11 family meetings and 25 daily intensive care rounds in an ICU with university affiliations. Additionally an unspecified number of semi-structured interviews were conducted with consultants, intensivists, nurses, pastoral care professionals, an ethicist and a nutritionist. Using grounded theory methods inductive analysis was focused on field notes, interview transcripts and researchers meeting minutes. Among the findings presented was the observation that

the role of life sustaining technology was highlighted as being integral beyond providing the ability to reduce mortality and morbidity. Intensive care technologies were likened to instruments in an orchestra, as they can be arranged to be withdrawn rapidly or slowly, to keep pace with what has been negotiated between the healthcare team, the patient and their family. Cook et al. suggest that a diverse range of factors influences attitudes pertaining to end-of-life care. They may arise from personal and social beginnings, steeped in values both collectively and community inspired, with additional aspects like skills and knowledge impacting on clinical ability, and the better these are understood, the more likely a good death will be achieved.

Glaser and Strauss (1965) discussed a significant finding from their research study into the awareness of dying; that of the “nothing more to do” phase of dying. This phase was characterised by a patient who is not going to recover from their illness or injury, and it is the doctor or nurses recognition of this that signals a change in focus from recovery, to the provision of palliative care. Glaser and Strauss highlighted that a consequence of the transition to palliation and comfort, changes the healthcare professional’s priorities, as their efforts are recalibrated in the knowledge of death as an imminent outcome.

The roles of physicians and nurses are placed firmly in separate spheres of responsibility. Historically, doctors drive diagnostic tests and treatment regimens, while nurses were responsible for implementing the plans and measuring their success. In ICU the decision to make the transition to end-of-life care is better understood and actioned, if it occurs collaboratively. Unlike Glaser and Strauss’s (1965) findings, which saw doctors as the keepers of the knowledge that a patient was going to die, only imparting this information when they perceived it was appropriate. Interestingly however, the nurses’ transition to awareness of dying saw them become the primary “custodian of care” (p. 204).

Glaser and Strauss (1965) portray the nurses who participated in their research, as a mix of autonomous thinkers and dependent supplicants. They suggest upon becoming aware that a patient has entered the “nothing more to do” phase, a nurse alters her priorities to focus on providing comfort care, rather than facilitating recovery via active treatment. The authors contend that in the absence of being able to attain the medical goal of recovery, and thus the highest reward available, nurses will as a result choose to limit their involvement and have less motivation to provide care. Therefore the authors suggested that, given the prominence of such a reaction amongst nurses, a physician might be reticent about communicating to nursing staff that there is nothing more to be done for a patient, if this is not already known. In contrast to this chain of events Glaser and Strauss also observed what has become more common in nursing over the past 50 years; that it is nurses who often realise before anyone else that a patient is dying, which then necessitates using effective communication skills to raise this awareness with doctors.

Effective communication

Working together, collaboration, shared decision-making and the interdisciplinary or multidisciplinary team have all been highlighted as important components in achieving optimal end-of-life processes in the ICU. Where and how the nurse as a health professional fits into shared decision making, requires further exploration. Baggs, Norton, Schmitt and Sellers (2004) conducted a literature review examining the best available evidence relating to the role of the multidisciplinary team when caring for a dying ICU patient. A literature search was conducted using MEDLINE and CINAHL with a search timeframe between 1990 and 2003. The researchers stressed that collaboration was the central activity of teams as defined by Baggs and Schmitt (1988) in the context of ICU. According to Baggs and Schmitt collaboration is “nurses and physicians cooperatively working together, sharing responsibility for solving problems, and making decisions to formulate and carry out plans for patient care” (p.146). Based on this literature review, Baggs et al. (2004) formulated the recommendations that nurses need to be routinely and regularly perceived as essential members of the critical care team, whose contributions to care of both patients and their families are such; they must not be ignored, or belittled. Improving communication effectiveness between key stakeholders – patients, their families, nurses and doctors - was seen as a way to bridge obstacles that could impede nurses delivering exceptional end-of-life care. A limitation to the study indicated by the authors was the exclusion of allied health professionals, the patient and their family.

A systematic review of the literature published by Puntillo and McAdam (2006) complemented the work of Baggs et al. (2004) and evaluated how communication between nurses and physicians working in ICU, can act as a target for advancing end-of-life care. Puntillo and McAdam (2006) analysed practical applications that aimed to improve collaboration and communication. They did not provide a clear explanation regarding how they searched the literature, opting instead to present the areas reviewed under clearly laid out sub-headings. Both professions cited feeling under prepared to care for dying patients, with nurses being educated to take a holistic approach to their assessments, while doctors are educated to diagnose and treat with a focus on cure. Puntillo and McAdam recommended that for communication between these two professional groups to improve, the use of joint grand rounds, interprofessional dialogue such as unit handovers and combined contribution at ward rounds are ways to make this happen. They suggested that engaged and assured health professionals will be noticeably better equipped to tender improved care to patients dying in the ICU.

Effective communication between team members, in particular physicians and nurses are agreed as being a cornerstone in the foundation of good quality end-of-life processes in ICU. In their research exploring moral distress in critical care nurses' related to end-of-life decision-making, Weinzimmer et al. (2014) reported that team dynamics impacted on how well nurses' perceived decision-making was received. The researchers interviewed 29 healthcare professionals who worked in two ICUs located at a tertiary, academic medical

centre. They reported findings from the nursing participants (n=13). Interviews were audio-recorded, transcribed, double-coded and analysed employing thematic content analysis. Weinzimmer et al. reported a leading theme across all the nurses' interviews was their opinion that effective communication directly influences quality of care. The concept of a "prolonged death" was ascribed by participants as relating to a deficiency in effective communication occurring between different specialities co-managing a patient's care, with the inability to reach a consensus ultimately undermining clinical requirements and care goals. Weinzimmer et al. (2014) findings highlight additional challenges nurses face when working in an open ICU, where physicians from other specialities have input into treatment decisions, and the cessation of treatment. Participants observed that if steps were taken to minimise what one nurse termed "communication fractures and breakdowns between team members", patient's families would receive a reliable flow of information, which may ultimately lead to palliative care occurring in a timely manner. Ultimately the source of distress for this group of nurses stemmed from poor team communication, which led to delayed decision-making and families receiving conflicting information, leaving nurses feeling powerless to explore and honour patient and family wishes.

The inclusion of this paper here is due to its findings regarding communication and team dynamics in the ICU environment. The findings of Weinzimmer et al. (2014) substantiate the findings of other researchers exploring parallel aspects of end-of-life processes, and demonstrate that while moral distress is not a focus of this thesis, effective communication within a team and how this relates to ICU nurses influences on end-of-life processes.

Decision Making

Critical or intensive care units provide specialised care to those individuals who have become severely unwell, through injury or acute illness. One to one nursing care, postgraduate education and technology work in concert to repair the insult(s) the body has suffered, with the intention of returning the person to an acceptable quality of life. What this means and at what point a person is being kept alive with no ability to recover, is a complex decision point to reach and solve. Miller, Forbes and Boyle (2001) consider the technological imperative is the second cultural force that influences end-of-life care in ICUs. Additionally in this discussion paper they examine other cultural concerns that exert influence over the process of end-of-life care; biomedical knowledge as the dominant framework, which precedes technology and ambivalence toward the end-of-life goals of healthcare professionals, patients and their families. Factors surrounding the critical care nurse's limited involvement in end-of-life decision-making were also examined. Miller et al. (2001) drew attention to the importance of a shared model of decision-making. Where participants actively engage with one another and share their personal narratives, thereby promoting an understanding of differing perspectives.

The process of decision-making has many facets, which are accompanied by marked differences in ability between experienced and inexperienced decision makers. For nurses this holds particular weight as day to day clinical practice regularly necessitates many

decisions, from the simple; when to change a wound dressing, to the complex; recognition and treatment of the deteriorating patient. It is recognised that a variety of factors contribute to the evolution of becoming an expert decision maker, including the culture of the practice setting (Orme & Maggs, 1993). Joseph, Maltronne and Osborne (1988) postulated that a collaborative team approach towards making decisions was a key factor in the development of this skill set in American nurses. More recently Bion and Coombs (2015) highlight that the reason collaboration is paramount, is that nurses, doctors and allied health care professionals in palliative care and intensive care teams, bring a range of complementary skills and knowledge to bear when making decisions at the end-of-life.

The confidence and judgement to take risks is considered a characteristic of the decision-making process. Joseph et al. (1988) reported that nurses were more likely to be accountable for their decisions if they felt supported by institutional policies that encouraged innovative thinking and promoted safe practice. In comparison, more recently, Coombs (2003) found ICU nurses were more likely to engage in clinical decision making if they had the support of their nursing colleagues. Coombs observed that RNs who possessed reliable clinical experience, found this useful when validating their reasoning for engaging in decision-making. Being taught the core skills that create a solid foundation, from which decision-making capability can develop, is fundamental for both nurse's professional development and the maintenance of patient safety.

Berggren and Severinsson's (2000) conducted a study examining the influence of clinical supervision on nurse's moral decision making. Semi structured interviews were conducted with 15 registered nurses. The data were analysed using a hermeneutic transformative process from which four themes were constructed. These were, an increased ability to take responsibility, an increased ability to support the patient, increased self-assurance, and an increased ability to form a relationship with the patient. The researchers concluded that clinical supervision was likely to increase the nurse's self-assurance, their skill to support patients through the creation of a therapeutic relationship, and the ability to take responsibility for the care they provided. Berggren and Severinsson reported that supervision motivated the nurses in this study, to reflect on and examine how they interacted with and responded to their patients, and in doing so they moved beyond focussing on care as a series of tasks and stand-alone events.

Clinical decision-making is vital to nursing practice and gaining a greater understanding of the cognitive processes that underpin this is a priority. Higuchi and Donald (2002) make this observation in their paper exploring the thinking processes utilised by nurses when making clinical decisions. The study was conducted in a 200 bed community hospital located in Ontario, with data being collected from 50 randomly selected patients' notes, identified from a chart audit. Narrative notes from eight different nurses, which had been written when a nurse decided to communicate information pertaining to a specific patient situation or problem, were analysed and coded. The narrative accounts were examined for three types of information: reports that identified problem situations, nursing actions and documented

instances of prior problem situations. In addition to contextualise decision-making in real clinical situations occurred, the participating nurses were interviewed and observed. The researchers concluded that nurses utilise numerous diverse thinking operations when documenting decision-making in clinical notes. Higuchi and Donald stated, “an important outcome of this study was the development of nursing exemplars of thinking processes that can provide a working vocabulary to describe the cognitive processes used in clinical decision making” (p. 152).

Bach, Ploeg and Black (2009) conducted a grounded theory study examining the role of ICU nurses in end-of-life decision-making. Fourteen RNs from intensive care and cardio respiratory care were interviewed. A conceptual framework of the nursing role in end of life decision-making was developed from analysis. Four major themes were developed. These were: A voice to speak up, being there, helping to let go and enable coming to terms. The four themes were clustered into one core concept namely “Supporting the Journey” (p. 496). “This study found that certain issues such as a willingness to initiate and enter into the discussion were central to the process of decision making for nurses” (Bach et al., 2009, p. 499).

Robichaux and Clark (2006) echo such a finding when they observed in their study of expert critical care nurses that these individuals frequently moulded the processes comprising end-of-life decision making. They achieved this by having the skills and willingness to advocate for the patients in their care, even if their actions did not alter the final outcomes.

Robichaux and Clark’s (2006) paper also explored the issue of the technological imperative and how this impacts on the decisions that nurses make at the end of life. The barriers that are created by the unpredictable nature of death and the process of dying in the critical care setting are derived from “this inability to identify a patient as terminal which often results in adherence to curative regimens almost to the moment of the patient’s death” (p. 487). For the nurse whose central tenet it is to work for and with the patient, and undertaking this within a team of physicians, family and allied health professionals, suggests a significant balancing act is in play. Therefore, the nurse is placed simultaneously in the roles of advocate, communicator, patient expert, health professional and human being. How these roles are handled and inform nurses’ decision-making is why research into this phenomenon is necessary.

Long-Sutehall et al. (2011) rose to this challenge in their grounded theory study of 13 critical care nurses who worked in four different intensive care specialities. And found four significant dying trajectories that lead to the formation of a theory of negotiated dying. The authors interviewed participants using clinical vignettes relating to the withdrawal of active treatment. The authors report that their motivation for conducting this research was that previous studies had identified withdrawal of treatment was a causative factor in tensions between nursing and medical staff, however the nurse’s role in facilitating this process has received limited attention.

Within Long-Sutehall et al.'s. (2011) research paper the term dying trajectories is attributed to the work of Glaser and Strauss (1965; 2005) as discussed earlier in this chapter. The theory of negotiated dying is described as a five-stage process that runs sequentially through assessment, facilitation, coordination, operationalising and negotiated dying (Long-Sutehall et al.). Each stage has conditions attached to it, which add depth to the theoretical process. Long-Sutehall et al. concluded that their findings demonstrate that when "planning and implementing withdrawal of treatment clinical teams need a 'shared' understanding of each other's roles, responsibilities, aims, and motivations; both attributed by others and assumed by the individual" (p.1473). A shared understanding strengthens decision making through team members having a better understanding of everyone's contributions, promoting a shared mental model within the team.

An evaluation paper from Rose (2011) supported the findings of Long-Sutehall et al. (2011) in the broader framework of ICU care, rather than care at the end-of-life. Rose aimed to examine factors relating to the complex nature of interprofessional collaboration and the subsequent impact on patient care. Components of successful interprofessional collaboration were identified and included mutual respect, interdependent and complementary roles that have been explicitly identified, shared partnerships and goals and power sharing (Rose, 2011). The author raises a concern that nursing's strong push towards creating autonomy when making decisions, may in fact work against the formation of a collaborative interprofessional team culture. In conclusion the author states it is clear that within the ICU setting the promotion of interprofessional collaboration and communication will result in improved patient safety and increased quality of care.

Hamric and Blackhall (2007) also examined factors that influence end-of-life processes by conducting a descriptive pilot study employing a survey design, to examine nurses' and consultant doctors' viewpoints regarding care for patients at the end-of-life, paying specific attention to nurse/doctor collaboration, and the relationships between ethical climates, moral distress and satisfaction with care quality.

The study took place across 14 ICUs located in two organisations in different regions in Virginia, USA. Twenty-nine consultant doctors and 196 nurses chose to take part, with data being collected via a survey questionnaire. RNs from the first site reported less collaboration, increased moral distress, and an ethical environment that was more negative along with decreased satisfaction regarding quality of care, than their physician colleagues. For both RNs and physicians the situations that incurred the greatest moral distress were those, where they felt pressured to persist with uncalled for aggressive treatment. At the second organisation, 45% of the surveyed registered nurses detailed that they had either left, or considered leaving a role due to moral distress. For physicians the presence of collaboration related to satisfaction with the ethical environment, and quality of care, while for nurses, collaboration related positively to satisfaction and ethical climate across both organisations. The RNs with elevated moral distress scores, experienced decreased

satisfaction related to quality of care, and a lower outlook regarding collaboration and the ethical environment (Hamric & Blackhall, 2007).

While moral distress experienced by critical care nurses was neither a component of my research question, or a significant finding, it does, as a concept, put in an appearance in the published literature on end-of-life decision-making and care, hence I have included it in the literature review as relevant. Given the studies conducted done in this sphere and the drive to link moral distress to every facet of nursing practice, the perspective articulated by Johnstone and Hutchinson (2013) makes for thought provoking reading. Their summation is that nursing dialogue concerning moral distress is not without controversy, due in no small part to it being conceptually faulty and hindered by both practical and theoretical difficulties. Making moral mistakes and being challenged by points of view that differ from our own, can act as sources of stress for nurses. However, they do not need to become polarising to the degree that a way forward cannot be found.

Disagreements are often the beginning of our thinking, not its end... because consideration of other points of view can (and does) enrich people's moral thinking and experience, can help individuals to think about old problems in new ways and can help people to identify and respond to previously unrecognised problems (Johnstone & Hutchinson, 2013, p. 7).

The foundation from which nurses feel empowered to make decisions can be precarious. The disparate power structures between the nursing and medical professions, mean that speaking up, or involving one's self in a team discussion related to a patients care can be fraught with indecision and fear. Norton and Talerico's (2000) grounded theory research comprised nurses, doctors and family members (n=20), and data collection was by semi-structured interviews. Participants reported that for those individuals who are more comfortable and experienced, the likelihood increases that they will engage with assessment and communication strategies that will assist end-of-life decision-making. The investigators' examined these strategies (being clear, being specific, using words such as "dying" and "death", understand patient's physical and end-of-life needs and developing shared understanding of goals and expectations) in the context of caring for the older adult however; they may have transferability to the critical care setting. The authors reported that within the increasingly complicated environment in which the delivery of health care takes place, decisions relating to the end-of-life are vulnerable to fragmentation.

However, this fragmentation can be addressed by employing dimensions of decision making; communicating willingly and clearly, and by providing clarification regarding treatment goals and prognosis (Norton & Talerico, 2000). Furthermore the researchers reported that undertaking an almost constant process of assessment is another key element in a healthcare provider recognising the need for end-of-life conversations. Achieving this meant having the ability to identify deteriorating health conditions, gauge understanding, discuss end-of-life preferences and the aspirations and expectations of patients and their family members. Norton and Talerico posit that all nurses are in a position to positively influence

end-of-life decision-making for patients and their families alike, due in no small part to their frequent presence.

Shared decision-making

A systematic review undertaken by Kryworuchko, Hill, Murray, Stacey and Fergusson (2013) aimed to find the components of shared decision-making (SDM) that had been tested with a view to improving communication, regarding life support decisions made in ICU between healthcare professionals, their patients and the patients families. The authors of this review state that best practice guidelines recommended employing an SDM model will improve the quality of decision-making at the end-of-life, however no information is provided as to how this should be done in practice. The review focused on randomised controlled trials of SDM interventions for decisions about withdrawing life support, or limiting its use for hospitalised patients and was very thorough in its analysis, beginning with over 3000 publications found searching databases such as MEDLINE and Embase over a pre-defined time period. Four trials were included in the review and were assessed as containing some of the nine SDM elements, which include: explain and/or define the problem that needs addressing, present the existing options, discuss perspectives on the benefits and risks these options contain, find out what the patients preferences are, and make or defer the decision (Makoul & Clayman, 2006). The authors concluded on the basis of their review, that there was inadequate evidence to surmise that SDM processes had been either instigated or effective (Kryworuchko et al., 2013). Therefore, Kryworuchko et al. recommended that while SDM demonstrates promise in strengthening ICU decision-making processes, more work needs to be carried out to examine interventions with practical application in the clinical setting. More research looking at how ICU nurses can engage with SDM would be of value, given that this professions voice often struggles to be heard both prior to, and during end-of-life decision-making.

Family involvement in shared decision-making

Prior to Kryworuchko et al. (2013) systematic review, White, Braddock, Berekenyei and Curtis (2007) completed a study examining family involvement in end-of-life decision-making in the context of shared decision-making principles. Data was collected from audio taping 51 physician-family meetings involving significant end-of-life treatment decisions, which occurred at four different hospitals and was then transcribed verbatim and coded and analysed using a previously validated conceptual framework. This framework comprised seven elements, including: the nature of the decision, the patient's role in decision-making and the benefits and risks associated with a decision and the patients understanding, developed to examine informed decision-making, and were synthesised from published literature (Braddock, Edwards, Hasenberg, Laidley, & Levinson, 1999). White et al. employed this instrument to assess 10 elements, among them: describing treatment alternatives, discussing the nature of the decision, understanding patient preferences and values and exploring the context of the decision. This study from the perspective of health professionals was predominantly physician centric, however, some of the meetings had a

multidisciplinary composition and included nurses, spiritual care providers and social workers.

Consistent with the findings of Kryworuchko et al. (2013), White et al. (2007) reported applying every SDM element to a decision is challenging, with only two percent of decisions in this study achieving all elements. The researchers correlated a higher degree of family satisfaction with the decision made, when SDM levels were greater, concluding that SDM may be an important area in ICU for quality improvement to take place. They also suggested SDM “allows clinicians and family members to contribute their expertise to arrive at a medically sound treatment decision that is consonant with a patient’s values and preferences” (White et al., 2007, p. 467). To expand on and deepen this study’s findings, additional qualitative research concentrated on the multi disciplinary teams experiences using SDM would be beneficial in better understanding its application in ICU.

In 2013 Adams, Bailey Jr, Anderson and Thygeson presented findings from a prospective pilot case study that employed the Adaptive Leadership framework with the aim of describing the behaviours used by health care providers when working with families who were confronted with the challenge of acknowledging that their loved one was dying in intensive care. The study followed a single patient in ICU who had an illness from which they were not expected to recover. The study comprised seven participants; a nurse, two physicians and four family members. The patient did not have the ability to make decisions. Data collection was by way of audio taping three family meetings and a family interview. Transcripts were then coded using priori codes to express behaviours representative of Adaptive Leadership. Analysis adhered to the principles of deductive content analysis and four Adaptive Leadership behaviours were discovered: providing decision support, providing information, addressing work avoidance and supporting realistic hope. These behaviours were seen by the investigators as facilitating health care professional’s ability to walk alongside families who have a relative facing imminent death, and support them to plot a course through the challenges that lie along the path between active treatment and palliation. Adams et al. reported decision points were characterised as adaptive challenges, and included making trade-off’s, identifying their values and goals for their loved one, comprehension that treatment was not working and reframing of hope from survival to that of a good death. The findings of this paper have positive implications for intensive care nurses, as they offer a tangible structure from which decisions at the end-of-life can be made. In doing so the researchers have highlighted the importance that exists around the relationship between nurses and family members, at every stage involved in the end-of-life journey.

Having an understanding of how healthcare professionals involved in end-of-life care within the critical care setting perceive this process, is important to the ongoing development of knowledge needed to do this well. Pattison, Carr, Turnock and Dolan (2013) aimed to achieve this in their phenomenological study involving 27 participants from a critical care unit in the UK. Using purposive sampling nurses, oncologists, bereaved families and palliative and critical care consultants were recruited and participated in in-depth interviews, which

were subsequently analysed using Van Maanen's phenomenological analysis framework. Three main themes were analysed: the meaning of decision-making, dual prognostication and end-of-life care practices: choreographing a good death. In addition Pattison et al. reported a variety of conditions described as core tenets for providing high-quality end-of-life care: Dignity, comfort, privacy and the decreased visibility of technology. The researchers concluded that a defining element in decision-making and commencement of the transition towards end-of-life care was arriving at a point of futility. Nurses were identified as playing a central role in the management and ratification of end-of-life care. Furthermore the study's authors contend that an original finding from the research "was the dilemma of treating patients over families at EOL in critical care" (p. 1451). Pattison et al. observed that this became particularly noticeable with regard to time, when to initiate the withdrawal process and when this meant death would occur. The dilemma arose over whether, at this stage, the wishes of the patient's family became more important than those of the patient themselves.

Nurse's decision-making ability

Hicks, Merritt and Elstein (2003) conducted a pilot study with the intention of investigating the relationship between level of education, the ability to think critically, and years of nursing experience working in ICU, on how this affected clinical decision making consistency. The studies design was correlational and non-experimental and involved 54 critical nurses employed in adult ICUs, located in three private teaching hospitals. Data was collected via participants working through two paper-based scenarios, designed to represent a low and a high complexity ICU situation that could be encountered in any intensive care environment. Critical thinking ability was appraised using the 34 item multiple choice tool the California Critical Skills Thinking Skills Test (CCTST), which uses three criteria: evaluation, inference and analysis to measure this decision making skill. Consistency between analytical and intuitive decision-making was examined using a Decision Analytic Questionnaire (DAQ), which comprised 57 items and was adapted to suit intensive care nursing. The authors highlighted the significant role that clinical experience and education play in the ability to make good clinical judgements, and how experience facilitated the establishment and formation of conceptual linkages and pattern recognition, while education creates a scaffold from which learned knowledge can be systematised. Hicks et al. came to the conclusion that neither experience or education were linked to increased critical thinking, and neither was critical thinking a predictor of consistent decision-making ability in this study. The investigators proffered the idea, regarding experienced nurses that perhaps the influence of education cannot be scrutinised in relative isolation. While "skills are important, this study suggests that clinical experiences are important determinates of a nurse's decision-making ability" (p. 176).

In 1995 the results from a large two-phase longitudinal research project were published. The aim of this study was to examine how to improve end-of-life decision-making and how to decrease the occurrences of mechanically supported, prolonged deaths (SUPPORT Principal Investigators, 1995). At the time this was considered a seminal piece of work, as it

featured a large sample size and was conducted across multiple sites. The study took place over a four-year period, commencing with a two-year prospective observational study (phase one), followed by a two year controlled clinical trial (phase two). Over 9,000 adult patients were enrolled in the study, all of which had been diagnosed with a life-threatening condition. Early findings from phase one indicated that significant shortcomings existed in relation to decision-making, communication and outcomes. As a result, an attempt to promote change was developed and this intervention was initiated in phase two, discussed below. The intervention aimed to improve decision-making and communication by making reliable and timely prognostic information available, through gathering and recording patient and family preferences and perceptions related to prognosis and treatment options and outcomes. The investigators concluded that they were “left with a troubling situation” (p. 1597). Their findings were that the care provided for both the seriously unwell and the dying at the time, was falling short. Patient’s and family members were not included in discussions, pain was managed poorly and the dying process unnecessarily prolonged.

The intervention used in phase two of the SUPPORT study was deemed unlikely to positively impact the identified issues, however, a united commitment supported by innovative thinking and additional front line buy in would provide the foundation for lasting change. Evaluation of phase two focused on improved communication between patients and their physicians, and positive impact on patient outcomes or care. Patients were allocated to one of two groups, either intervention or control. Five measures were used to assess the intervention: Preferences to withhold resuscitation as agreed between patient and physician, the timing of a documented do not resuscitate (DNR), duration of ICU admission either receiving ventilation, or being unconscious prior to dying, assessment of pain severity and frequency and use of hospital resources (SUPPORT Principal Investigators, 1995). Overall the investigators concluded that no significant improvements had occurred and that “to improve the experience of seriously ill and dying patients, greater individual and societal commitment and more proactive and forceful measures may be needed” (p. 1591).

The decision to include the SUPPORT study in my review of the literature, was because it initiated research to be undertaken in the ICU setting, into the issues around postponing end-of-life care for patients, until death is obvious (Nelson & Danis, 2001). This study was a major proponent in raising awareness around the benefit of ICU staff being more forceful and proactive, in their initiation of end-of-life conversations (Larson & Tobin, 2000). It is my belief that many of the studies I have included in this literature review, would not have come about, if not for the existence of the ‘SUPPORT’ study.

The timing of decisions to transition from active treatment to palliative care

Interwoven throughout end-of-life processes in ICU is the timing of transition from cure to comfort. Badger (2005) undertook a qualitative descriptive study to examine how medical ICU (MICU) nurses moved from actively preserving life, to letting death run its course. Using focus group interviews and brief observation (n=24) the study was conducted in an 18 bed

MICU located in a 700 bed acute care US hospital. Data analysis and data collection were concurrent. Pre assigned categories were used for data analysis. While Badger's findings did not indicate a clear demarcation line between the cessation of active treatment and the commencement of palliative care, participants did report that family disharmony, the patient's age, indecisive treatment decisions, and family misunderstandings about their loved ones illness culminated in making the transition to end-of-life care challenging. Conversely participants also reported what they believed were supportive conditions enabling them to make the transition to palliative care. These were, developing a consensus between patients, ICU staff and family members regarding the direction of care, lack of response to treatments and running out of treatment options.

That Badger (2005) utilised a qualitative approach and used two different data collection methods strengthened the information obtained. Perhaps a more decisive and clear choice of research methodology within the broad qualitative umbrella, such as grounded theory may have added more depth to this valuable research. Examination of the transition that takes place between moving from active treatment to initiating comfort care is important, as this is an integral factor in ICU nurses providing patient centred end-of-life care.

How ICU culture may influence decision-making processes

A further challenge facing end-of-life decision-making in the ICU environment is these units may have differing cultures, which play a part in how this process unfolds. Baggs et al. (2007) investigated end-of-life decision-making in the four participating ICUs "by systematically examining their cultures and evaluating similarities and differences and the relationship of those cultures to end-of-life decision-making" (p. 160.). The study employed a prospective ethnographic design involving four adult ICUs located in the same 740-bed United States hospital. The participating ICUs were a MICU, a surgical ICU (SICU), a burns and trauma ICU (BTICU) and a cardiovascular ICU (CVICU) with data being collected from healthcare professionals, patients, care providers and family members, over a seven month period. The researchers reported that where possible they interviewed participants who were connected to the same situation; interviews were semi structured, audio recorded and lasted between 15 and 60 minutes. Interview participants were identified during observations of ward rounds, and staff undertaking their day-to-day work. Interviews were transcribed and along with field notes reviewed to confirm accuracy and entered into a computer analysis programme ATLAS.ti. Data was coded and analysed to identify relationships between emerging patterns and themes, with the resulting codes being categorised.

The investigators found that ICUs are not the same and that both similarities and differences existed in how end-of-life decision-making took place, while at the same time adhering to a pattern specific to the particular ICU (Baggs et al., 2007). Differences in understanding related to informal rules, such as dissuading nurses from initiating conversations with families, and formal rules like those pertaining to DNR orders were sources of possible discord between physicians and nurses, leading to confused decision-making. The authors

recommended that both informal and formal rules are clearly identified within units, thus enabling streamlining of unit specific end-of-life processes. Across all four ICUs ward rounds were deemed an essential occurrence although differences existed as to how they were conducted, with some taking place at specific times and being perceived as an opportunity for all healthcare team members to collaborate on care and raise any concerns. For others rounds were physician lead and fragmented taking place at non-specific times and registering little interest in what the nurse at the bedside had to offer. Baggs et al. found that two ICUs held interdisciplinary discussions daily around treatment limitations, while in another, these issues were only approached when prompted by serious events and in the fourth ICU these conversations took place when instigated by a nurse practitioner or nurse. To better comprehend and progress decision-making at the end-of-life in ICU, “greater attention needs to be paid to the structure, culture, and variations in provider roles of specific units” (p. 166).

The focus of Baggs et al. (2007) research is significant, in that it has increased the body of knowledge around how end-of-life decision-making is affected across ICUs with different specialities. In opting to utilise a qualitative approach the investigators designed their study to effectively capture data that would enable them to evaluate their objectives. A key aim was to undertake prospective research, rather than follow in the footsteps of previous retrospectively aggregated studies. As Giacomini, Cook and DeJean (2009) observed with regard to qualitative studies exploring life support decision-making in ICU, studies that incorporated observation in their design directly follow this process and engage an array of participants, generating valuable perspectives around dynamics, interactions and communication.

The work of Bucknall (2000; 2003) and Bucknall and Thomas (1996; 1997) around critical care nurses and decision-making has been a valuable addition to this field of study. Bucknall and Thomas (1997) conducted a survey involving 230 Australian critical care nurses, who were recruited from the members of the Confederation of Australian Critical Care Nurses Victorian Branch and represented a 58% response rate, after members not working in ICU at the time were excluded. Bucknall and Thomas aimed to collect ICU nurses reflections on what they believed were issues associated to making decisions in the ICU environment, with survey questions developed from a small pilot study and a literature review. In addition to answering the survey questions, participants were invited to make comments in writing. Participants reported the following problems, in relation to making decisions in ICU: Conflict between nurses and doctors, dissatisfaction related to the medical management of patients with a poor prognoses, time restrictions on nursing care, nursing knowledge and autonomy and the relationships between junior doctors and experienced nurses.

Bucknall and Thomas (1997) concluded that a foremost source of nurse discontent was around decisions to treat patients who had a poor outlook, and perceived that the doctors they worked with initiated inappropriately, treatment plans that would unnecessarily prolong

life. Participants also expressed strong views regarding junior doctors emphasising their authority, with a number of nurses regarding their own expertise to be superior. The nurses additionally expressed resentment at being required to abide by instructions they did not subscribe to. The researchers insightfully identified that a direction for further study might involve conducting interviews, with a smaller group of these nurses.

In 2000 Bucknall conducted a study involving 18 nurses working in ICUs in three diverse settings; an urban private hospital, an urban public hospital and a rural public hospital. The aim was to observe and describe critical care nurse's decision-making activities within real life clinical environments, with observation periods lasting for two hours during which audio taped researcher commentary captured in detail each nurses actions. Content analysis resulted in three prominent categories with frequency of decision-making being associated with nurse's seniority of role, experience in critical care, employment location and the particular shifts rostered. The author suggested these findings strengthened the indication that both environmental and individual factors influence the clinical decision-making ICU nurse's make.

Bucknall published another paper in 2003 using the data collected during her research three years prior, to explore the environmental factors impacting ICU nurse's real time decisions. In this paper Bucknall reported that the primary environmental influences on clinical decisions were; resource availability, the patient's situation and interpersonal relationships, while risk and time guided all aspects of clinical decision-making. The researcher reported that participants cited conflict, as impacting on decision-making, however conceded that at the time of writing, at what juncture conflict starts to shape decision-making is unknown. In order to facilitate approaches to address these negative influences further research into their existence in other ICUs is necessary. The barriers to critical care nurses engaging in end-of-life processes must be acknowledged by all team members, along with the solutions to address them.

Summary

While critical care nurses are perceived as being integral to end-of-life decision-making and care, barriers are widespread regarding their consistent inclusion in the decision-making aspect of this process. In this chapter literature pertaining to critical care nurses, end-of-life decision-making, and end-of-life care have been critically reviewed. The qualitative approaches employed by researches that have undertaken research in this area, have for the most part been well conducted and appropriately chosen to investigate varies aspects relating to this field of study. It is clear ICU nurses have much to offer when it comes to philosophies underpinning end-of-life practices, and changing the perception that death in this environment is not a failure, but an opportunity to facilitate a good death. Critical care nurse's 24 hour presence at a patients bedside, means their insight and input into end-of-life processes is invaluable, and needs to be encouraged for the benefit of those who will die in ICU.

Chapter Three: Methodology and Method

Introduction

The aims of this chapter are to present the methodological approach and the methods employed in this research, and discuss the theoretical perspective of symbolic interactionism underpinning this study. The qualitative research methodology of grounded theory, as conceived by Corbin and Strauss (1990; 2008), and its use in this research are laid out. How participants were recruited and their composition will be described, along with how rigour was maintained, ethics approval achieved and data collection conducted. The process I followed for data analysis is explained including coding and memo writing.

In this study literature acted as a touchstone, providing a sense of context and history to the findings I have made in this research. Foray's at regular intervals into the body of information that exists around end-of-life decision-making has continued to stretch and push my thinking, until the final words were set. My reading has not solely been focused on this central subject. I also accessed material to sensitise my thinking about particular concepts, which, in turn deepened my analysis.

Symbolic Interactionism

"Grounded theory method, as it is used in qualitative social science research, has its roots in the symbolic interactionist tradition that grew out of the Chicago school of sociology between 1920 and 1950" (Robrecht, 1995, p. 169). Symbolic interactionism is the theoretical underpinning that guided my research and assisted me to understand more fully the perspectives I uncovered regarding how critical care nurse's influence end-of-life decision making and care. Grounded theory using the underpinning of symbolic interactionist foundations posit that meaning in a particular context is derived from interactions with others, and that objects are devoid of meaning unless it is ascribed to them as part of an interactive process (Blumer, 1969). Exploring how nurses working in critical care give meaning to the end-of-life decision-making process was deepened by symbolic interactionism, which underpinned my analysis.

According to Blumer (1969) who named symbolic interactionism, individuals act toward things in certain ways based on the meanings that they hold for them. Different interpretations lead to different actions, which are sculpted by a myriad of environmental factors and influences. My research aimed to highlight these influences and examine how they influenced actions, which could ultimately impact on end-of-life decisions. Because the people who make such decisions "interact over a period of time; out of that interaction they come to share a perspective; what they see will be interpreted through that perspective; often each perspective tells us something very important about what is really true" (Charon, 1998, p. 1).

In her interview Adrienne provided a clear example of how removing the endotracheal tube (ETT) as part of the withdrawal process, had the potential to be a negative experience if the nurse did not understand how to prepare family members. This becomes a shared perspective in that both the nurse and the patient's family wish to provide the patient with a good death, however if the extubation process is unpleasant, then it can come to symbolise killing the patient, rather than making them comfortable.

... We're removing the ETT, there's been occasions where the family have just not been prepared for what that might be like and it's not a nice process... if you haven't geared them [the family] up and especially if you haven't prepared your patient with regards to medication and everything else. So those things make the whole situation a lot worse and it's then a horrible experience for that family to remember for the rest of their lives. (Adrienne)

Symbolic interactionism is theoretically driven by the acting individual, with the individual being perceived as determining, not determined, while society is composed of the purposeful actions of both individuals and groups (Klunklin & Greenwood, 2006). The theories that comprise symbolic interactionism according to Charon (1995) are inductively and empirically developed, with its primary concepts including the world, the self and social or joint action. Blumer (1969) held that from the social interactionist perspective the world is constructed of symbols, however this world is the "objective world". Objects only become symbols once they have been assigned meaning, and a symbol is anything that can be allocated to the self and then reflected upon (Klunklin & Greenwood, 2006). Monitors attached to the patient providing quantitative data on their physiological status, can become a focal point for loved ones who ascribe positive meaning to numerical information they are ill equipped to contextualise. Interpretation therefore becomes about formal knowledge. Many of the nurses I interviewed saw monitors as a distraction that pulled family members attention away from engaging with their loved one, as they were dying. Monitors are symbols that represent the likelihood a patient is going to recover. Once the transition to palliative care has taken place, they no longer have a relevant role to play. "She went quite pale and you had the monitor and you didn't have any alarms on. I think I possibly even turned it away so the family couldn't see it or even turned it off at that stage" (Holly).

So you turn the monitors off as well, cause they're just like the patient's here and they're like, look at the monitors, so you turn it off, put the pumps out of view if you've still got them, take the bits and bobs out if you can is much more human, and make sure that they are holding hands, cuddling, lying on the bed, that human touch, all those kinds of things. (Ashleigh)

Connections both human and technological vie for attention within the intensive care setting. At the end-of-life having the focus move away from equipment and what it can achieve is a significant component associated with withdrawal of treatment. It symbolises the nurse's role in supporting the patient and their family to make the transition towards maximising their time together, rather than being overwhelmed by complex interventions. This reflects a symbolic interactionist's principal tenet whereby the existence of an experience is required, for the establishment of meaning to occur, with social interaction being an important element (Aksan, Kisac, Aydin & Demirbiken, 2009; Aldiabat & Le Navenec, 2011). Such a change is

not giving up, but a chance to take control with a different set of priorities during end-of-life care. My intention through the use of grounded theory was to understand my study participant's meanings, regarding their involvement in end-of-life decision-making and care.

Grounded Theory

Glaser and Strauss developed grounded theory in 1967. It is a qualitative research methodology that strives to create meaning regarding a specific issue through systematic data analysis, abstraction and conceptualisation, all of which are components of the theory generation process (Hallberg, 2006; Starks & Brown Trinidad, 2007). Grounded theory research is both an inductive and deductive data collecting methodology, as the researcher does not have any predetermined ideas that they wish to substantiate, rather it is through the information imparted by participants that issues of importance are uncovered (Ghezeljeh & Emami, 2009). It is for these reasons that grounded theory was a good methodological fit to investigate my research question. While various versions of grounded theory exist, I employed Corbin and Strauss's (1990) interpretation as I found their structured approach to collecting data easier to follow than in other interpretations. I have also read widely around works of additional grounded theorists, including the writings of Kathy Charmaz (2011), which have been immensely helpful, particularly around analysis and memo writing.

The grounded theory of Strauss and Corbin (1990) has a strong pragmatic approach, which holds that, while reality may not be capable of being completely known, it can always be interpreted (Hallberg, 2006). Hallberg suggests that listening to the voice of the participant is of great importance, with the theory generated being a created reality, and assembled from both the data and the researcher via a transactional process. The intention of grounded theory is to assist with understanding and explaining how complicated phenomena are enacted within the field of study (Brown, Stevens, Troiano, & Schneider, 2002). The intention of my research was to understand critical care nurse's involvement in end-of-life decision-making, and to explore the actions that exist within this process.

According to Mills, Bonner and Francis (2006) Strauss and Corbin (1990) recognised that the interview is an interaction where the co construction of meaning between participant and researcher can take place and as a result the knowledge gained is deeper and more meaningful. They acknowledge that reality cannot be completely known, but argue it can always be decoded and maintain their description of grounded theory is informed by their experiences as researchers (Hallberg, 2006). Hallberg suggests it embodies a pragmatic stance, strives to hear the voice of the participant and as a result the research journey develops a shared authenticity formed by the relationship the researcher enters into with their data. Creating a safe environment where the participants in my study felt that they were not simply a means to an end was very important to me, and another reason behind my choice of Strauss and Corbin's approach.

An example of this shared authenticity is provided in the following excerpt, where a shared understanding born of different encounters around loss facilitated a meaningful discussion on how experience informs, and deepens empathy.

... There are certain situations that will catch everyone out, for example, an unexpected death of a child. One of our senior nurses was really caught out by that because he has a young child and things started clicking in terms of that. It comes with experience... because the more deaths you see and the more different people you see talking to family, you pick up on what they say and think, "hey that was really great; I'm going to utilise that in my practice." (Gerard).

Grounded theory through its belief that people possess, but do not necessarily employ, the means by which to shape their own fates via individual responses to their environment plays a significant role when exploring what is happening in the setting of interest (Corbin & Strauss, 1990). Critical or intensive care is a highly structured environment that not only expects much from staff, but has high expectations from health professionals outside the units and the societal population it serves. It is a setting where complex and difficult decisions are made on a regular basis, in response to situations that are encountered every day. End-of-life decision-making is an example of a set of circumstances where grounded theory is well placed to uncover not only conditions relevant to this situation, but also how nurse's involved in this process would react to shifting circumstances and to the consequences of their decisions (Corbin & Strauss, 1990). The following interview excerpt underscores the complexity imbedded here, when the conversation turns to the indicators of survival.

... We throw everything we can at them and despite that they're still getting worse... "We've offered everything that we can; despite our best efforts we can't improve the outcome, we think this person is going to die..." We think at this point it would be better to shift our focus from a treatment to a comfort measure situation..." (Gerard)

In the above two sections I have used direct quotes from participants to bring to life how symbolic interactionism and grounded theory, supported me as a researcher to engage deeply with my data. The following section introduces these nurses, and their recruitment while maintaining their confidentiality.

Participants

The inclusion criterion for the study was critical care nurses with a minimum of one year's experience working in intensive care. Nurses with less than a year's experience were excluded. This strategy known as purposive or selective sampling enabled me as the researcher to select participants who were likely to have experienced aspects of the phenomenon I sought to explore (Beanland, Schneider, LoBiondo-Wood, & Haber, 1999). Because the study aimed to examine critical care nurses' influence on end-of-life decision making processes, nurses still undergoing mentorship and developing the specific skills required to work in critical care would not be able to fully engage with the research topic, hence their exclusion from this study. Participants represented a cross section regarding length of experience in critical care nursing. See Table one Participant Information (p. 43).

Participants were recruited via an advertisement placed in the critical care unit where the study was taking place. Copies were placed in all nursing staffs “pigeon holes” and a poster was placed in the staff tearoom. These advertisements offered a brief summary of the research I was planning to undertake, along with my name and contact details. Anyone who was interested in participating or who wanted more information could then make direct contact. After I was contacted, I then sent the interested parties a covering letter, a participant information sheet and a consent form via internal mail. See Appendices for copies of these documents.

The role of participants in this research was to share information. As I began to write up my findings I adhered to the concept of credibility. Credibility acts as a tool by which to measure the faithfulness and vividness of how the phenomenon is described (Beck, 1993). To establish this Beck suggests participants and readers, who have experienced the phenomenon, must be able to recognise what the researcher had described, and that the depiction was faithful. On completion of my thesis I presented my findings to participants. The principle of protection guided my recruitment process to safe guard against coercion. Participants were welcome to bring a support person if they chose, however no one elected to do so.

The group of participants comprised nine registered nurses who work in a closed critical care unit, at a tertiary teaching hospital in New Zealand. Eight nurses were female and one male. Their years of critical care experience ranged from one and a half to 23 years and was gained in a range of geographical locations including England, Scotland, India, the Middle East and Canada. Prior to the commencement of each interview participants returned a signed copy of the consent form. No identifying information has been kept or included in the completed thesis. Pseudonyms were applied by the researcher.

Table 1: Participant information

Interview Order	Pseudonym	ICU Experience	Post Graduate Education
Nurse 01	Holly	1.5 Years	Unknown
Nurse 02	Melissa	12 Years	Masters Student
Nurse 03	Rebecca	5 Years	Unknown
Nurse 04	Gerard	9 Years	Unknown
Nurse 05	Adrienne	10 Years	Unknown
Nurse 06	Rachel	23 Years	Unknown
Nurse 07	Reen	6 Years	Unknown
Nurse 08	Ashleigh	15 Years	DHSc Student
Nurse 09	Laurie	8 Years	PG Dip

Choosing to take part in a qualitative research project is a non-compulsory decision on the part of the participant, and for many researchers this raises the question of why people opt to engage in research at all (Clark, 2010). Being humbled by the number of nurse's who took the time to discuss their experiences of end-of-life decision-making, prompted me to think what benefit did they receive by interacting with my work? In his study "on 'being researched': why do people engage with qualitative research?" Clark interviewed 13 experienced researchers on their interpretations of this phenomenon. Findings were grouped under two headings: Supporting engagement at an individual level and supporting engagement at a collective level (Clark, 2010). The former incorporated subjective interest, curiosity, enjoyment, individual empowerment, introspective interest, social comparison, therapeutic interest and material and economic interests, while the latter discussed representation, political empowerment and informing 'change'. While I did not ask the participants in my study their reasons for agreeing to participate, Clark's findings appear to offer logical rationale. Moreover, these findings were supported by Adams (2010) discussing the challenges, and delights intrinsic to qualitative research interviewing. Adams asserts that for the first time a participant may feel they are genuinely being heard. Drury, Francis and Chapman (2007) elaborate on this observation when they discuss that for interview participants, being able to talk about specific events may in fact be therapeutic. These authors intimate it is an opportunity to contextualise experiences, actively problem solve challenging situations, or simply take advantage of being able to share a story with an individual who was committed to listening.

Rigour

To ensure my research maintained rigour, the concepts of credibility, transferability, dependability and confirmability as per Strauss and Corbin (1998) were used. As a starting point, I consistently applied the grounded theory methods of theoretical sampling, constant comparative analysis and maintenance of an audit trail to assess my rigour.

Credibility

Credibility acts as a tool by which to measure the faithfulness and vividness of how the phenomenon is described (Beck, 1993). To establish credibility, Beck asserts participants and readers, who have experienced the phenomenon, must be able to recognise that, which the researcher had described, was faithful to what actually occurred. On completion of this study I undertook member checking, and presented my findings back to those who participated, and gained feedback as to the accuracy and representativeness of what I discovered.

Articulating my personal views regarding my research was acknowledged by way of a personal narrative. Explaining how the researchers own perceptions of the phenomenon being examined impacted on the interpretation of the data gathered played a central role in the enhancement of credibility (Chiovitti & Piran, 2003). To achieve credibility, when I wrote up my findings I used direct quotes from participants that reflected what my analysis was

uncovering regarding end-of-life processes. Furthermore, I wrote memos, which aided keeping track of ideas, insights and decisions to track theoretical sampling, as they occurred during data collection and analysis (Hutchinson, 1986). Additionally, memo's assisted me in maintaining an overview of codes and categories as they were analysed, acting as a record keeping system that added to the trustworthiness of the study (Corbin & Strauss, 1990).

Transferability

Transferability is characterised by how applicable one set of findings are to a different setting (Brown et al., 2002). To address this matter I examined my research question from the perspective of a diverse group of participants, with varying nursing backgrounds and lengths of critical care tenure. Clear information regarding the context in which the study took place has been provided, through the description of setting and sample characteristics, which will enable other researchers and readers to assess transferability for themselves (Chiovitti & Piran, 2003). Additionally I showed my theory to four nurses who do not work in ICU, to see if they understood it and could apply it to situations they encounter in their practice. The overall response was positive; with each nurse believing the theory had wider applicability.

Dependability

The concept of dependability refers to the assurance that the data gathered is representative of the experience under study, and any changing conditions (Brown et al., 2002). It relies on adherence to grounded theory methodology where auditors will recognise that dependability has occurred through their comprehension of the coding and the emerging theory, its correct application and categories. This was achieved by having my research audited by a researcher versed in the use of grounded theory methodology. Moreover, my thesis auditability was demonstrated in the findings chapters by the congruence between and within findings.

Confirmability

The final concept is confirmability or auditability, which refers to the consistency of a research study and is demonstrated when another individual is able to track the decisions made by the researcher during each phase of data analysis (Beck, 1993). This was achieved by adhering to Corbin and Strauss (1990) and their recommendation that an explanation be provided apropos to why and how participants were recruited. See page 42 for a more detailed explanation. According to Corbin and Strauss the generalisability of any grounded theory study is achieved in part by the use of abstraction, which occurs over the duration of a research project. They attest that a theory will have wider applicability the more abstract its concepts, especially in relation to the core category.

Member Checking

Member checking is a grounded theory process whereby a researcher takes their findings back to the participants. During data collection and analysis I met regularly with my primary supervisor and methodological advisor to discuss progress. Part of this process involved

going over memos, which comprised a significant part of my analysis. On completion of a memo I would forward it to my supervisor for feedback, prior to a Skype or face-to-face meeting. The concepts uncovered in these memos were also reached by my supervisor, which meant that the analysis I was conducting followed a reproducible strategy that another researcher was able to follow. In addition, during my eighth interview I discussed my emerging categories and showed Ashleigh a basic diagram displaying these. Experienced understanding received positive feedback from Ashleigh, who articulated that she felt it described the process fluently. “Yeah I really like that, that’s great. I love that. Is that a phrase that’s been used in the literature before?” (Ashleigh). Ashleigh also confirmed that the term ‘a good death’ is recognised and used by critical care nurses. “Oh yeah we definitely use that term”. While these were the opinions of only one participant I felt encouraged I was on the right track with my analysis, and the explanatory theory that was emerging. In addition to Ashleigh, I also discussed the theory with four nursing colleagues, all of whom felt it was clear and had applicability to other clinical situations.

Ethics

Ethics approval was granted by AUTC on the 11th of July 2013, reference number 13/130.

The undertaking of my study adhered to the principles of self-determination, privacy, dignity, confidentiality, fair treatment and protection from discomfort and harm (Beanland et al., 1999). All eligible potential participants received information on why I was conducting this research and what their involvement would entail. Through the disclosure of this information, participants were able to start the process of making an informed decision on whether or not they wished to take part in the study. Participants were informed that the option of withdrawing from the study at any stage was acceptable – without negative consequences to themselves or their work. The information about the study was provided in the form of a participant information sheet. See appendices p. 144.

It would be salient to acknowledge that as the primary researcher, the identity of the participants would be known to myself. Throughout the duration of the study and beyond, participant’s confidentiality would be maintained. For this to be achieved, participants were given an identification number and pseudonym with all the information generated by the study being kept securely in my Primary Supervisor’s office at AUT: In a locked cabinet. Additionally, digital voice recordings and electronic material were stored in a password-protected file, located ‘in the cloud’. The individual identities of participants were not linked to data (Beanland et al., 1999).

For the convenience of participants, interviews were conducted in a private room away from the hospital unit. The rationale for this decision was to provide participants with an easy to access location that offered privacy and comfort. The recollection of difficult clinical situations posed some risks to participants, in that contributors could experience distress. The participants were made aware that if difficult emotions arose during the interview, the

interview could either be stopped, or the topic causing distress could be sidestepped and revisited if appropriate later in the conversation.

All participants were registered health professionals working within their scope of practice. A part from the potential for distress mentioned above, no other additional risks were perceived while the research took place. The opportunity to talk about experiences can be healing rather than harmful. Hutchinson, Wilson and Wilson (1994) describe, “catharsis, self-acknowledgment, sense of purpose, self-awareness, empowerment, healing, and providing a voice for the disenfranchised were the sometimes unanticipated benefits reported by interview participants” (p. 161). Health Counselling and Wellbeing at AUT was organised, with up to three free counselling sessions for participants who may have required them.

Provision was included in the interview consent form for all participants to request to read the completed thesis. All interviews were digitally recorded and transcribed by a professional transcription service after completion of a signed confidentiality agreement. See Appendix 11 (p. 149).

Data collection

Interviews

One on one face-to-face interviews were conducted in a quiet, comfortable space to facilitate a conversational atmosphere. I allowed time prior to a participant's arrival to prepare the room with; two chairs facing opposite one another and digital recording devices placed optimally on a table to record our conversation. Participants were interviewed once with these varying in length from 44 to 68 minutes.

The interview is among the most widely used tools for obtaining data in qualitative research (DiCicco-Bloom & Crabtree, 2006). The interview assists the researcher to engage with participants through verbal interaction, and is a data collection method that promotes the acquisition of rich information (McCann & Clark, 2004). Research using qualitative methods allows for a degree of flexibility for the researcher to pursue leads that arise during both data collection, and analysis (Charmaz, 2006). My research question guided the interview as a data collection method as this approach had the benefit of providing optimal rich, in depth data. This was an appropriate fit with my decision to use grounded theory as my overall research methodology.

The semi-structured interview is considered formal, and uses pre written open questions, with further questions being asked as they emerge from the dialogue-taking place between the interviewer and the interviewee (DiCicco-Bloom & Crabtree, 2006). This approach allows for more specific information to be obtained, and is also congruent with grounded theory methodology as it enables the researcher to facilitate “flexibility in the sequencing of questions and in the depth of exploration” (Duffy, Ferguson & Watson 2004, p. 70).

The interviews I undertook followed a semi-structured approach, which I found to be very supportive in my capacity as a novice researcher. I felt that the ability to ask specific

questions and use prompts to guide the participant during the interview opened up more avenues of discussion and covered areas I had not previously considered. This is consistent with grounded theories principle of starting data analysis once the first interview had been completed. Subsequent interview questions could then be formulated to explore new aspects of the phenomenon under study. As I gained confidence from each interview, I became more adept at incorporating the questions I wanted to cover, and following up on answers that warranted further exploration.

When developing initial interview questions, I took into account the criticism levelled at grounded theorists that we do not demonstrate sufficient concern for the specific data gathered and its accuracy (Wimpenny & Gass, 2000). To address this I looked to Charmaz (1994) who advocated that data needed to offer a complete account of the issues and processes being studied. How interview questions are structured when using grounded theory can assist with the above. Charmaz suggests “this process includes setting the tone, seeking information in depth, feeling and reflection, searching for the narrative and ending on a positive note” (Wimpenny & Gass, 2000, p. 1488).

After I conducted the initial interview I used a list of pre prepared questions or statements, to guide the subsequent conversations. As my data analysis progressed and I saw that a particular concept was developing, my primary supervisor introduced me to the strategy of asking theoretical questions. It was during one of our regular supervisor meetings that this arose and related to asking participants specific questions pertaining to data or concepts that consistently developed during analysis, to see if they identified with this themselves. During each interview the question what do you think makes for a good death was intentionally asked, and in doing so it became methodological. Having come across the term a good death during reading of the literature around end-of-life decision-making and end-of-life care, it became increasingly interesting to explore the part it plays in these processes.

The research I completed utilised the individual in-depth interview, to allow me to co-create meaning with participants “by reconstructing perceptions of events and experiences related to health and health care delivery” (DiCicco-Bloom & Crabtree, 2006, p. 316). Through the use of open-ended questions within the one-to-one interviews, I was able to form trusting and collaborative relationships with participants. Achieving these relationships was important; asking nurses to offer insights into their role in end-of-life decisions had the potential to raise painful recollections. Many very personal experiences were recounted during the interview process, which helped to paint very clear pictures about particular situations, past events and insights pertaining to end-of-life processes. As Nunkoosing (2005) stated both the interviewee and the interviewer are altered by the conversation that occurs during the interview. “It seems to me that only grounded theory, in its principles of theoretical sampling, acknowledges that the process of successive interviews has the capacity to change the knowledge of the interviewer” (p. 704).

Data Analysis

Asking questions of the data

Throughout data analysis, looking for process was a constant consideration. Regularly asking the question 'what is happening here' kept my thinking attuned to see instances of process taking place. As Corbin and Strauss (2008) attest "along with variation, process can lead to the identification of patterns as one looks for similarities in the way persons define situations and handle them" (p. 100). For example all nine-study participants reported, differing perspectives on negotiating the timing of treatment withdrawal with the team. Laurie reported that staff were receptive when a colleague decided to try another intervention as part of working the problem. "Actually we're going to give him a dose of steroids... you know, everyone's fine with that... I think it's a collective decision and most people are keen to do whatever the consultant wants anyway and good for the family" (Laurie). In contrast to this Laurie also observed

It's more of a collective decision between the consultants. A few years ago one in particular you'd think, oh good, she's coming on and then she's going to make the decision, cause other people would prolong; but now I think it's more of a collective decision and I think that's quite good for the consultants – it's not ultimately on one person's shoulders. I don't feel that nurses really have too much input. I guess it's a combined decision but generally we don't have much input. (Laurie)

Melissa's perspective was influenced through the role she held as a charge nurse, which she reported assisted her voice in being both heard and listened to. "I guess when it comes to making end-of-life decisions I'm quite fortunate with being a charge nurse because obviously in that role and in our environment, our opinion is valued and listened to" (Melissa).

When examining process, breaking down what is taking place into sub-processes can be assistive (Corbin & Strauss, 2008). Sub-processes are concepts that act to highlight in greater detail how the overall process is conveyed. The five sub-categories that were integral to the formation of the theory of experienced understanding comprise concepts and dimensions.

Diagrams

The use of diagrams to present information is a well-recognised tool in grounded theory's tool kit. They can assist with showing where the researchers' thinking is going, and the steps they took to reach their conclusions. Diagrams help with abstraction, supporting written text to explain complex relationships between categories and how they relate to the overall theoretical explanation. Corbin and Strauss (2008) advocate for the use of integrative diagrams at the researchers discretion; as a preference or because they are a visual individual who finds that using a diagram is more helpful than writing a narrative to explore and explain categories. They recommend diagrams not become too complicated, requiring a lot of accompanying explanation to highlight the focus. Digging into the details remains a task better suited to writing.

Strauss (1987) outlined a number of “rules of thumb” when it comes to using integrative diagrams. While undertaking this research I referred to these regularly as I began to employ diagrams to further analyse and present my findings. Rules one and two in particular, according to Strauss were motivational in nature and provided encouragement that the process I was describing was both important and interesting. These rules discussed how integrative diagrams help with seeing where you have come from in your research, while simultaneously gaining an understanding about where to go next. A loss of perspective became a familiar feeling, while working with grounded theory and symbolic interactionism. Referring back to the works of Strauss and Corbin, Corbin and Strauss, Strauss, Charmaz and through regular contact with my supervisor, kept me from staying lost for too long.

The work of Scott and Howell (2008) was of considerable assistance when it came to adding depth to my analysis, through the provision of two practical frameworks; the conditional relationship guide and the reflective coding matrix. Established by Scott (2004) as tools to support grounded theory analysis, they were both solidly based in traditional grounded theory created by Glaser and Strauss, (1967) and Strauss and Corbin (1998). The conditional relationship guide draws upon Strauss and Corbin’s investigative questions of: what, when, where, why, how and with what consequence/s, likening the researcher to a journalist or detective. The creation of a conditional relationship guide is a method that helps uncover the patterns, which contextualise the central phenomenon including the “relationships among the categories from which those patterns are constructed” (Scott & Howell, 2008, p. 4). Once this guide has been assembled the researcher is then able to compose a reflective coding matrix, which as McCaslin (1993) articulated moves toward a narrative and developing theory, which is represented illustratively in a conditional matrix. I found Scott and Howell’s (2008) approach relatively intuitive to apply to analysis, with the coding matrix following a set of steps that facilitated organisation and presentation of findings into a configuration, where the connections between the categories could be appreciated. I used one conditional relationship guide and five reflective coding matrices as part of my analysis process in this study, and these all feature in the findings chapter of this thesis, beginning on page 57.

Open coding

After conducting my first interview I began to analyse the printed transcript. Analysis and coding of data occurs across three stages: open, axial and selective coding (Starks & Brown-Trinidad, 2007). Open coding involves comparing, examining, categorising and conceptualising data (Strauss & Corbin, 1998). Commencing data analysis as soon as data collection begins is a key tenet of grounded theory. The initial part of this process involved preparing the document for annotation by creating a wide right hand margin on the page. Continuous line numbers enabled me to keep track of codes once I began to analyse multiple transcripts. I started by coding paragraphs; this gave me a good grounding in what was being said across the interview and revealed area to explore or gain clarification in from subsequent interviews. For each line a code was assigned describing what was being

expressed in this piece of text (see Table two below, for an example). These codes were written using gerunds to help their creation flow. A gerund is “a verb form which functions as a noun, in English ending in – *ing*” (Compact Oxford English Dictionary, 2005, p. 422). After each transcript was coded using this method I up lifted the codes and presented them in individual word documents, which together with memos represents the thinking aspect of grounded theory. By doing this I was able to maintain a clear perspective on how my analysis and thinking were progressing.

Gerunds support grounded theorists to look for actions when coding, allowing both collective and individual examples to become visible while helping to define action, through the excavation of both codes and the data they were derived from and, what gives grounded theory methodology its uniqueness (Charmaz, 2011). In my initial coding outlined above, the use of gerunds kept the data I was collecting in perspective, supporting large quantities of information to be broken down into manageable pieces. My introduction to this grounded theory analysis tool came via my primary supervisor, who encouraged me to employ it after completing my first interview.

Codes were taken from the data and by asking what is happening here? They were also formulated through the researcher’s nursing experience and thinking about clinical situations that related to what participants were reporting. For example the work I do as a resuscitation education facilitator, involves working with groups of nurse’s undertaking simulation. A common occurrence during a simulation involving a deteriorating patient who then progresses to a cardiac arrest, is the challenges the simulation participant’s face in organising themselves to function as an effective team, when they often don’t know one another. Once they begin to speak with each other, allocating roles, identifying the priorities that need to be addressed for a patient who is deteriorating, or who has had a cardiopulmonary arrest and creating a plan to solve these, this effectiveness becomes evident.

Table 2: Open coding

Raw Interview Data	Open Codes
<p>And also in this ICU in particular, there’d be very few consultants... there’d be nobody in the medical team that I wouldn’t feel happy going up to and saying, “I’m not happy about this decision; can you go through it with me again? Can you explain why this end point has been reached?” I think most of the nursing staff would be really happy to discuss that with the doctors and if they weren’t there would definitely be a senior staff member that they could go to and say, “I don’t feel comfortable about this.” I think it’s really important that the entire medical team, both medical and nursing, feel comfortable about that decision before it’s broached with the family. (Rebecca)</p>	<p>Feeling Comfortable Being Approachable Speaking Up Seeking Clarity Having Senior Support Being in Agreement</p>

Line-by-line coding was undertaken, with codes being assigned at the paragraph level. While some grounded theorists advocate a more micro approach to open coding, it is not essential. Coding line-by-line and paragraph by paragraph straight from the transcribed interview documents yielded large numbers of codes, which allowed for categories to be formed based upon similar occurrences in the data being brought together in the one place. This enabled conceptual labels to be generated and I was able to gain new perspectives by thinking outside the box with regard to the phenomena under examination (Corbin & Strauss, 1990).

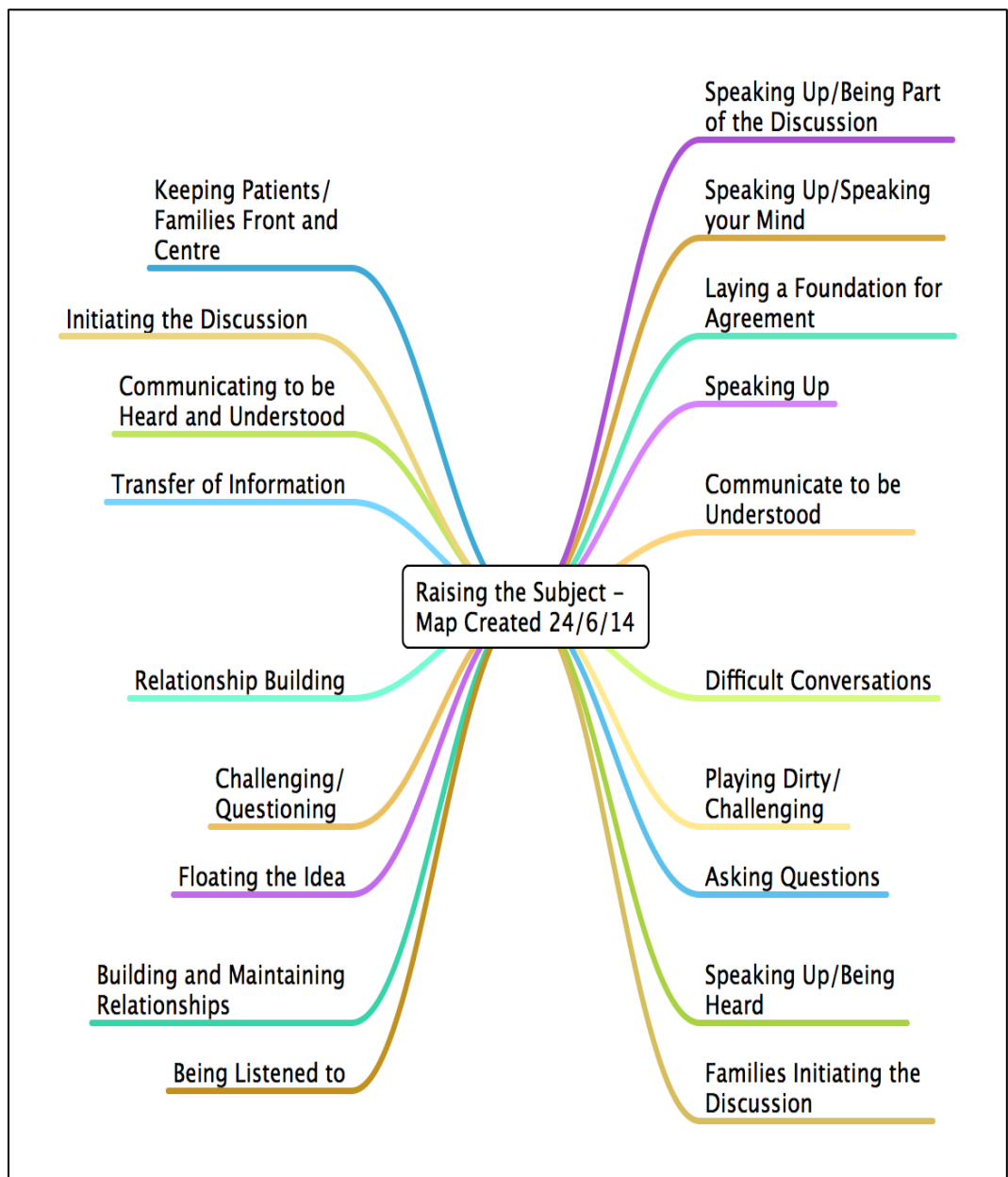


Figure 1: Demonstrates the use of MindNode to bring open codes together in one place to form a category

Axial coding

Axial coding is concerned with rebuilding data into clusters based on patterns discerned from the categories found in the data (Strauss & Corbin, 1998). Mind mapping using a piece of software called MindNode allowed me to see the codes I was writing from a different perspective (see Figure one). As I continued to place like codes into group's categories began to form. On completion of the process, five categories had emerged that clearly explained the process '*Experienced Understanding*'. Categories and their relationships to the codes from which they are derived are tested against their appearances in the growing body of data (Corbin & Strauss, 1990). After each interview was transcribed open coding would be completed with codes then being allocated to the clusters they were analytically compatible with (see Table three, for an example).

Table 3: Example of axial coding

Raw Data	Category	Open Codes
So the actual withdrawal of interventions like ETT and the withdrawal of blood pressure support, those need to be managed by I would say senior nurses rather than junior nurses who haven't seen this a million times and know what to expect and haven't prepared the family, because that can change somebody's experience for life of what can be a reasonably pleasant... I mean, it's never pleasant when somebody dies... but what can be a reasonably calm experience in comparison to what can be traumatic for people. (Adrienne)	Support + Looking Back = Experienced Understanding.	Support: Being Supported. Accessing Senior Help. Looking Back: Having Experience of Death. Drawing on Experience.

Selective coding

During selective coding the researcher recognises and describes the core category found in the data (Strauss & Corbin, 1998). Theory is generated once this process has been completed with the core category pulling together all concepts drawn from the data, in order to propose an explanation of the phenomenon under examination (Goulding, 2005). The theory is then written up and combined with existing theories to demonstrate relevance and fit (Goulding, 2005).

Memos

Writing memos as part of the data analysis process is an important component of grounded theory methodology. After completing an interview part of my initial analysis involved taking a paragraph of transcript text, and writing a memo that adhered to the conventions recommended by Corbin and Strauss (1990). Memo writing according to Corbin and

Strauss acts as a system through which aspects of the analytical process, such as category development and methodological questions can be kept organised and accessible. These grounded theorists state that the use of memos are not just a mechanism for recording “ideas”, but are an integral part of theory formation and revision. They caution researchers that if memoing is not undertaken when analysing data, a significant amount of useful information may be lost or the emerging theory lacking in depth.

My experience with this grounded theory procedure was valuable. It assisted me in performing manageable blocks of analysis, while creating a record of where my thinking was during this time. As the number of memos increased, I began to print copies, attaching them to the walls of my study for easy reference. The process of writing focused accounts of particular aspects of my analysis; acted as a form of documentation, tracing the progress my thoughts were taking (Montgomery & Bailey, 2007). While the memos I wrote often-varied in length they remained an important reflection on the conceptual speculations I was making (Montgomery & Bailey, 2007). Utilising memo writing as an analysis tool facilitated asking questions of the data, as discussed by Chiovitti and Piran (2003) and include: What is happening in the data? What does the action in the data represent? Is the conceptual label or code, part of the participant’s vocabulary? In what context is the code/action used? Is the code related to another code? Is the code encompassed by a broader code? And, are there codes that reflect similar patterns? These authors formulated these questions based on the work of Glaser (1978), Strauss (1987), and Strauss and Corbin (1990). I have one exemplar featured here and I have also placed a further example in the appendices of this thesis. It was written during analysis of Holly’s interview transcript, prior to pseudonyms being assigned. It examined the open code “being heard” and highlighted the style used to structure my memos.

Date Memo Started: 06/10/2013

Nurse 01

Code: Being Heard.

If you had a patient that's becoming rapidly unwell or you can see a deterioration, or the prognosis is looking quite poorly, we have ward rounds twice a day at least, if not more, depending on the patient you've got, and sometimes at the beginning of the ward round we get asked our opinion as nurses, "How do you feel the patient's going?" You can voice your concerns or your worries and at times, when the patient's been deteriorating and things aren't flash, you can voice that you're quite worried and don't think they are progressing very well.

Memo:

In the opening section of transcript text the word "*becoming*" is used ahead of "*rapidly unwell*" which invokes a sense of fast moving change. In my clinical experience a patient's status can change both quickly or slowly for a variety of reasons, with or without warning. The ongoing 'shifting sands' feel of a patient's level of un wellness can invoke a sense of powerlessness or inevitability, particularly if all the stops have been pulled out to treat them. In the critical care setting people are admitted who are already considered very unwell and a worsening of this status would I imagine produce unique challenges?

So what are the parameters of being unwell in ICU? What factors come into play to determine this? My experience informs me that diagnosis and co morbidities play a significant role in recovery, along with response to treatment. More elusive dynamics such as family presence and a 'will to live' may also feature.

Who notices these changes? Who processes, interprets and understands their significance and their ultimate meaning? My understanding is that in ICU patients are cared for by one nurse (a 1:1 patient ratio). Therefore a nurse is ever present at the bedside. Such a constant presence makes for a position of constant observation.

"*Becoming*," signals a movement towards a change. "*Deterioration or the prognosis looks quite poorly*" hone in on a state the patient is in that may require asking difficult questions around where do we go from here? Nurse 01's comment that ward rounds occur twice a day at least speaks to the existence of a pre planned structure in which all patients are seen a minimum of two times. Is this within a 12 or 24-hour period? During a round in a ward setting the treatment a patient is receiving is looked at, along with their response to this. How they are managing with their Activities of Daily Living (ADLs) is assessed. What impact is their illness or injury likely to have on them once they leave hospital? For people who are deemed to be dying such conversations will necessitate a different focus. Are there circumstances where a medical review would take place outside of this pre-determined schedule?

Nurse 01 goes onto elaborate that rounds can occur "*more depending on the patient you've got*". Does this indicate that the more complex a patient is, necessitates further input and problem solving? Who are the people that make this decision and what sort of processes

are followed? The level to which nurses are included in a round appears to fluctuate in the critical care setting. What therefore are the variables that come into play here? Different clinical areas approach this interaction in differing ways: for example I have experienced complete inclusion and the voicing of my opinion as a given. To virtually no involvement as rounds were seen as the domain of the charge nurse or second in charge. The phrase *“and sometimes at the beginning of the ward round we get asked our opinion as nurses, “How do you feel the patient’s going.”* Raises an array of questions around what constitutes *“sometimes”* and how a nurse’s opinion is received and taken into account, with regard to the patient’s ongoing management.

Summary

In this chapter, how grounded theory and symbolic interactionism have been utilised in this study was discussed, in conjunction with detailed descriptions of the methods used and their application. When writing this section my aim was to show the reader how I went about conducting this research, providing an easy to interpret blue print for other investigators to follow, should they wish. Grounded theory research is comprised of a number of essential elements: purposive sampling, the manner in which coding is undertaken, maintaining rigour and how data is obtained; in the case of my study, via interviews. The researcher enters the field of study with an idea of what they are researching, and their knowledge grows as the study continues, data is analysed and codes and concepts become categories and a theory. As Jeon (2004) succinctly stated, “... the task of the study is to discover what is going on in the processes through which...” (p. 251) critical care nurses influence end-of-of-life decision-making and care. Ethics approval for this study was granted by AUTC on the 11th of July 2013, reference number 13/130.

Chapter Four: Findings

Introduction

In this chapter the findings of this study will be presented by way of five sub categories; raising the subject, working the problem, making the transition, time/timing – getting it right and a good death is dying well, which are interlinked and form the core category and explanatory theory of '*Experienced Understanding*'. Over the course of this analysis using grounded theory methodology, these five sub categories have been built, and together explain the process involved in how critical care nurse's influence and shape end-of-life decision-making. As these categories came together it became increasingly evident that decision-making at the end-of-life encompassed more than the decision to discontinue treatment. It involved the conversations that take place, which define how end-of-life care will be managed. End-of-life decision-making and care are interlinked and my findings show how intensive care nurses are important to the former, and indispensable to the latter. Figure two below shows the five sub categories as being interlinked, with each one providing support to the other.

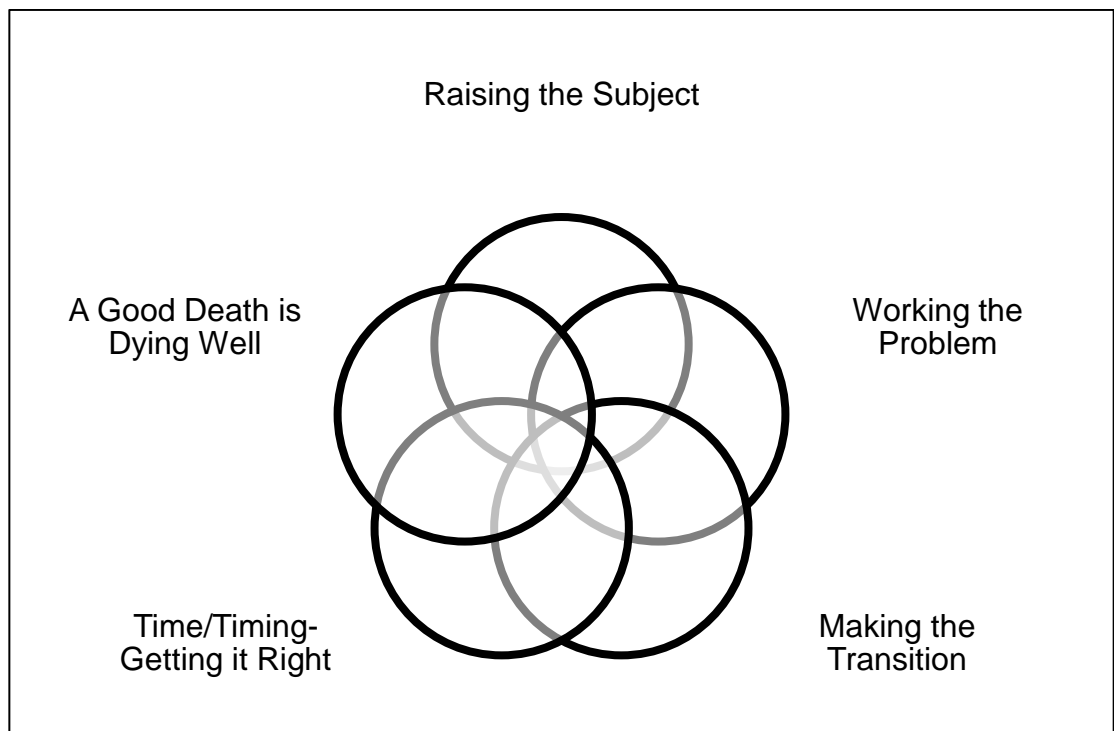


Figure 2: The five sub categories as interlinked concepts

Table four shows how I used a conditional relationship guide (Scott & Howell, 2008) to explore the relationships between the five sub categories. Columns are intended to be read horizontally.

Table 4: Conditional relationship guide: Asking questions of the categories

Conditional Relationship Guide						
Category	What	When	Where	Why	How	Consequence
Raising the Subject	"Speaking up"	During severe illness or injury If concerned	In the patients bedspace At handover In family meetings	Dignity is compromised Patient is not responding to active treatment "Death is not a failure"	Straight talking Planting the seed Keeping communication open	Accountability
Working the Problem	Evaluating Assessing	During treatment	In raising the subject In discussions with colleagues	Because continuity of care has value	Asking questions Being on the same page Being listened to	Consensus
Making the Transition	Withdrawing treatment Moving to a side room	Working the problem	In the side room	Enables end-of-life care to commence	By switching off the monitors	Realisation
Time/Timing – Getting it Right	"That's a time when they can prepare"	Raising the subject Working the problem	During interactions with family	Time is a precious commodity	Negotiating	Coming to terms
A Good Death is Dying Well	"Free of pain" "Surrounded by things that are special to them"	During palliative care Withdrawal of treatment	All nurse/patient interactions	Avoiding pain and suffering Personal and professional experience	Providing adequate pain relief Facilitating privacy	A good death

Raising the Subject

Introduction

Critical care nurses who choose to raise the subject of dying drew on strategies that would acquire a response from an intensivist. How fast this conversation was initiated depended on the individual nurse and the approach they chose to take, be it direct or indirect. As a category raising the subject is comprised of different conditions that demonstrate the developmental progression which lead to its formation, including planting the seed, recognising a crossroads, speaking up and influencing thinking.

Table five shows the formation of the sub category '*Raising the Subject*' along with descriptors that explain its role in the formation of the core category '*Experienced Understanding*'. Columns are read across and then down.

Table 5: Reflective coding matrix: Raising the subject

Reflective Coding Matrix		
Category	<i>Raising the Subject</i>	
Process (Action/Interaction)	Planting the seed	Recognising a crossroads (Where to from here?)
Properties (Characteristics of the category)	Speaking up	Influencing thinking
Dimensions (Property location on continuum)	Initiating the discussion Resilience Rounds and family meetings Being direct or indirect	Being proactive Communicate to be understood Individual confidence levels
Contexts	Understanding the patient's wishes	Working as a team
Modes for Understanding the Consequences (Process outcome)	Everyone is on the same page	A clear plan

(Scott & Howell, 2008)

Raising the Subject: Recognising a Crossroads; Planting the Seed

In this section the actions of recognising a crossroads and planting the seed are explained, along with the conditions, which all promote these to happen namely, unlikely to improve, running out of options, advocacy and bringing the team together, all of which supported these interactions to occur. Figure three shows the links between raising the subject and these actions.

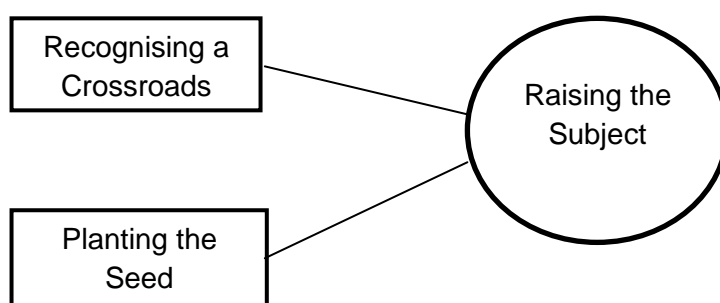


Figure 3: Process elements of raising the subject

Recognising a crossroads

Reaching a crossroads reflected a key motivator behind a nurse's decision to raise the subject to discuss end-of-life care. For the nurse's involved in the care of a patient who was not responding to treatment, there came a time where participants reported a need based on client assessment to ask the question; what is happening with this patient. Depending on the particular nurse, how this conversation was initiated, and with whom varied. The nurse at the bedside may opt to discuss this issue with an intensivist, an associate charge nurse, or float one nurse, all of whom are able to promote a discussion around the merits of moving to end-of-life care. The factors that play a part in prompting this decision included the situation where it is the belief that no intensive treatment will return the patient to their former selves. In others the driver was, we have tried, but now our focus needs to change and address the challenge of good end-of-life care.

For Holly caring for a patient who was struggling to respond to active treatment resulted in recognition that a crossroads had been reached, and raising the subject pertaining to stopping active treatment needed to be initiated. In this case the doctors and the patient's family reached a consensus once the severity of the patient's condition was verbalised. In this situation the nurse acted more as an observer, and did not actively need to raise the subject herself as the doctors and the patients family came to a decision to make the transition themselves.

I had a situation where a lady had a big cancer removed... she'd had skin cancer and it got into part of her jaw and they [the doctors] removed the first lot and then her wound broke down... They fixed it and then they found out later that they didn't get all the margins and it was in her bone. Her quality of life had been deteriorating the whole time during this process and so we removed it [the ETT]... she was... septic... They talked to the family... The family said, "Look, we think she's suffered enough. We don't want to put

her through this.” The doctors were actually quite good saying... “We actually agree with your wishes...” (Holly)

Reaching a crossroads and deciding to raise the subject did not always result in an immediate decision to make the transition to comfort care. Rather a period of working the problem was entered into, with further treatment options being discussed or embarked upon (see p. 67).

Planting the seed

Once a nurse recognised that a crossroads had been reached, planting the seed was a strategy utilised by some, and involved raising the subject of end-of-life care in an indirect way, thereby giving the doctor the impression they had the idea themselves, making them more likely to be open to the discussion. While teamwork and a collaborative approach to decision-making were evident throughout this study, an inherent power and knowledge structure existed between nursing and medical staff. Here Melissa provided an example where planting the seed was a strategy that RNs employed to become a part of the end-of-life decision-making process:

So, decisions tend to come, are more nurse directed, although we let the doctors believe that it's them. But it's quite good; I mean once you've been there a while you can sort of see that, “Mm, this person's not going do so well,” so you want to try and get them thinking about it a bit more... you plant little seeds... because obviously they need to feel like it's their idea. (Melissa)

Laurie contrasted Melissa's perspective, as she believed that nurses have limited decisional input, and that planting the seed, as a mechanism to raise the subject of palliative care did not categorically apply to all ICU RNs. Nurses could have a say if they chose, but doctors were not obligated to listen, unless they were seeking support for their point of view.

You might say how you feel, however, at the end of the day it's the doctor's decision... even if we said, “Hey, where are we going with this person at the moment?” I don't feel nurses have input into it. If the doctors have made a decision and they want a bit of backup, then they'll say, “What do you think?” but I don't think that nurses really do have much of a say. (Laurie)

Laurie went on to indicate that the decision-making was more of a joint collaboration between consultants. Rebecca reported that planting the seed takes place within each individual as they reconcile for themselves through conversations with their colleagues that a patient is not going to live. This demonstrated how symbiotic recognising a crossroads and planting the seed were, and that an RN needed to make a mental shift away from active treatment, to palliative care in order to raise the subject.

I don't know what other ICUs are like but certainly here it's a very open door policy and anybody can talk to anybody. So I think that's generally how a decision is arrived at – it's informal chitchat until it gets to the point where everyone's made a decision about it in his or her own heads. (Rebecca)

Raising the Subject: Speaking Up; Influencing Thinking

The characteristics of speaking up and influencing thinking are presented in this section, with their relationship to raising the subject demonstrated in figure four below. These property elements relate to nurses levels of self-confidence and experience, and the formation of professional relationships and trust.

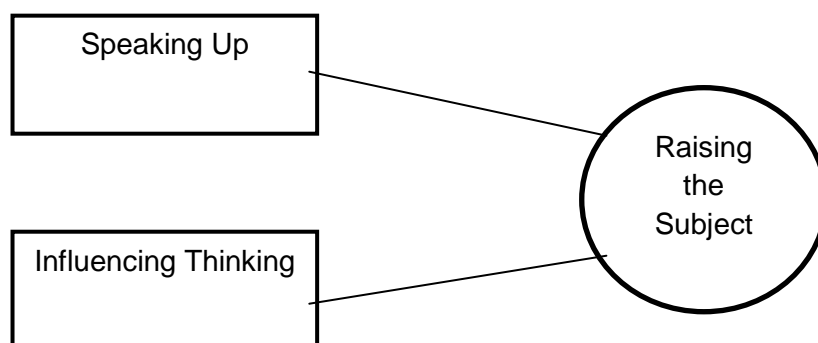


Figure 4: Property elements of raising the subject

Speaking up

Speaking up was a more direct way of raising the subject and was reported to correlate with a nurse's experience, and their professional standing with medical colleagues. Adrienne reported that being asked by a doctor for her opinion made speaking up more comfortable. She also articulated that experience had a role to play, the implication was that that this helps RNs build confidence, resulting in greater engagement and a readiness to be heard.

I think with regards to the decisions that are being made, on a day-to-day basis, the ward round takes place, and if we're thinking about end-of-life care for a patient the doctors will generally discuss it. So the doctor comes in, there's the nurses looking after the patient that day, and they discuss with that nurse and with the person in charge: These are our feelings. And, of course, if you've got a longer length of experience you're more likely to say: I think that's probably best for the patient or: Actually, I disagree... (Adrienne)

Speaking up involved nurse's understanding the dimensions of their patient's clinical presentation, "In terms of particular clinical indicators; sometimes you get a really bad gut feeling about people and sometimes it maybe right, other times it may not be right, but you still bring up the question" (Gerard). This contrasted with Gerard articulating elsewhere in his interview that a degree of uncertainty can also exist when deciding to speak up.

Melissa reported that for her speaking up was not difficult, particularly as a charge nurse, however she identified that for others, this was more of a struggle and Melissa attributed this to her colleague's perception that death is a failure, and felt more comfortable using a senior nurse as a proxy to raise the subject with a doctor.

... Some of the nurses in the bed space have to come through us first, or they won't speak up, obviously with being from different cultures and because of the hierarchy they don't tend to speak up. It's challenging... I feel very comfortable and don't see death as a failure, but not everyone is as fortunate to feel like that; they see death as a failure or that we haven't done enough. (Melissa)

Gerard also reported being co-opted as a proxy, in his capacity as an associate charge nurse manager, where becoming involved in raising the subject could arise from receiving an update on a patient from the nurse caring for them. This nurse might feel more comfortable having this conversation with a senior nurse, who they perceived would then raise the subject with a consultant. This approach was indirectly direct and meant that speaking up may rely on multiple individuals.

... I quite often have nurses on the floor saying, "What the hell are we doing here? This patient is going to die." After that conversation, I say the same thing to the consultant; I say, "Where are we going, what are we going to do with this?"... (Gerard)

Influencing thinking

Influencing thinking as a property of raising the subject brought planting the seed and speaking up together under the one umbrella. Ward rounds, which took place every 12 hours, acted as a condition where participants reported there were opportunities for the bed-side-nurse to discuss any concerns, or seek clarification around why a particular course of action was being pursued. "... If the doctor's come around and are setting limits or goals that are maybe unrealistic... You just mention 'well, what do you want me to do if they don't achieve that'..." (Ashleigh).

Reen reinforced the opportunity ward rounds afforded nurses to raise the subject and discuss with the doctors what was happening with their patients, and influence thinking regarding making the transition to end-of-life care.

... As the nurse at the bedside we're the ones that are with the patient all the time whereas the registrars, the consultants, they pass by every now and then or they're there during the ward round. So ward rounds are the time we give our impressions of what's going on with the patient – if we feel that they're improving, or not improving, what's actually happening, what may need to happen. (Reen)

Raising the subject via influencing thinking, benefited from the formation of partnerships between doctors and nurses and nurses and their patient's families. Such partnerships created an environment where discussing end-of-life with family members also set the scene for who had the overall say.

The family are generally pretty good; they'll say, "No, mum wouldn't want this at all," so then you form this partnership with the family about what needs to happen to move forward... "Look, this is not your decision; this is a medical decision," so they feel that it's your responsibility for turning life support off... "This is our decision at the end of the day but we'd like to make it in partnership with you so we're all on the same page." (Gerard)

Being proactive

Participants discussed that advocating for patients was an important part of their role. Being proactive and either planting the seed, speaking up, or influencing thinking were a part of raising the subject of end-of-life care was an initiative a nurse at the bedside was well placed to undertake, given their long periods of uninterrupted interaction with both the patient and their family. As such they are an integral instigator of this conversation, while also holding valuable information that can add to the depth of this decision-making process as Adrienne indicated here.

... With regards to nursing handovers and medical handovers we'll normally talk about this patient's looking unlikely to survive, or this patient's got a condition which they're unlikely to survive, or the actual outcome for this person would be so terrible that, depending on your beliefs, is it right to actually keep them going or would we be better to allow them to pass away with dignity? (Adrienne)

Not discussing end-of-life care could lead to a patient being treated indefinitely, ultimately dying while receiving full treatment. In some countries it is taboo to even raise the subject of death, meaning that patient's in ICU are not transitioned to palliative care, and are actively treated until they die. Rachel discussed this culturally different aspect of raising the subject, based on her experiences working in India and the Middle East. Nurses' who held the belief that withdrawal or withholding treatment was wrong, were reported by participants as having difficulty in raising the subject. No participants opted to participate in this study that were from the cultures that Rachel indicated.

Data analysis revealed that there were times when a patient's family raises the subject, asking about treatment decisions, or expressing that their loved one would not want to exist like this and requesting that treatment be stopped. One participant highlighted how there were times when family members might raise the subject by asking the question where do we go from here? Nurses were reported to be enlisted by family members to act as conduits to set up discussions with the wider team.

... We have had families that have come to us and said, "Look, I don't think he would like to be in this position," and we talk to the family and say, "We can organise a family meeting and then you can discuss that with the doctors and get the medical perspective on what's happening"... (Reen)

In this instance the healthcare team has to work through this decision with the family, ensuring they have a clear understanding of its implications. Having this discussion initiated by family members would potentially mean that the process of withdrawing treatment and commencing palliative care might happen more quickly than if these conversations are not held until the healthcare team is on the same page.

"I say the same thing to the consultant; I say, 'where are we going, what are we going to do with this?'... In ICU, especially our one, it's quite open and we can say, "I think this is futile; what are we doing?" (Gerard). The tone of this excerpt supported the thinking that this intensive care unit has a strong focus on bi disciplinary collaboration, either directly or indirectly.

Making assessments regarding a patient's chances of survival required a reference point from which to begin. Experience in recognising the unwell patient, and an understanding of the pathophysiology behind illnesses and injuries, made being proactive and engaging in team discussions less intimidating.

... It's usually approached quite early. So with regards to nursing handovers and medical handovers we'll normally talk about this patient's looking unlikely to survive, or this patient's got a condition, which they're unlikely to survive... Usually starts between nurses and doctors and then we have the conversations with family... (Adrienne)

... I don't think this is working... we make a decision within the team, like this is what it is – nothing is working, nothing is improving and prolonging is going to prolong his agony and it's an irreversible change... (Rachel)

Adrienne and Rachel both made similar observations here, regarding what was happening with the patient. Adrienne highlighted that this discussion occurs early, between nurses and doctors, with a variety of aspects of a patient's presenting condition and treatment being assessed.

One participant reported how a condition of being proactive involved the consultant group providing decision support to one another, and would discuss amongst themselves making the transition to palliative care.

It's generally a discussion that's had between two or three consultants; it's not one consultant's decision unless it's the middle of the night. They would all sit down on the couches and say, "Hey look, I want to discuss this patient. I think where we're going is futile, this is the situation"; all the other consultants will look at it and give advice... (Gerard)

However, within this collaborative sphere, disagreement could occur, with consultants being at odds with one another regarding a patient's ongoing management. These active discussions were reported as resulting in all aspects of the decision being examined and a collective outcome reached.

I can think of a consultant from a different cultural background who felt that a patient needed several days to recover after a cardiac stunning, while the other consultants felt that given the patient's past medical history their quality of life, if they did recover would be rubbish. It ended up in a big discussion involving the whole consultant group and a collective decision was made, with family staying involved through the whole process. (Gerard)

Summary

Raising the subject is the complex interplay of conditions. ICU nurses, who were not confident to raise the subject directly with a doctor, would employ alternative strategies to have their voice heard, which included planting the seed and influencing thinking. Senior and/or experienced nurses were more likely, according to these findings, to raise the subject with a doctor and were also the people more junior, or less experienced nurses would access to have their voices heard. In the context of end-of-life decision-making my findings indicated that raising the subject may occur as follows: A nurse caring for a patient sees that they are not responding to prescribed treatment interventions. The source of this information is the patient themselves, gathered through the recording of vital signs, the assessment of physical appearance, previous experience caring for the dying and an in depth knowledge of what ICU treatments can achieve. The nurse then raises this directly or indirectly with the intensivist rostered on, or another nursing colleague. Strategies employed by individual nurses varied, depending on level of confidence, working relationships and strength of conviction. Ward rounds provided a twice-daily opportunity for nurses to engage with an intensivist, without having to actively seek them out. For those who found raising the subject of end-of-life care with an intensivist too intimidating, then accessing a senior nursing colleague was a legitimate alternative.

Working the Problem

Introduction

Working the problem comprised what nurse's reported they looked for, when formulating their opinion regarding a patient's chances of survival. During this phase, nurses were constantly gathering, collating and evaluating information about their patient. Responding to treatment, gut feelings based on experience and quality of life/functional status, all featured throughout the data. Interpreting the information through a humanistic lens required skill with both elements of the art and the science of nursing. Value judgments and an understanding of ethical principles are a part of this decision-making, even if participants did not articulate this. Participants talked of forming a picture of who the patient was without necessarily being able to confer with them directly. In this section the following concepts in relation to working the problem will be presented: Unpacking the options, measuring a life, riding the rollercoaster, a process of elimination, collaboration and refocusing attention.

Table six shows the formation of the sub category '*Working the Problem*' along with descriptors that explain its role in the formation of the core category '*Experienced Understanding*'. Columns are read across and then down.

Table 6: Reflective coding matrix: Working the problem

Reflective Coding Matrix		
Category	<i>Working the Problem</i>	
Process (Action/Interaction)	Unpacking the options	Measuring a life
Properties (Characteristics of the category)	Riding the rollercoaster Active problem solving	A process of elimination
Dimensions (Property location on continuum)	Collaboration Drawing the line	Refocusing attention Skill level Interpreting changes
Contexts	Severity of the situation	Building trust
Modes for Understanding the Consequences (Process outcome)	Striking a balance	Not responding to treatment

(Scott & Howell, 2008)

Working the Problem: Unpacking the Options; Measuring a Life

The actions unpacking the options and measuring a life are part of the process of working the problem, as shown in figure five below. They are comprised of the concepts doing the best for the patient, getting to know the patient, not simply focusing on age and quality of life.

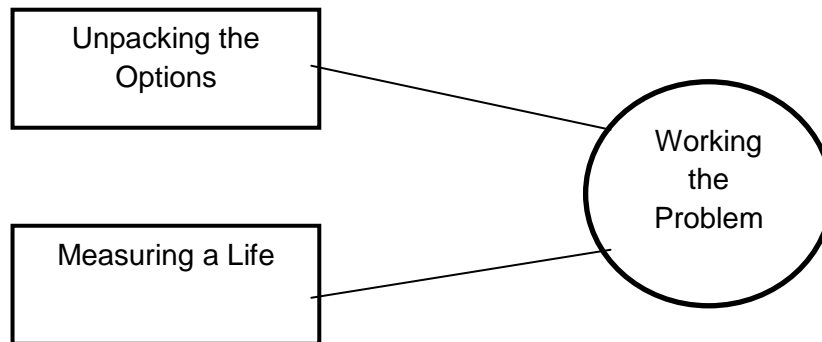


Figure 5: Process elements of working the problem

Unpacking the options

Once the process of working the problem has commenced due to a patient's limited response to treatment, a period of unpacking the options occurred. This involved holistically assessing the patient, their level of physical functioning prior to ICU admission, the likelihood that receiving full treatment will return them to their pre illness state and the wishes they had expressed on what they would prefer to happen, should they find themselves in this situation. This concept is not limited to weighing the decision to stop treatment and move to palliative care, but includes actions following the decision to raise the subject and the management of that decision.

When the two consultants discussed... how he [the patient] did over the previous night and the morning when the new doctor was coming on shift, and they talk and they discuss and see that in the last 24 hours I was here this is what's happening. The one coming on says, "Okay, let's see for the next 24 hours"... to assess what's happening... (Rachel)

Participants reported that the timing of withdrawing active treatment was unique to each patient and their situation. The intensivist may decide to pursue treatment interventions for a set period of time, monitoring the patient's response and any lasting changes. If it became clear that these were not having the desired effect then this prompted raising the subject. Therefore participants reported maintaining a patient's comfort and dignity were key goals when navigating working the problem. As reported later in this chapter, timing and getting this balance right with regards to how long the working the problem phase should continue, saw RNs drawing on their experience to keep the patient front and centre, while acknowledging family members need to come to terms with what was happening.

Once that clarity is there [the decision has been made to make the transition] it's such a nice process because then you've got the time to make sure the patient and the family are looked after in a holistic way. You can make sure they've got cups of tea and

everybody's around and the patient is kept nice and clean... and it's treating them with dignity and respect. (Ashleigh)

Unpacking the options was reported to involve managing active treatment interventions and monitoring patients responses. This acted as a process of elimination that in some cases resulted in RNs raising the subject of palliative care, if a patient was not improving as a result of these interventions.

So he came in and he had a hypoxic brain injury and he had myoclonic jerks and he was basically a vegetable; there was nothing that we could do... I'm looking after a patient and they need their Norad [Noradrenaline] to go up, and say you're already on 45 mic's [micrograms] and in half an hour you're up to 60 mic's of Norad. And you would ring the doctor and say, 'seriously? We're on 60 mic's of Norad, what do you want to do now'? If someone [a patient] has been in the unit for a couple of months, which happens on occasion, and they've just had infection, after infection, after infection... (Melissa)

In the scenario above the patient was experiencing a complex health problem. It became apparent while reading and re reading these narratives that patients were like a mathematical problem. Some were more difficult to solve than others, while every so often one appeared to be unsolvable. Therefore, instead of spending a limited time pushing to solve the equation, an alternative approach was raised, that of transitioning to end-of-life care.

The participants reported struggling with the patient's options and their responses reflect the thinking that goes into working the problem. The idea of keeping a fellow human being alive, after experiencing an event from which they will never recover, cuts to the heart of this study. For a nurse working in ICU, being able to balance the reality of caring for people in an environment with so much lifesaving technology, and know, yet despite this, many were unlikely to survive, would be a mammoth challenge. For example, recognising indicators of poor response for Reen was an assessment skill honed by experience. "Yeah, experience does come into it a fair bit. You just see on the monitors, the numbers on the monitor just don't seem to be improving" (Reen). Reen goes onto explain that seizure activity is also an indicator that relates to poor prognosis, in relation to hypoxic brain injury, "you see spasming, having seizure activity which... from past experience I know that's not a good sign as far as brain activity goes" (Reen).

Melissa reported that when it came to understanding what the clinical picture was adding up to, reference points were needed. To contextualise what these pieces mean in relation to one another requires clinical experience or input from others.

... "They're going to withdraw treatment on them, but they squeezed my hand when I did my neuro obs" [neurological observations]; you would actually look at the nurse and their level of knowledge to see whether it was a reflex, which it more than commonly is, or whether it was an actual improvement, which does happen; not very often and normally it's just a minimal improvement before they go downhill again. (Melissa)

Measuring a life

Measuring a life reflected the enormity of how to decide whether a person was going to benefit from the treatments they were receiving. This dimension of working the problem

involved the pieces of information that are put together in order to gain an accurate picture of the individual lying in the bed. The discussions pertaining to this that have taken place throughout the interviews, have examined quality of life prior to admission. RNs engaged with this aspect of working the problem by understanding their own perspectives, and how these acted as filters through which they processed the information available to them. How patients family/whanau reacted to a dying loved one, also impacted these RNs approach.

... Her heart wasn't coping. And so I think the family were very brave in their request because the husband was absolutely devoted to her, but he did not want her to suffer and I think that was very brave of him to do that... (Holly)

Determining a patient's quality of life is not an exact science, and is predominantly a value judgment. Rebecca reported that for her, age was not a determinant when learning about the life a patient had lived, up until this point. Age was taken into account as part of a broader whole person approach.

For myself the reference point for quality of life is what they were like beforehand and how their family and friends perceive their quality of life, because you can't go on age alone; you may have a 30 year old who's got a really poor quality of life because of different disease processes, either physically or mentally, and who is not enjoying their life; and then you may have an 89 year old who may be physically frail but might be fully involved in all facets of life. (Rebecca)

Within this critical care unit while age was not seen as an appropriate independent indicator of whether to raise the subject of palliative care, as part of working the problem, one nurse reported that when she had worked briefly in Vancouver, Canada age was no limit to the level of care provided.

It's really interesting because I remember in Canada I was really shocked in a spinal unit over there. I was on a sabbatical for three weeks in Vancouver and a patient was in the unit who was in there 90s and had fallen off a roof and had a high cervical spine injury, fully dependent and on a ventilator. Well here [New Zealand] we wouldn't treat them; we wouldn't even admit them... I must admit I do get it here, I do understand. I think it's a better approach personally. I just think why go through all that just to make the family happy and the poor patient... it's not a dignified death. I actually prefer the way that they do it here. You've got to have dignity when you die. (Ashleigh)

Patient's, who are unable to tell their story due to intubation, rely solely on the information provided by family members to assist nurse's in gaining an understanding of who they were caring for. While this may be an informal process, all parties involved were vulnerable to the pressures of making the best decision they can make here, with many factors being taken into consideration and interpreted through different lenses. Participants reported there was a risk that nurses and family members could end up at odds with each other if the reasons for seeking information regarding a patient's life prior to admission were not clearly discussed. Family members might see this as their last chance to advocate for ongoing treatment, while nurses want to piece together who their patient is, beyond just another disease process or injury. As Rebecca observed when it comes to making the overall decision as to whether a patient is for end-of-life care, she is glad this is not her responsibility. "I'm just really pleased that I don't have to make that decision because it's a horrible decision to have to make..." (Rebecca).

Working the Problem: Riding the Rollercoaster; A Process of Elimination

The characteristics of riding the rollercoaster and a process of elimination are presented here, and consist of nurses supporting families to understand what is happening for their loved one, planning treatment withdrawal, being present for family meetings, providing information, listening, pacing, communicating effectively and understanding the patient's wishes. Figure six below highlights the links between this sub category and these property elements.

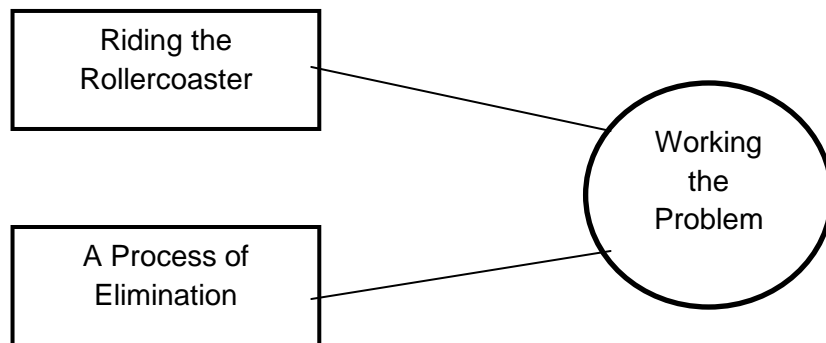


Figure 6: Property elements of working the problem

Riding the rollercoaster

Riding the rollercoaster related to relative's levels of understanding about what was happening to their loved one, and the role nurses played in achieving understanding that a shift away from active treatment was coming.

... Also the length of time in which they've been in the unit; especially if they've gone from bad to good, to bad again; and they've seen [the family] how much of a journey it was to go from bad to good and then have bad again with no reserves left. (Melissa)

An option within the context of deciding that a patient needed to be transitioned to end-of-life care was while no additional treatments were to be started, existing ones may be withdrawn over a negotiated period of time. For example, the weaning of noradrenaline, a drug used to support blood pressure, could be interpreted by family members as their loved one improving. These micro rallies could be confusing if the nurse in the bed space was not able to provide a context for why these actions were occurring. That they didn't necessarily signal a turnaround, but are a component of the dying process, was key information that participants reported needed to be discussed.

... You will have a patient's family that comes in and can see for themselves that the situation is not good. But then you will come in and you will have other families that will hang off absolutely every word that you say, and because our nurses are not comfortable with saying "There is a strong possibility he may die," and instead they say "Oh he's very unwell" and they end up with this false hope. You might turn the patients Norad [Noradrenaline] down and it doesn't matter that you had turned it up within the last little while... they fixate on that. "But you've turned his Norad down, he's getting better." It's different from family to family. (Melissa).

Family meetings were a mechanism by which family could be updated on progress and ask questions. Participants indicated these meetings were a time for families to receive updates, clarify expectations, and have both the nurse and the intensivist in the same space at the same time. Additionally, family meetings were a forum within which raising the subject could occur, with family members being guided through why the focus on attaining a cure was going to change.

... That's one thing our doctor's do extremely well is provide family with regular updates. There's always a first family meeting to say "Hey things aren't going well," and whether this is at the bedside with key family members or whether it's in the whanau room where they have a discussion, and it's normally with the consultant... and the nurse who's looking after them... They do it in such a way that although they have made the decision that this patient is going to die, the family feel part of the decision-making and feel that they are actually releasing that person from their agony, even though it wasn't their decision. (Melissa)

While nurses perceived their input during these meetings was often minimal, they recognised the importance of being present to act as a buffer, translator and witness to the conversations. How regularly these meetings took place was based on need and where on the death trajectory the patient resided. Outside of the family meeting relatives would often have more questions that they sought to have answered by the nurse at the bedside. It was important therefore that the bedside nurse be supported to take part in these meetings, so they knew what had been discussed. "... You have to be really diplomatic and really careful with what you say. You have to listen. That's the biggest thing..." (Holly).

Support to attend family meetings was facilitated by either an associate charge nurse, or a float nurse. The allocation of a family spokesperson was reported as an effective strategy to keep information flowing outside this forum, promoting continuity of communication; "...Generally we let them come to us... and ask questions... but we'll definitely try to clarify things as well, make sure they're okay. And generally there's a spokesperson; that you've had dealings with quite a bit" (Laurie).

For some families once the subject of changing focus to end-of-life care was raised, a period of coming to terms was entered into, and facilitated by the healthcare team through a balancing act of getting the timing right regarding making the transition.

... Some people will be accepting that, okay, yes; I can see that it's not looking good. And others will be... some families often ask, "Can we wait another 24-48 hours?"... You have a mix of family; some are accepting straight away, "Yeah, they've had a good life. They wouldn't want to be like this. Just let them be." And others are like, "No, I'm not ready. Can we try a little bit more?" (Reen)

A process of elimination

Deciding whether or not a patient is responding to active treatment is not exacting, and can vary from patient to patient, which means making the decision to commence end-of-life care can be fraught with ambiguity. Participants reported that consistent communication particularly with family members was an important part of this process. "Communication is absolutely key...and documenting exactly what you communicate. There's been an

improvement with the doctor's actually documenting what they communicate in family meetings; since we started the Pathway" (Melissa). Many participants cited the introduction of a modified LCP as a valuable addition to how end-of-life processes are undertaken in the unit. Conversations with family members, to discuss their loved ones treatment options were guided by verbal and physical cues and what their expectations were. This required nurses to gauge each situation as it occurred, and judging how ready families were to have this difficult conversation.

If it's a family where they expect the medical professional to know the answers and not waiver the discussion takes place on a different level... they [the doctor] might be a bit more didactic and say, 'this hasn't worked, let's try this; it still [might] not work but let's try it. (Rebecca)

Rebecca contrasted her above quote, when she later reported what happened when a family understood "that it's a process of elimination and something might work for some people and not for others...'this hasn't worked so we'd like to try this and there's a possibility that it might work or it might not'... involving the family in the decision-making process". Examples of active treatment included mechanical ventilation, inotropic support, intravenous fluids, parenteral feeding, dialysis and other complex therapies. Participants reported that discussions within the team were positioned to reach a consensus:

Everyone has to be really comfortable on the healthcare team before that's broached with the family. I think having all round discussions makes sure that there's no stone unturned and that everyone is comfortable, and if someone says, "We haven't tried this," and, "Do you think we should try this?" people discuss it and it's either decided, no, we have tried it, or, no, I don't think it's going to work, or, okay, well let's give 12 hours of that and see what happens... If we get to the point of end-of-life discussion, then everybody is comfortable with the fact that everything's been tried and discussed. I think that's really important. (Rebecca)

The patient themselves provided indicators as to whether or not they were responding to the interventions being undertaken. Family members were also able to offer insights into what their loved one may or may not want.

We might cap inotropes and if they're not flying and they've been there for a while or they're not responding to treatment then we need to look at what we're going to do next. And usually the family give you some input regarding how that person would want to be... And I think nurses and doctors have their own opinions and we think, oh, we should do this or we shouldn't be doing this... (Laurie)

Summary

Working the problem describes how critical care nurses manage, on a case-by-case basis to use their experience in pursuit of solutions pertaining to when and how to raise the subject. To judge for themselves whether a patient needed to make the transition from active treatment to palliative care. Working the problem is interlinked with the sub categories of raising the subject, making the transition and time/timing – getting it right.

Making the Transition

Introduction

The aim of this section is to present the sub category making the transition. Once the stages of raising the subject and working the problem have been progressed through, and the decision made to withdraw active treatment, the process of transitioning to end-of-life care commences. However, all three of these sub categories overlapped at times and were strengthened by this interlinking, and the experience many of the participants brought to the situation.

Table seven shows the formation of the sub category '*Making the Transition*' along with descriptors that explain its role in the formation of the core category '*Experienced Understanding*'. Columns are read across and then down.

Table 7: Reflective coding matrix: Making the transition

Reflective Coding Matrix		
Category	<i>Making the Transition</i>	
Process (Action/Interaction)	Changing the physical environment	Shifting from active treatment to palliative care
Properties (Characteristics of the category)	The death and dying room	Withdrawing treatment
Dimensions (Property location on continuum)	Privacy Flexible visiting hours Increased visitor numbers	Pulling back in stages
Contexts	Acknowledging death	A different focus
Modes for Understanding the Consequences (Process outcome)	A more personal setting	Dying well

(Scott & Howell, 2008)

Making the Transition: Changing the Physical Environment; Shifting from Active Treatment to Palliative Care

The following section reports on the actions of physically changing the environment, which occurs once a patient has been made for end-of-life care, and how nurses manage and guide the process of shifting from active treatment to palliative care. These elements facilitated the provision of greater privacy, a more constant family presence, being a part of care and the journey from one part of the unit to another. Figure seven depicts how these two actions are linked to making the transition.

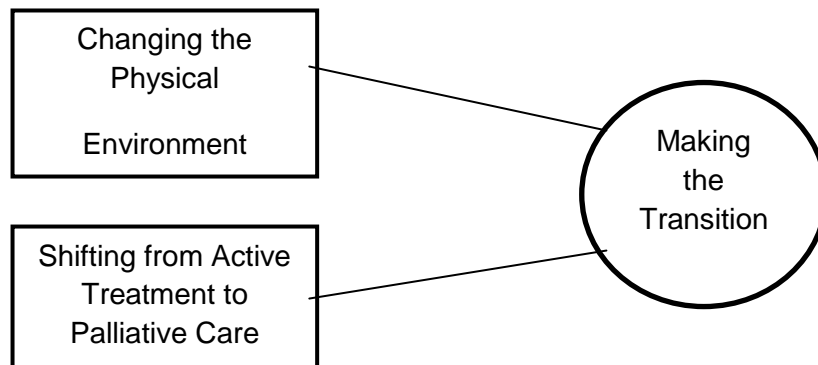


Figure 7: Process elements of making the transition

Changing the physical environment

A significant aspect of making the transition involved a physical change of environment for the patient; within the intensive care unit, from the main open plan area to a side room. Moving the dying patient into a side room was recounted in a number of interviews, and seemed to be an important part of making the transition. One nurse referred to it as the “death and dying room”. The importance of this space was reported in relation to increased privacy, families having more sustained access to their loved one and to protect the other patients in the unit from the dying process.

It means we can provide an area for family to come and go as they please, open visiting, they have access to tea and coffee and the nurse is still present all the time, as much or as little as the family like. The nurse will sometimes sit outside the room with their notes and just go in and do personal cares and check on the family, and see how everybody is. At other times it depends on the relationship the nurse has built with the family, or if the family are nervous about being alone with somebody who's dying, and you just judge that on an individual basis. (Adrienne)

Gerard reported that caring for the dying patient in the side room facilitated supporting the entire unit through this process. Greater access for family members and the promotion of connectedness had a positive impact on the other patients in the unit, who may be uncomfortable being in such close proximity to death.

It takes it away [death] from the main floor where there are eight patients and if you want to sing or wail, or do whatever you want it can be very upsetting for the other patient's families whose loved one is going to be okay... It's a chance to move to a private area

where you can come and go; you can sleep overnight and just spend time with your relative. (Gerard)

RNs had an important role to play in meeting everyone's needs as palliative care was initiated, and I logically derived during analysis that previous experience caring for the dying informed this sensitivity, to provide privacy that was beneficial for the whole unit.

It's a good idea, not just for the family but also for other members of the community in critical care. It's upsetting when you know that somebody's passing, you don't want that for everybody to see because it freaks all the other patients out. (Ashleigh)

Once the decision had been made that a patient was for end-of-life care and moved into the side room, additional care needed to be taken if not all family members were aware of what was happening, and what making the transition signified.

The patient's partner arrived and no one had told her. God, it looked like he was going to die any minute and his partner didn't know so she was in shock... We found out that she didn't really understand everything that was being said, because English was her second language and she was getting other people to interpret words she did not know, and she had not let us know. She hadn't been to all the family meetings because the patient's son and daughter had not told her they were happening. (Holly)

As part of the transition process, the patient's family are also made aware that their loved one could die during the transfer. Nurses would work together as a team to make the transition a logistically well-run undertaking.

We always warn the family that sometimes the patient might die in transit, because just disconnecting [from the ventilator] and putting a patient onto an Ambu bag [bag-valve mask] so you can move them round the corner could precipitate this, and you need to prepare family for things like that... You find it's a quiet time. It's a time where people just get on with it. There's not a lot of conversation. Everybody seems to know what their job is and what to do. (Adrienne)

The act of physically moving a dying patient to the side room, accomplished two goals. Firstly it created flexibility around friends and family visiting. The term "open visiting" referred to multiple people being able to visit at the same time, at anytime of the day. Secondly the open plan design of the unit meant that large numbers of visitors could be disturbing for other patients, hence the practical element afforded by the side room.

Shifting from active treatment to palliative care

Making the transition also involved the cessation of active treatment and the commencement of comfort care. Melissa reported that during this time there is a necessary focus on the nurse caring for the patient undertaking this shift. Components of withdrawing treatment, such as extubation and elements of palliative care, like the administration of morphine were reported to present personal challenges for some nurses. This then necessitated more experienced RNs supporting less experienced RNs to prepare for making the transition.

If the nurse doesn't feel comfortable then you step in. And so if it was decided that the patient was to be extubated and there was a relatively junior nurse in there that didn't feel comfortable doing that, or starting them on a morphine infusion, or giving them the initial bolus. Because what happens is quite often to stop them having dyspnoea when we extubate them we'll give them a 5-10 mg bolus of morphine, and they feel uncomfortable giving that. And so that's when someone more senior like myself... will actually

administer that on their behalf, because they don't feel comfortable doing it. Or if they don't feel comfortable extubating the patient and they want someone in the room with them then we facilitate that someone's there with them. (Melissa)

Melissa's assertion that a junior nurse might not feel comfortable with either of these tasks, may relate to a lack of experiential knowledge, which is another concept featuring strongly in these findings. The administration of morphine caused discomfort for some ICU nurses, because they associated it with hastening death, and as also reported in this study, some nurses interpreted that being the one who administered morphine as being tantamount to ending a life. The intention behind drug administration also features later in the findings chapter, under a good death is dying well, and underscored the interlinking that was happening between the subcategories.

As the transition to palliation commenced and the focus shifted from cure to comfort, a lottery of time was activated. How long the patient takes to die as is suggested here correlates to the amount of time family have to adjust to losing their loved one. This contrasted aspects of what arose from analysis in relation to the sub category time/timing, where negotiation between family members and the medical team to buy time would occur, pertaining to when to commence making the transition. RNs reported that they perceived this as being highly valued by families, having a semblance of control at this stage, buying time to gather and prepare for the pending death of a loved one. Once all treatment had been withdrawn any control over when death might occur was lost. Rebecca (and others) made it clear that as treatment interventions were stopped, family members could remain present if they wished, each step of the way.

Once a decision is made a physical change occurs, but also the family can be involved as much as they like or as little as they like. If we're extubating and giving patients some drugs to dry up their secretions, if the family want to be present when we do that then they can be. More often than not they want to go out until we've removed all the equipment that's going to be removed and then they come back in. So, I think that once the decision has been made the transition happens quite naturally because there's quite a few changes that are made and quite often the patient doesn't die straight away so there's a lot of time for the family to get used to that scenario. (Rebecca)

For everyone involved in the patient's care the transition phase marked an explicit shift, acknowledging that death for this person cannot be prevented, and success now rests with the ability to facilitate a "good death".

Rachel described being surprised during a family meeting where making the transition to palliative care was discussed, how accepting the family was about this decision, compared to her previous experiences in the Middle East.

... This is what we [the healthcare team] think we're going to do in the next 24 hours... I was surprised how the family... they accepted it, because if I was in their place or if it was somewhere in the Middle East speaking of death while the patient is being treated is a big taboo; it never happens... (Rachel)

Removal of the ETT was a significant aspect of making the transition to palliation. Death may result soon after this intervention, rendering transition short. In deciding how much of the transition process they wanted to be present for, family members were supported to be

involved every step of the way. Adrienne reported her insights into how to prepare family for what to expect as extubation was undertaken.

I think sometimes especially if we withdraw and we're removing the ETT, there's been occasions where the family have just not been prepared for what that might be like and it's not a nice process. Sometimes the patients are really sedated and they're unconscious and their GCS is three or they've had a lot of morphine - that's fine. But when the patients have actually been more responsive and we take their ETT out, that's pretty horrific for the family if you haven't geared them up and especially if you haven't prepared your patient with regards to medication and everything else. So those things make the whole situation a lot worse and it's then a horrible experience that the family remember for the rest of their lives. (Adrienne)

The discontinuation of ventilator support, given via an ETT, marked the end of a treatment modality that was specific to the intensive care setting, and which also symbolised what is thought of as life support. In many ways its removal concedes the finality of the transition process. Adrienne explained above how getting the conditions for extubation right are important for both the comfort of the patient, and those family members who chose to remain present. Previous experience added depth to Adrienne's understanding of how distressing extubation can be, if pre planning did not take place.

It was perhaps the possibility for some families that this final act of retreat might be too much to be a part of that saw them choose to distance themselves, until the extubation was complete.

And that's always with the family saying, "This is what we're going to do; would you like to be present?" The same with extubation... Because that could be their last breath and some family really want to be there, and others say, "No I don't want to be in that room, just come out and get me when everything is done." (Gerard)

Making the Transition: The Death and Dying Room; Withdrawing Treatment

This section reports on the characteristics of the death and dying room and withdrawing treatment, which are key property elements of making the transition, as depicted in figure eight below. These focus in more detail on how a patient's imminent death is acknowledged by nurses, through facilitation of a private space in which to die, a relaxation of visitation parameters and clear communication around how treatment interventions will be withdrawn.

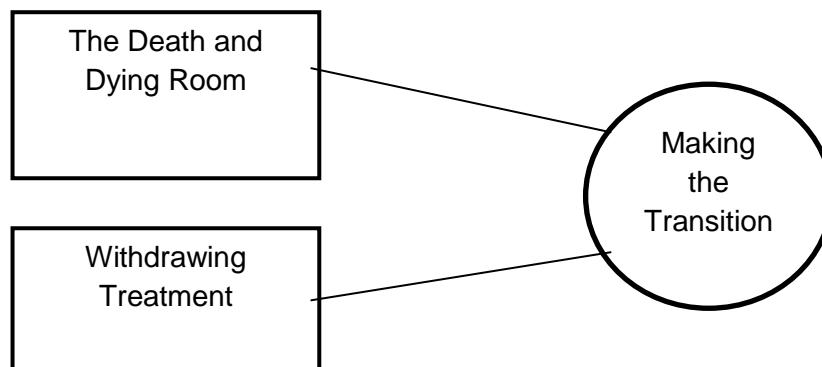


Figure 8: Property elements of making the transition

The death and dying room

In the above section I explained the concept of changing the physical environment. This included how the side room became a space for death and dying. Many other participants reported their experiences regarding the role this space played in making the transition. It was evident that this space had many positive aspects. The perception that the ideal place to die was at home came through in some interviews, but in recognition of the practical limitations around facilitating this creating a comfortable, private space was seen as a positive alternative. "... I think it's really important to try and make it as non-clinical as possible; ideally people should die at home or where they choose. That would be my idea of a good death" (Melissa).

Laurie talked about how a death and dying space was also available in the HDU, however if a patient was still being ventilated, then they needed a nurse to be with them. This was an alternative space to the one in ICU, when extubation had already taken place. Unlike ICU, HDU has a 1:2 nurse patient ratio and the ability to provide staff impacted this area being used.

We were going to palliate a patient on a ventilator on Monday but then if they're on a ventilator you need to have a nurse there and we were short staffed so we couldn't do that. So they stayed in ICU... That room is going to be well set up... There's a call bell... It's going to have an iPod, music... cell phone chargers so that people are comfortable in there. (Laurie)

Making the transition could also involve discharging the patient to a ward to die and making this decision related to how long the patient was expected to take to die.

... If the doctor's predict they're going to last for more than 24hrs... I suppose that's quite difficult on its own because then they've got to get used to a whole new environment, new nurses. So I suppose that is quite difficult on the family as well so maybe dying in ICU is a good thing. You have the nurse there the whole time... it is probably the ideal place to die in hospital. (Laurie)

Participants reported however, that their preference was to be a part of patient's final journey and keep them in the unit to die. This preference was part of the desire to provide continuity of care (reported later in a good death is dying well p. 92). "... I think sometimes it's really messy to actually move them [the patient]... I actually don't know how appropriate it is..." (Holly).

Withdrawing treatment

This property is a focused continuation of shifting from active treatment to palliative care and reports on the role a modified LCP used in the unit played in the process of making the transition. Here a staged approach to making the transition is explored. Stage one involved placing the patient on an end-of-life care pathway, an adaptation of the LCP. Participants reported that this tool supports the entire healthcare team to move forward with a shared understanding of how withdrawal of treatment was going to be managed, including how to facilitate a good death.

... Once the decision is made to palliate we start with our LCP. When I left the unit [finished a shift] we had just started the patient on it. We hadn't started morphine or anything like that. The only decision the first day was to lower the inotropes slowly, not stop them straight away - go down slowly. That was my first experience with end-of-life decision-making being made in ICU. (Rachel)

Using the modified LCP as part of the withdrawal of treatment process supported both experienced and less experienced RNs to plan and manage care for a dying patient, by acting as a decision-support tool. ... "I think it's a good thing to have clear guidelines... it's good for all cultures and all people and I think it's adaptable for everybody..." (Laurie).

With the decision to palliate a patient made, doctors no longer saw the patient as much, with RNs managing treatment withdrawal in accordance with the modified LCP. ... "If they're [the patient] palliative they [the doctors] don't come now, that's just part of the pathway [modified LCP] ... nurses will let the doctor know what they need" (Laurie). Making the transition marked not only a shift in focus for the patient, but also a shift to greater responsibility for nurses.

Summary

The sub category making the transition describes the significant shift that takes place once the decision to palliate has been made. For the patient, their family and nursing staff, moving into the side room represented that the focus had now become about comfort and dying well, with care now primarily in the nurses domain. As these findings reported, while nurses do not have the final say in making the decision to withdraw treatment and commence end-of-life care, their involvement in all other facets of decision-making that exist either side of the withdrawal decision were extensive.

Time/Timing – Getting it Right

Introduction

In this section the intention is to explain the sub category Time/Timing – Getting it Right. A number of conditions make up this category; how long will death take? Negotiating, pacing, extra time and when to withdraw. Time is an ever-present element throughout end-of-life processes, affecting every facet. From how long it takes for a nurse to raise the subject of end-of-life care, to death taking place, time can be controlled in a unique manner in ICU. Due to the life sustaining technology available in ICU and the degree of specialist knowledge and skill held by staff members, a patient could be kept alive for longer than if they were at home, or in another part of the hospital. Therefore a patient who is no longer going to be actively treated will not necessarily die straight away, meaning that the patient themselves (if conscious) and their family have some time to prepare. Participants reported their desire to facilitate this process without compromising the patients' comfort and dignity.

Table eight shows the formation of the sub category '*Time/Timing – Getting it Right*' along with descriptors that explain its role in the formation of the core category '*Experienced Understanding*'. Columns are read across and then down.

Table 8: Reflective coding matrix: Time/timing – getting it right

Reflective Coding Matrix		
Category	<i>Time/Timing – Getting it Right</i>	
Process (Action/Interaction)	Buying time	How long will death take?
Properties (Characteristics of the category)	Negotiating	What happens while we wait?
Dimensions (Property location on continuum)	Finding the balance Prolonging Time to prepare	Deaths time Deciding when to die
Contexts	Working the problem	Post making the transition
Modes of Understanding the Consequences (Process outcome)	Family being present	Death occurs

(Scott & Howell, 2008)

Time/Timing – Getting it Right: Buying Time; How Long will Death Take?

The actions of buying time and how long will death take are the focus of this section, and are key process elements of this sub category, as shown in figure nine below. They are comprised of the conditions gathering together, pushing the boundaries, late arrivals, playing catch up, time to prepare and reaching a consensus.

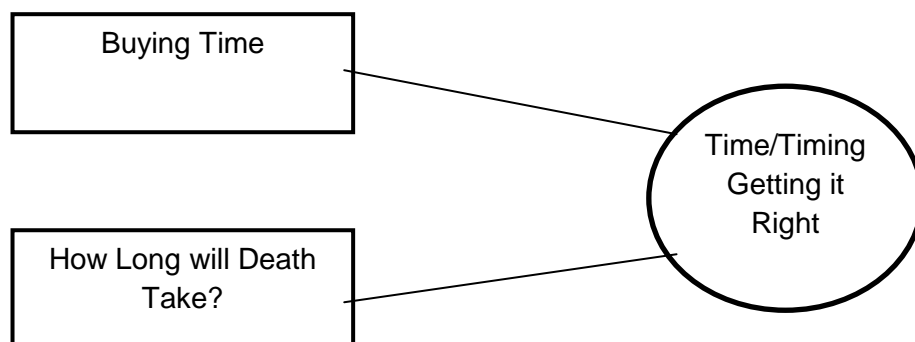


Figure 9: Process elements of time/timing – getting it right

Buying time

The time for a relative to prepare for the death of a loved one, or to understand that this was even happening, did not occur at a set pace. The distinction Holly reported between quality and quantity of life highlighted that during the end-of-life decision-making process, what is important to nurses may at times be at odds with family members priorities. Therefore a significant part of the nurse/family partnership involved gaining an understanding of each other's perspectives, and finding common ground.

... For us it's about quality of life and for her [the relative] it was quantity of life. That's really hard for people to realise until they're going through it and realising that's not what that person would want, but at the same time... no one had prepared her for it. (Holly)

There are two elements at play here with regards to time. How long an individual will live for once withdrawal of treatment has commenced, and the idea that spending time as an ICU patient may prolong life, providing a person with "extra time".

Are we going to, by getting them better, get them to a better... quality of life; are they going to end up worse and have an absolute hell six months, and this may not be what their wishes are. Some of them have said, "... Look if it gets to this I don't want any of that." And when they do that that's really helpful because we can act with their wishes. ... "No, mum wouldn't want this at all," so then you form this partnership with the family about what needs to happen to move forward. (Gerard)

The idea of creating time for family to process that their loved one was going to die continued after the decision had been made to withdraw active treatment. Once the decision to transition to end-of-life care was made, how active treatment was then withdrawn took into account the needs of family, so the change in focus was not too jarring.

... There is a... window where we do give the family time to adjust... we don't withdraw treatment but we will cap it so it doesn't go anymore than what they're getting now and during that time is then to come to the acceptance of what is happening. (Melissa)

The relationship that the nurse caring for the patient developed with family members was a key aspect of the transition that took place between active treatment and palliative care. What became evident during analysis was the condition of buying time; families negotiating with nursing and medical staff for time, to enable relatives who were not local to travel and see the patient, before they died.

... You get a lot of issues with people who are coming from overseas; can you wait two days for them to arrive and then that becomes a very big moral issue that we cannot really do that. If they're going to die they're going to die and we should not prolong that process... That's not in the best interest of that person in the bed space. (Gerard)

As reported by participants, playing catch up for late on the scene relatives could be a stressful experience for nurses and family alike, including the latecomers. Tensions arose around what was perceived as giving up, that not enough had been done to promote a cure, or reversal of irreversible injuries. Understanding family dynamics was a dimension embedded in the end-of-life trajectory.

Advocating for the patient regarding buying time was reported as being an important skill, in an environment where prolonging life was possible.

It's an uncomfortable feeling when you know someone needs to die because things are futile, everything is going bad, and you're maxed out on your inotropes to keep this person alive for someone coming in. I can understand the family's point of view; you know if my dad was dying I'd want to see him before he died but at the end of the day I think we're very much advocates for the patient in the bed, and what the family may see as the best thing for them, may not necessarily be the best thing for the patient. (Gerard)

Gerard reported that for families, like nurses, it was important to see the situation from the patient's perspective.

You sort of have to say... would you want to sit lingering in the bed wanting to die but not being able to because interventions were put in place. You have to put the family in the patient's perspective as well and quite often the family will then start to think, "Well actually, no I want you to stop it here"... Just because we're in ICU it doesn't mean that we should go all out... it's about making end-of life... as pain-free and as dignified as possible. (Gerard)

How long will death take?

The concept of time and timing was intrinsically linked to making the transition. Here Holly discussed how rapidly the death of a patient occurred, once making the transition began. That death took place within approximately eight hours stands out for her as being very quick.

... That was probably the quickest turnaround I've seen because I was on that day and it was my patient. She died before the end of my shift, which was unusual. I think it was eight hours, maybe less, from the family talking to the doctor and him talking to other people, that we had her in a side room and we were palliating her... and she died... (Holly)

Once active treatments had ceased, how long death took was reported as difficult to pinpoint. The competing priorities of nurses wanting to facilitate a “good death” while family negotiate to buy more time so that overseas relatives could arrive, had to strike a balance. All involved parties were therefore challenged to keep the patient front and centre, as they navigated their way through this event. Striving for a high level of communication with family members, so they had a clear understanding of what to expect once withdrawal of treatment was commenced, becomes a key part of the nurse/family partnership.

... We try to get everyone here if the patient is stable enough to last that long. We definitely try but we can't do it for weeks; 48 hours is generally the maximum amount of time we'll wait for that kind of thing. Of course, people always say to you, “How long? How long?” but I just say, “We're not sure how long. When they're ready to go they'll go,” and just try and support them through that. (Laurie)

The likelihood that once the ETT was removed death would occur quickly was made more likely. Due to this, family members were able to remain present while this took place if they chose, (see findings; making the transition). Extubation re humanised the patient as they were dying, with physical interaction such as mouth cares, touching and kissing by family and friends made more intimate. Time had close ties to making the transition and a good death and affected all facets of each of these sub categories. In timing extubation, considerations around secretion management versus having the patient looking more like themselves, informed the outcome of this decision. Ashleigh wrestled with these issues, making cases for both rationales beginning with secretion management.

I think a lot of the time you'd leave the tube in because it helps with secretion management. The last thing you want the patient to do and the family to see is that they have choked because they've got lots of secretions. (Ashleigh)

Contrasting her own perspective, Ashleigh then went on to provide an equally compelling reason for extubation, based around family members seeing the patient as they were accustomed too, and increasing the physical connection between them and their loved one.

They've had the tube in for so long and they're producing lots of secretions, so it depends if you can manage those, if you can manage secretions without the tube then great, it's much better to get it out because they can kiss them and talk to them and they look a bit more like they're used to seeing them. (Ashleigh)

Facilitating a discussion around whether to extubate, and if so when was the right time, in conjunction with having family present were key decision-making points. As reported earlier, extubation could be an unpleasant experience for family, and a clear understanding regarding what to expect was paramount if they wished to remain present while this occurred. Indicating to family it might be a good time to take a break, while the extubation was performed, was reported as a strategy employed by nurses who felt there was little for family to gain by remaining present.

I think normally I pull the tube out when the family's not there. You'll kind of do it at the time when you're giving a wash or repositioning, you'll say you're going to pull the tube out as well, go and have a cup of tea because you know it's a bit yucky and unpleasant. (Ashleigh)

“Some families don’t want them to be extubated. They feel that by extubating them we’re killing them” (Melissa). For some families as Melissa highlighted, extubation was equated with killing, and that by agreeing to have the ETT taken out effectively meant ending their loved ones life. Working the problem and when to make the transition relied upon getting timing right for all those involved. Participants reported they had a responsibility to their patients to not prolong suffering, while at the same time listening to the needs of family and finding the balance around pacing withdrawal of active treatment.

While there were times where the ETT was left in, the ventilator it was attached to was switched off. When this approach was taken, family who chose to stay present needed to understand what had taken place, even if this process did not have the same overt physical intensity as extubation. Melissa reported an account where the sister of a patient became upset when the ventilator was being turned off.

... I went in to turn off the ventilator because they didn’t want us to extubate him... And his sister, who had turned up late, absolutely flew at me because I was going to kill him... I was trying to explain to her that he’s actually no longer alive and what we are doing is ventilating a dead body and that’s not cool... She just collapsed into tears; you know it was her last attack... (Melissa)

This account highlighted the challenge that occurred when decisions reached between some family members and nursing staff, were not communicated to others as they entered the partnership. Melissa went on to explain that ultimately the experience with this patient around turning off the ventilator went well. She attributed this to having stood her ground and drawing on her experience caring for dying people, to advocate for the patient. “And I took the tube out, extubated, and his mother helped and it was like that last breath of air came in and she was like “His spirits been freed,” and it actually turned out to be quite beautiful” (Melissa). Without experience of how to engage with family members and how to pace the timing of communications, less experienced nurses were reported to be intimidated by such a confrontational yet natural reaction. “... It’s quite tricky; the family members can be quite opposing and if that was one of our [names ethnicity] nurses they would have gone running screaming from the room” (Melissa).

Maintaining control of the withdrawal process along with the time family had in which to mobilise relatives who are restricted by distance, necessitated effective time management skills. Keeping someone alive, who without ICU level care would not otherwise live, meant that the concern raised by Melissa around a patient’s dignity, and not compromising this while family members were in transit, was very real for participants.

The other thing that happens is the family make the decision that yes, let’s stop or withdraw care because there’s no point continuing, but they have family members that are coming from nearby and they want to leave everything as it is until people arrive, which I completely understand but I find a bit more difficult to cope with because it’s happened on more than one occasion that a certain family member arrives and then they go, “Oh actually we’ve got an aunty coming as well and can we wait for them?” and it ends up being quite prolonged. At some stage someone, and it’s usually the medical team and/or the nursing team together, say, “We will take the tube out in two hours’ time,” and that’s the end of it. (Rebecca)

Previously it has been observed that Melissa and Rebecca viewed the time it took for family members to accept that their loved one was dying, needs to be limited so as not to compromise dignity. Here Adrienne has a different perspective on the same issue, which is more family focused.

Giving family the time, whether that takes a day, is actually giving them the time to come to terms with what's happening and makes a difference. I've been involved where end-of-life care is happening and it all happens within a few hours and sometimes the family just weren't quite as prepared as what you thought they were; whereas when they've had a period of 24-hours, you find the families get to the point where actually they're like: Right, we're ready... they realise that their relative's going to die. (Adrienne)

Such an approach facilitated family members coming to the conclusion that treatment was not working. The idea of striking a balance around how withdrawal of treatment is managed is very evident here. "It's weighing up that is it appropriate to 'cause a kind of longer death in order to give the family some time to deal with it?"

Family meetings were reported as the forum in which updates regarding a patient's treatment and care could be explained and discussed. These meetings occurred as often as families required. When the decision had been made to withdraw treatment, family members were able to have input into when this would happen, giving them a semblance of control.

Next meeting call the family in. This is what is happening. Maybe tomorrow we'll do another review and we'll let you know... Gently tell them nothing is working and when everybody comes and everybody's on the same page, and the family has accepted the information... It's their time... (Rachel)

The concept of time present here touches on how long death will take once all interventions have been withdrawn. This is closely linked with how long participants perceived it was appropriate to hold off death while family members prepared themselves.

Once the decision is made, between you, the doctors and sometimes the family, if the family were waiting for other people to arrive, as the nurse you would go, okay, we'll leave this for a little bit longer. Once they're here I'm going to start turning it down. And we just let the doctors know that that's what we hope to do and if they're happy with that we can go ahead with it. (Reen)

Reen echoed the understanding that family needed time to gather, however this could not be supported over a period of days. The relationships that were formed between nurses and their patient's families were vital in navigating the withdrawal of treatment component of the end-of-life journey.

... Its either the bedside nurse who has to answer the question, or sometimes if they are busy they will ask the float one nurse or, a charge nurse, who can answer questions if they are not sure. Most of the time the common question is: Once you extubate how long will it take... (Rachel)

Time/Timing – Getting it Right: Negotiating; What Happen while we Wait?

This section presents the property elements of negotiating and what happens while we wait, which are characteristic of this sub category as depicted in figure ten below. Negotiating, while similar in nature to the action of buying time reported on page 81, it is broader in scope, and encompassed transparency around the limits participants placed on boundary pushing, and supporting late arrivals to maximise the time they had left with their loved one. What happens while we wait involved nurses staying available to answer questions and provide a commentary on the dying process.

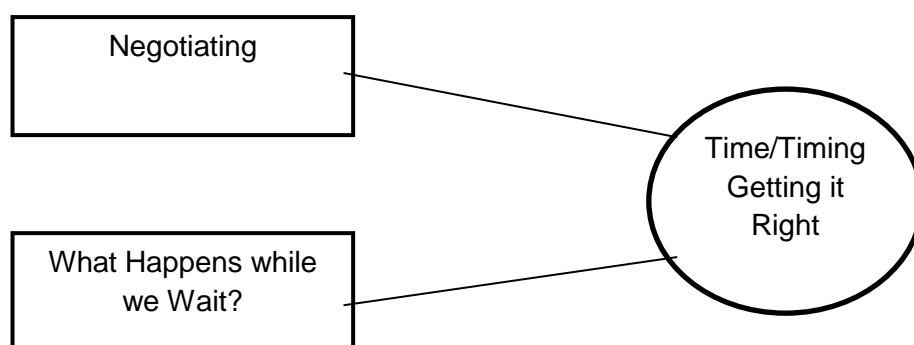


Figure 10: Property elements of time/timing – getting it right

Negotiating

The property of negotiation was a key part of getting the timing of the transition to palliative care right, and took place between nurses and families around preparing for death. Negotiations involved the withdrawal of life sustaining treatments and how long once this process was commenced would the patient take to die? (See p. 82). While no specific time frames could be given, nurses advised families to prepare themselves that it might not take long. Nurses reported that entering into a process of negotiation with families around how withdrawal of active treatments would be managed, was an accepted part of end-of-life care. However, it remained important to also do what was right for the patient.

In ICU often the decision to withdraw treatment usually revolves around extubation or ventilation, which is quite a major thing that ends life. So, if the family want to feel that keeping maintenance fluid going or keeping pain relief going is going to keep their family member comfortable, then generally we do that because it's not actually going to change the outcome; the extubation is going to change the outcome. So, I think it's really important that family feel that their person is being looked after, as they want them to be up to the last minute. (Rebecca)

Melissa reported that conversations were initiated with family members regarding who they wanted to be present as making the transition was commenced and the timing of withdrawal was made explicit. This involved RNs being transparent regarding the parameters they would not step beyond, if death occurred before family members were ready.

... If the patient dies before that time we won't do any heroic measures... It's all about a negotiating process with the family to a certain extent. There are some things that we won't be pushed on; especially if we think it's undignified for the patient. (Melissa)

Family members who arrived later into the dying process were reported to struggle with what was happening, and would want to negotiate keeping their loved one alive so they had more time to say good by. For these family members, becoming focused on maximising the time they had left, drew them away from what they actually wanted, which was to be with their loved one. Participants reported the stress this invoked among families and the role RNs took in re-establishing clarity regarding focusing on the patient.

It's those ones that come in late that haven't been there to see the anguish that the patient has been through that then demand that they be kept alive longer. And we see that quite often. And we decline that request because obviously it's not appropriate...it's very upsetting for the rest of the family... You have to be quite frank and quite direct because they haven't got as much time... to reach acceptance. And so they can blow their opportunity to be with that person by feeling angry with us or with the rest of the family and actually miss out on what's important. (Melissa)

What happens while we wait?

The property, what happens while we wait, pertained to family members entering the phase of waiting for their loved one to die, and what this period of time involved. Participants reported that how this was undertaken depended on the treatment the patient was on, and what had been negotiated prior (see p. 79) between the patients RN and their family, as to how withdrawal was to be staged. Again the constant awareness for nurses of not compromising the patient's dignity, or causing discomfort was an ever-present reminder guiding the pacing of the transition process.

... Sometimes once the decision is made they can start turning things off straight away. Sometimes you'll allow family to come in, start slowly weaning things down over the afternoon. Or sometimes you start turning things down over 12/24 hours. Once the decision is actually made, generally we try not to delay it too much but SLED [Sustained Low-Efficiency Dialysis] they will often stop before they make that decision to completely withdraw; that's a fairly invasive procedure. (Reen)

Participants reported that during the dying phase being present for the patient and their family was important, providing explanations on what was happening and attempting to ease anxiety. Some families anticipated that death would occur quickly, once active treatments had been withdrawn and nurses experience around having cared for dying patients before, enabled them to provide a commentary for family members on what was taking place as their loved one died.

... We're just supporting the family... I think the family were surprised it took as long as it did... it wasn't simply we took the tube out and she died... I think it took a couple of hours... She started Cheyne-Stoking... and the family ask what is happening and you're explaining, "This is normal," and encouraging them to hold her hand and talk to her so that she knows they are there. (Holly)

This nursing presence was facilitated by the continued 1:1 nurse patient ratio maintained throughout the dying process in ICU, which meant that the patient and their family had a constant resource upon which to draw. "Sometimes families will just keep saying to you: What do we do now? What's next?" (Adrienne).

Summary

This section reported on a number of time dependent factors that critical care nurses work with, during the process of end-of-life decision-making and care, as part of the sub category time/timing and getting it right. Experience in caring for the dying deepened nurses understanding of how to engage with patients and their families, as this final journey unfolded.

A Good Death is Dying Well

Introduction

In this section the sub category a good death is dying well, is presented. The perspectives shared by participants were at the same time both similar and individually unique, and connected with the previous categories presented earlier in this chapter. Being able to facilitate a good death for a patient was deeply meaningful to the nurse's in this study, with a variety of actions, characteristics and strategies being drawn upon to achieve this.

Table nine shows the formation of the sub category '*A Good Death is Dying Well*' along with descriptors that explain its role in the formation of the core category '*Experienced Understanding*'. Columns are read across and then down.

Table 9: Reflective coding matrix: A good death is dying well

Reflective Coding Matrix		
Category	<i>A Good Death is Dying Well</i>	
Process (Action/Interaction)	Being pain free	Continuity of care
Properties (Characteristics of the category)	Maintaining dignity Adequate pain management	Keeping the patient front and centre Good nurse allocation
Dimensions (Property location on continuum)	Maintaining trust Understanding the role of analgesia	Open communication Time out
Contexts	Managing dying well	Strong support
Modes for Understanding the Consequences (Process outcome)	Acknowledging a shift in priorities	Minimising change

(Scott & Howell, 2008)

A Good Death is Dying Well: Being Pain Free; Continuity of Care

Being pain free and the facilitation of continuity of care as figure 11 below displays were both actions that were reported by participants to achieve a good death for dying patients. ICU nurse's cultural perspectives, the provision of support to those with less experience and an affinity for caring for the dying, were all embedded within these processes.

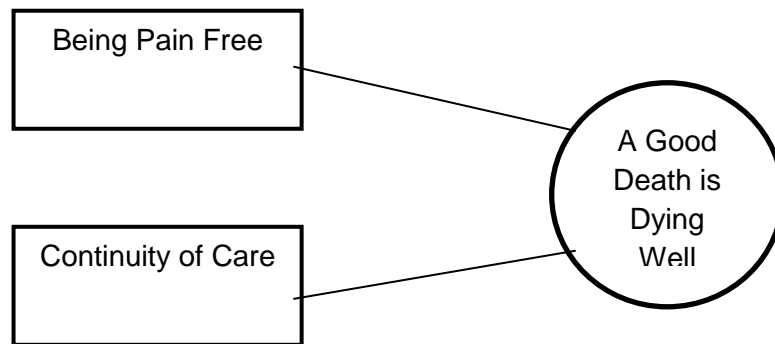


Figure 11: Process elements of a good death is dying well

Being pain free

Dying pain free was reported as an important condition of dying well, and an excellent starting point from which to achieve a good death.

I think at the end of the day a good death is one that you can relieve the pain and anxiety for the patient... and relieve the anxiety for the family... And it's always very rewarding when the family come back and thank you for what you've done because it sort of validates what you have been trying to achieve. (Gerard)

Rachel reported how a nurse's culture impacted on the administration of analgesia, with some nurses not feeling comfortable administering large morphine doses, as they believed doing so would hasten death.

... There were quite a few people who said, "no I wouldn't give a 10 mg bolus because I know when the tube is out the patient, in the next couple of hours, is going to die." I would think that it's because of my morphine bolus that it happened. Though it's not because of that; I know it's going to happen naturally. But maybe it's because of my culture that I feel that I am responsible. (Rachel)

Rachel's strategy to avoid being placed in this position, was to enlist the help of a charge or float one nurse "... We've got the charge nurse and as I said there's a float one nurse" ... (Rachel). However, the charge nurse became the primary source of support if Rachel herself was working as a float one nurse.

... If I'm there as a float one nurse and if there is another person just like me then maybe I'll have to ask my charge nurse to come and help. There would be somebody within the unit who doesn't share the same culture and they can come and help. (Rachel)

Maintaining awareness around providing support to nurses with less experience of palliative pain management was a condition reported by participants as essential in facilitating a good

death. "I can understand why some less experienced and junior nurses would freak out at that because they feel like they're the ones that are giving them the lethal injection" (Ashleigh).

In contrast Melissa reported how her first professional experience of death caused her to reflect on the role of drug administration, and the questions she asked herself appeared to centre more on lack of experience than balancing cultural beliefs.

... My first death in the unit was a 26 year old; I was 25... And I look back on that and I think that there was so many things I could have done better, but I was scared and I didn't fully understand or comprehend that there's nothing that we could do for this guy. I knew that, but it was the whole if I give him drugs I'm going to kill him. You know if I give him 10 milligrams of midazolam to stop that jerking that's going to mean his breathing is going to be affected; we were already giving morphine. In hindsight he needed the 10 milligrams of midazolam because it was upsetting to his girlfriend, his sister and his mother to see his eyes fluttering. It was awful... (Melissa)

For Melissa this experience as a nurse occurred just prior to a personal death, where she lost a family member. This underscored how ICU nurses would draw on such past experiences with death, and use them to shape their understanding of what it is to die well. This encounter with death

Got me interested in making sure that people have good deaths... it was a horrendous death, absolutely horrendous. He died in pain and it was the most horrendous thing I have ever seen and I vowed that if I was ever looking after a patient that they would never go through the kind of death that he did... It's on life experience. Anybody who has experienced the death of a loved one, whether it be at home, whether it be in hospital, whether it be good, or whether it be bad, that's what drives the kind of care that you give to that patient in the bed space. (Melissa)

Therefore in order to facilitate a good death being able to draw on one's own experiences, deepened empathy and laid the foundation for a strong caring partnership to be formed. Having a relative die in pain just placed things into perspective; it enabled a sense of understanding to develop about what it's like to be a family member watching a loved one die.

In hindsight I would go back and I would make that person look as peaceful as possible and remember that euthanasia is about the intent and he was dying and he could have died better if I had either had my life experience earlier, or I had a better understanding. But a lot of nurses in the unit are quite young and they haven't had that life experience of someone close to them dying, to see the difference between a good death and a bad death. So I definitely think that if you've experienced death and it was of someone who's close to you, it helps you to deliver care to people who are dying. (Melissa)

Rebecca expanded on the concept that life experience influences caring for the dying patient, and like Rachel discussed how culture impacts on the caring partnership, between the nurse at the bedside, the patient and their family.

Yes, it definitely does play a part. I used to think it was age-related, that the older nurses were better at dealing with it, but I don't think that's the case; I think its life experience and maybe people's spiritual perspective. But younger staff can be just as good or as bad, as older staff can be just as good or as bad. I do think it boils down to experiences that they've had and their communication skills and also different cultures. Some patients that we have are of a culture that sometimes it's easier to be looked after by a nurse of that culture because they know what to expect, they know how the family are managing

with it and dealing with it. Although I think that our team do really well in looking after every culture in a very mindful manner... (Rebecca)

Continuity of care

A dimension of how life experience promoted a good death was continuity of care, where nurses who have a passion or a skill for end-of-life care were routinely, where possible, allocated to care for these patients.

... There are some staff members that get to care for dying patients a lot more than others, and I think that's just because there's a general recognition that some people are more comfortable with it and there's no point putting a staff member into a situation where they feel really uncomfortable especially when it's a very sensitive time in people's lives. (Rebecca)

A challenge for ICU nurse's was being able to develop the skills needed to provide a high standard of care for dying patients, learning from their colleagues who may have more experience, while at the same time understanding that nurses new to the critical care environment may not be new to nursing, and therefore have a wealth of experience gained from other clinical settings. "... We're saying junior nurse, but actually a lot of the nurses who come into critical care have got experience elsewhere so they're not completely junior" (Ashleigh). However, based on the skill mix of the nurses rostered on a particular shift, and the complexity of the patients in the unit informed allocation decisions.

Whether or not you get put back with the same patient all depends on skill mix. Because I am now a more senior nurse they like to keep me available for looking after paediatric patients and often if you're dealing with a palliative patient then they're not a complex patient anymore, so they will tend to give them to the more junior staff if that's the situation on the day. (Reen)

Melissa reported on how nurses with a lack of experience in caring for dying patients were supported by other members of the nursing team.

... In the charge nurse role if someone is for end of life care we look very carefully whom we give to that person. Obviously it's a global view so you have to take into consideration the other patients in the unit, so we try to put the best person there but sometimes that's not always the case; but whoever goes in there they get lots of support. We always ensure they have somebody relieving them, someone checking in with them, because it's not easy, not an easy thing to do. (Melissa)

Ashleigh summarised the day-to-day balancing act behind nurse/patient allocation decisions. She cited the importance of role modelling and supporting junior nurses to develop end-of-life experience.

... It depends on the unit and the level of skill mix at the time. You could say that a patient who's at the end of life is quite low rent; you don't need somebody who's very senior. But then the other argument is actually you do because it depends on the family dynamics and there's a lot of skill involved in looking after patients with their needs. They need a lot of care and skill and attention. It's not the physiological side but the holistic side of things... I would always be a bit disgruntled if there was always a junior nurse in there because I think you need to get a lot of senior nurses in there as well and a lot of experience, for role modelling to show the junior nurses various ways of doing things because it involves a lot of different approaches. (Ashleigh)

Additionally, building a relationship with the patient and their family was assisted by minimising interruptions to the nurses allocated to their care. The dimension of nurses requesting to return to the same patient was reported here, demonstrating that this was not a passive one-way process, whereby nurses at the bedside had no input into allocation decisions.

Generally people ask to go back but sometimes you might look and think, oh, that person was there, and you might put them back. And you'll say to them, "Are you happy to go back?' And they'll either say yes or no. And we can always change it but it's quite nice for the family as well to have continuity of care and nice for the nurse as well. Most people like to go back and they go through that journey with the patient and the family, that's quite nice. (Laurie)

Mitigating circumstances also existed, where a nurse would not be re assigned to the same patient. These included nurses becoming exhausted, or simply requiring a break from the type of intensity care at the end-of-life entails.

The only time we won't put nurses back is if the nurse is finding it difficult to deal with that situation or if the nurse isn't coping... or if the nurse has been given a particularly difficult family or patient to care for, which is sort of mentally exhausting. Those are the only times that they [the patient] might end up getting a different nurse... (Adrienne)

A Good Death is Dying Well: Maintaining Dignity; Keeping the Patient Front and Centre

Maintaining dignity and maintaining a focus on the patient were characteristics of a good death, and comprised, continuing to perform basic nursing cares and the importance of continuing to talk to patients, even if they were unconscious or sedated. This acknowledged that they continued to exist as a human being. Figure 12 below highlights the relationship between this sub category and these property elements.

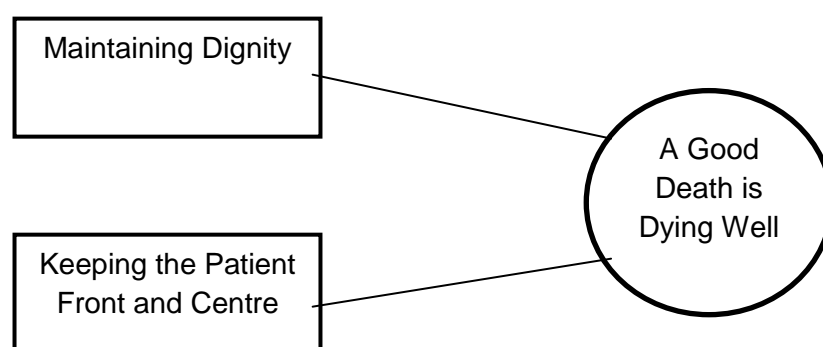


Figure 12: Property elements of a good death is dying well

Maintaining dignity

Participants reported maintaining dignity was as an important aspect of facilitating a good death. Throughout the participant accounts gathered as part of this study, the idea existed that the often invasive technology utilised in ICU to treat and cure patients, must not be

continued for longer than was necessary, if its benefits did not outweigh compromising dignity.

... Where patients are usually just sleeping and they're on high doses of adrenalin, high dose oxygen. You turn both of those off and the patient dies before you even need to take lines or tubes out, and the family really seem to have an understanding then that the only thing that's keeping this person alive was all this equipment and nothing else. (Adrienne)

Maintaining dignity required nurses to understand that once palliative care had begun, there were many nursing cares, which needed to be performed in pursuit of a good death.

... The actual caring aspect and nursing part of it... is being with the families, the mouth cares, the personal cares – which used to be exactly what a nurse did before we all went to university and learned all these other skills, but it is that art of nursing. It's about being that person by the bed who washes and does all the basic pressure area care and all of that still continues while the patient's dying. You don't ever stop talking to them... you still talk to somebody who's completely brain dead... you still talk to them on a first name basis. (Adrienne)

Additionally, participants reported on the importance of talking to patients, particularly in the context of forming strong relationships with family members and working together to keep them humanised and at the centre of any decisions or cares undertaken.

I think in general in ICU when someone is intubated we all know that sometimes they pull things out of what's been said, so we always treat any patient who is intubated and ventilated as if they're awake, and explain what's going on; and just talk them through it. And then you have a lot better dynamics with the family and work closely with them, because obviously you can't interact back and forward with the patient if they're not compos mentis, and then the family comes in a whole lot more, and you have a lot more engagement with them. (Gerard)

Keeping the patient front and centre

Keeping the patient front and centre was a prevailing driver behind all five of the sub categories. Participants reported that from raising the subject, to a good death is dying well, remembering that the patient was always the reason for them being there, provided the overarching motivation to manage end-of-life processes well.

... I like it when family and friends are in the room talking, doesn't have to be with the patient, but about the patient, about good times, about memories. Or when it's a large Polynesian family there's often lots and lots of different conversations happening in the room at the same time, and... I think that's a lovely environment for people to die within, because we don't know whether people can hear voices or not, but it must be really nice to have lots of voices that you're familiar with talking... (Rebecca)

Summary

Facilitating a good death was a key goal for the nurses who participated in this study, all of whom had a clear notion of what this meant and how to go about its achievement. A shift in thinking took place when nurses stopped seeing death as a failure, but rather as an opportunity to see success as something other than striving for a cure.

Chapter Five: The Explanatory Theory

Introduction

In this chapter the theory of '*Experienced Understanding*' will be explained. The data analysis undertaken throughout this study has resulted in the formation of the core category experienced understanding, which draws the categories Raising the Subject, Working the Problem, Making the Transition, Time/Timing – Getting it Right and A Good Death is Dying Well together, showing that critical care nurses experience is central to their influence and engagement with end-of-life decision-making and care. '*Experienced Understanding*' is gained through clinical and life experience all of which supply nurses with the skills and knowledge to navigate this clinical landscape. Figure 13 below depicts the explanatory theory of '*Experienced Understanding*' and the essential interplay between this, the core category, and the supporting five sub categories. This is an interconnected and fluid process, which deepens and strengthens as nurse's progress through their careers.

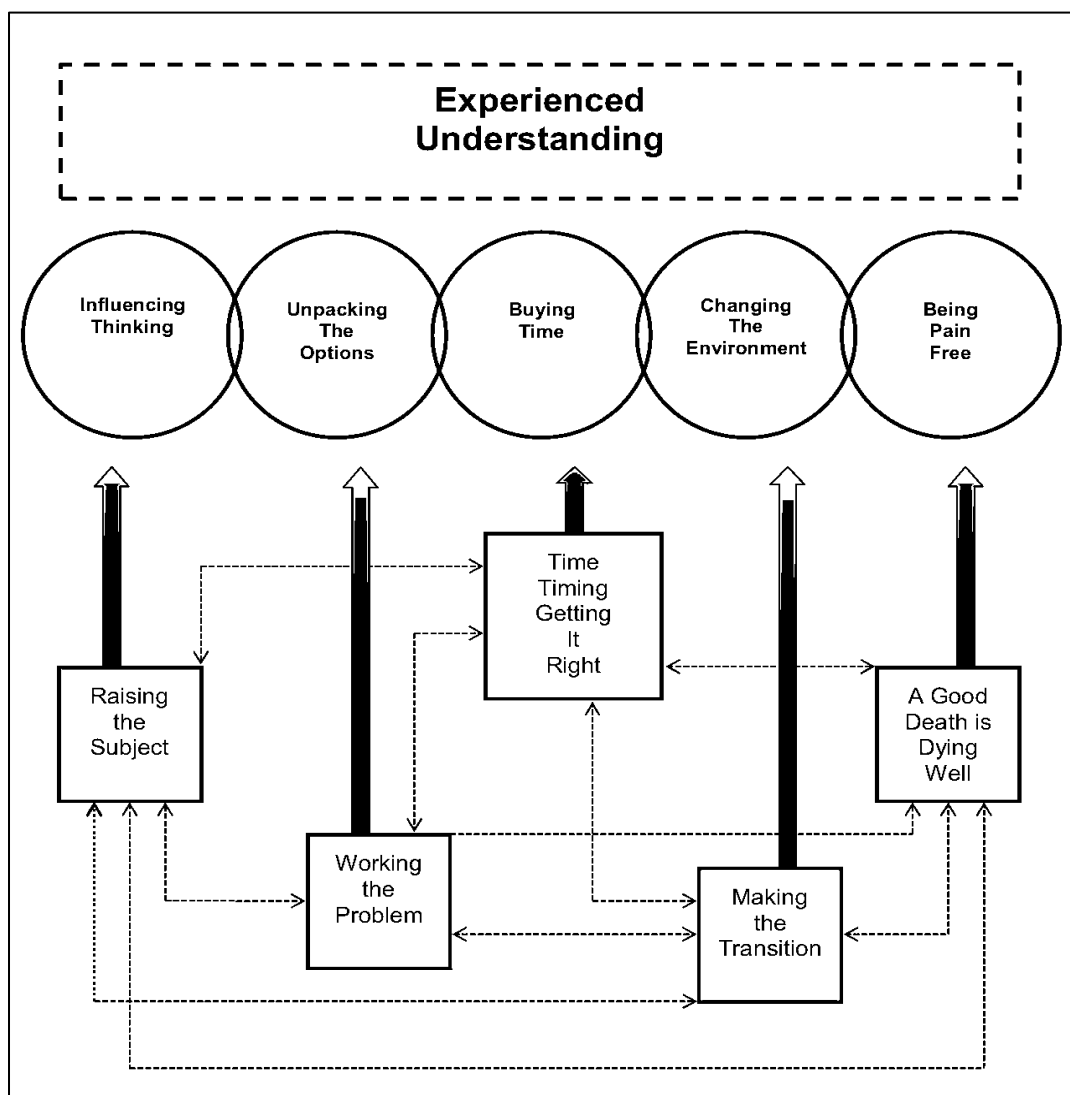


Figure 13: The explanatory theory of experienced understanding

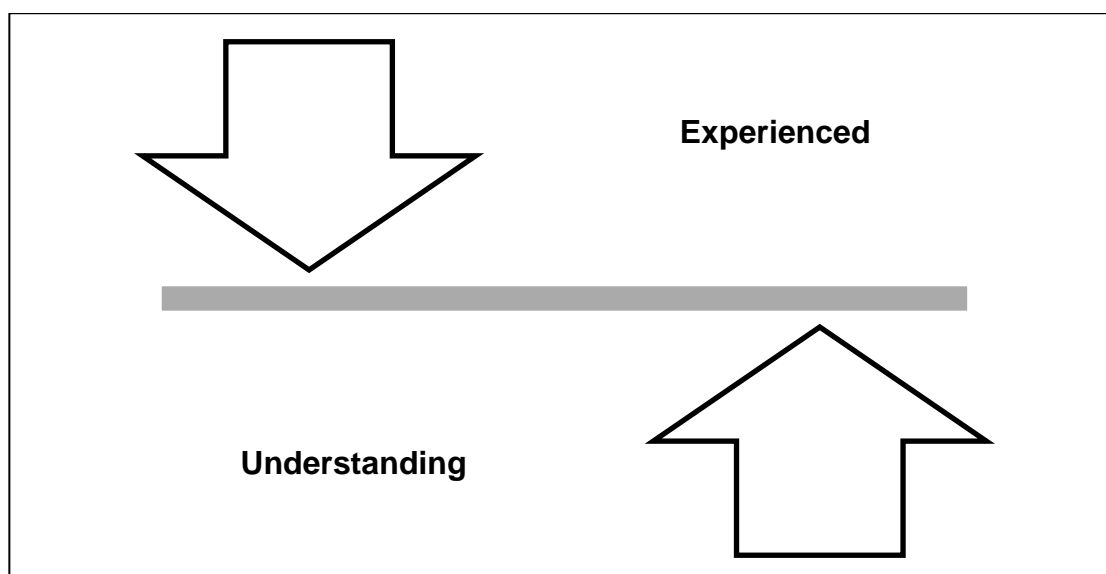


Figure 14: Experienced understanding as a balancing act

In this Section

Providing support, looking back and cultural perspectives are all actions and characteristics of experienced understanding. They underpin and provide examples of how different levels of nursing experience influence end-of-life decision-making and care. As figure 14 above depicts, experienced understanding is a balancing act that is in a constant state of development. It is important to note here that the provision of support reported below, pertains to nurses, patients and their families.

Providing support

Participants reported that they felt supported by their medical colleagues, when caring for a patient who “might not make it”. Within the way this ICU is structured, interdisciplinary accessibility was considered an important aspect of providing a high standard of care. Consultants (intensivists) by walking around at intervals during their shift maintained a level of visibility that nurses could then access when wishing to discuss a patient. Then nurses in this study constantly filtered what was happening for their patient through a lens of their own understanding. Personal and professional experiences melded together to form the foundation from which assessment information was contextualised, and acted upon.

And then throughout the day if you’ve got concerns you might talk to the reg [registrar] and you’ll find that the consultant will walk around a few times too and if things aren’t improving you might actually talk to the consultant and say, “Oh, I’m not 100 percent happy,” or, “Would you be worried about this?” (Holly)

Within the wider context of providing support, participants report that opportunities existed to improve end-of-life processes, such as providing more consistent level of engagement from nurses assigned to care for the dying. Distancing was in evidence at times, once making the transition to the side room had taken place. This involved some nurses deciding to position themselves outside the room, rather than within.

... We're changing the way that we do end-of-life care in the unit... The nurse would pull the trolley out and they would sit outside and go in when the family asked for something. So there was no sort of involvement, there was no sort of communication with the family, or getting to know the patient, getting to know the family... I mean dying in hospital is horrible for anyone, let alone having someone who doesn't want to communicate. (Melissa)

In contrast to Melissa's observation above, Rebecca offered an alternative perspective on why nurses chose to position themselves outside the death and dying room. Her view was that support could be provided through being accessible, without needing to be visible. She saw sitting inside the room as "intruding into the family's space". "... Sometimes we pull the trolley out so that the family has the room and we're there for questions and there to give care but we're not actually intruding into the family's space..." (Rebecca).

Experience informed participants to explicitly let family members know that care for their loved one was not going to cease, now that making the transition had commenced. For some participants the choice to position themselves outside the patient's room, was decided after consulting with family members, as to their preference.

I think each situation needs to be assessed individually because I think some patient's families are just really freaked out and don't want to be there... They have a fear of the unknown and they just want their family member to be looked after with the same intensity... But then others are quite chilled out, "No it's alright, we'll call you when we need." So from my experience I'd always ask them... (Ashleigh)

For Laurie, previous experience had shaped her understanding that like Ashleigh, communicating with family members to ascertain what their needs were, assisted in individualising the support provided. Clearly articulating that the nurses positioning inside or outside the side room could change as required, meant that sensitivity to changing needs was maintained.

... If there's not a lot of family I will because it's nice to have an extra person and someone that they can talk to; but if there's a lot of family I might just sit behind the curtain... But I won't be far away... But generally I think I need to be there if people want to ask questions... (Laurie)

The float one nurse played a key part in supporting nurses who were caring for dying patients, and was integral both in terms of practical input (toilet and meal breaks), and emotional support (check that they're alright and not feeling isolated). This was reported as being of particular importance to support nurses who had limited experience with death and dying.

I think we are quite open and if there is a new person on the floor or a new person being with death and dying, we make sure we've got a float one nurse and I say, "Look, just make sure you float around and give a bit of support," and generally the death and dyings are in a side room so it can be quite isolating... (Gerard)

Participants underscored their belief that in providing support to nurses, when they were caring for the dying, to ensure they did not feel isolated. Experienced nurses employed this understanding to utilise the float nurse to provide support to a nursing colleague, allocated to manage the care of a patient at the end-of-life. "If it's busy you can end up feeling very

isolated round there [the side room]. It is very emotionally taxing... Charge nurses are usually fairly good at coming round and checking in on you and offering support” (Reen).

The side room used in this ICU to care for dying patients is located away from the rest of the unit. For nurses used to working in an open and social environment, being supported by their colleagues when undertaking end-of-life care was reported as being very important. The float nurse system bridged this gap providing experienced assistance to nurse's in the bed space. For the nurse assigned to the care of a dying patient, knowing that their nursing colleagues understand how important having their support was created a solid foundation from which to facilitate a good death.

Junior nurses who were assigned to care for the dying, received experienced input to learn and understand this process. Experience was reported to be gained and built upon over the duration of a career, and guided nurses making the decision to raising the subject, and identify the right time to commence withdrawing treatment and appreciating that not every situation was the same.

As you start to grow and develop and your knowledge grows stronger... and your experience... for me, my experience has changed completely and my feelings on end-of-life care have completely changed from my first experience to where I would be at now. (Adrienne)

Experience regarding seeking support to relieve pressure points invoked by involvement in stressful care situations was reported as being beneficial in the maintenance of personal well-being. Having a clear understanding that support was available, along with the familiarity of how to engage it, via charge nurses and the unit psychologist, were also instrumental in ICU nurses feeling supported to engage in continuity of care (as reported on p. 92).

... I had a few occasions where I looked after little babies and they didn't survive. It's really hard because when you go back home you have got your kids, so you can relate... You can go and talk to the charge nurses who were on your shift. You can go and talk to our psychologist; she's really good with helping us deal with difficult situations. (Rachel)

Additionally, supporting the nurse at the bedside was considered future proofing. Nurses whose experiences of caring for dying patient's were remembered as well managed and supported, were less likely to distance themselves from undertaking such care again. A good death was reported as being a significant part of this process. “We try and make it so that it's not a horrific experience for the nurse because a bad death is enough for a nurse to hang up her coat...” (Melissa).

Looking back

Reflecting on practice is an activity nurses are regularly encouraged to engage in, either as part of producing a professional portfolio, or as a mechanism for learning from a particular clinical experience. The concept looking back draws upon this activity and describes how the nurses in this study employed this skill to increase their ability to be a part of making sound end-of-life decisions and provide good end-of-life care. The following example

illustrated how this nurse's previous experience with extubation informed her practice in this situation.

I'd personally cared for a patient who we knew was dying. The family were all on board. We were going to stop treatment but we weren't going to remove the ETT. That decision was made with the family. We would disconnect the ventilator but not remove the ETT because we'd discussed with the family that sometimes the patient can choke and gag and it can be quite awful and that you can't always predict what the patient will do, so you can only prepare them for what might happen. (Adrienne)

Adrienne then went onto report how the situation began to change and a different course of action had to be discussed.

He ended up surviving for more than 24 hours... so we talked about the fact the ETT was still in and keeping his airway open... that this piece of equipment was possibly prolonging his death. We gave him a little bit of extra morphine before we took the ETT out so that it wouldn't be distressful, but... there was a whole lot of sputum that came up and he coughed and gagged and his eyes rolled into the back of his head and one of the family members screamed and cried and jumped over, and I just remember her grabbing on to me: What are you doing? Oh my god, you told us it wouldn't be like this. That was very hard... I apologised and said sometimes we just don't know that this is going to happen... (Adrienne)

Knowledge gained from previous experiences caring for dying patients enabled senior nurses to remain aware that less experienced colleagues were likely to need support as the journey towards death unfolded. "I think the more experienced nurses have been through it. They can reflect on how their feeling...I always make sure that the nurses are okay" (Laurie).

Experienced understanding lead to recognition by participants that looking back and reflecting on strategies that had worked for them, regarding keeping the patient front and centre (see p. 94) involved "taking the role of the other" (Melissa).

I always tell the nurses to think about taking the role of the other; you know it comes up time and time again, if that was your mother, your brother, your sister. Because yes they're a patient that's dying in the unit and your feeling scared because you don't want to kill them by giving them drugs and you don't want to administer this because what if it speeds things up, but they have to take out its not about them and what they believe; it's about what the patient needs. And in our setting it's about what the family needs as well... It's definitely about life experience. (Melissa)

In relation to the administration of analgesia, experience meant understanding the intention behind its administration. "... For nursing staff it's about keeping patients comfortable, but you do hear consultants say, "Well this might bring along the end a bit earlier, but our primary focus is keeping them [the patient] comfortable..." (Gerard).

Experience with end-of-life decision-making and care is a skill that deepens with having the opportunity to grow and develop, learning from others, looking back on ones own learning curves and passing this knowledge onto other nurses. Gerard and Rachel both reported on previous experiences that shaped their understanding in relation to end-of-life processes, which succinctly summarised all participants reports.

For me, my first year in ICU I hated everyday of it because I didn't understand the equipment; things were going on that I didn't quite grasp, and it wasn't until I got passed

that first year, and was able to have the technological stuff down pat that I was able to focus more on the families... (Gerard)

... For me this was a very new experience, how we make this [end-of-life] decision. I have improved a lot... I am more comfortable talking with the family confidently, I don't panic now... earlier I would have avoided it and did not want to talk about it... (Rachel)

Experience was reported as being advantageous when supporting family members after a family meeting had taken place, and being able to answer their questions, particularly if raising the subject of making the transition to end-of-life care had been discussed. Participants highlighted how essential the bed space nurse was to these conversations.

... Generally the family will come to the nurse with... a lot of questions about what will happen... Most of those questions don't happen at the meeting; they happen afterwards with the nurse at the bed space. That's when you really rely on having an experienced nurse in the bed space to be able to help answer those questions effectively and to be comfortable answering them as well. There's a whole other conversation that takes place after those meetings, which are very much, nurse led rather than doctor led. (Adrienne)

Gaining experience took time and as Adrienne reported, experience of death may not happen until working as a nurse. This emphasised the important role senior nurses had in passing their knowledge on, and supporting the up skilling of their colleagues.

Understanding end-of-life care and the morals and ethics behind it is very difficult when you are new and... new to the experience of death in general. I haven't really had any relatives in my family die so the first people I'd ever seen die would have been in hospital as a nurse and generally in the ICU. (Adrienne)

Cultural perspectives

Working in other parts of the world prior to coming to New Zealand, added an additional layer of experienced understanding to how cultural perspectives impact on end-of-life decision-making and care. As reported else where in the findings chapter, both the cultural perspectives and needs of ICU RNs, their patient's and family members must be taken into account, from raising the subject, to orchestrating a good death. As Rachel reported here, in India and the Middle East, end-of-life decision-making does not exist, and the subject is never raised.

... You don't speak of death... I'll give you an example. We had a patient suffering from lung cancer. They were intubated for six months; the outcome was poor. He was going to die but they kept going, on and on. He died on the ventilator. (Rachel)

Some participants reported that for nurses with language barriers, or for those new to ICU, or who were uncomfortable with end-of-life processes, negatively impacted on the likelihood they would speak up to be heard, during, or to initiate raising the subject.

... There's lots of nurses that I work with who tend to step back... because perhaps they're not comfortable with death, they're not comfortable with the withdrawal of active treatment, they're not comfortable with end-of-life decision-making... or perhaps they're quite new to the environment and therefore actually communicating with the families, because English is a second language; that can be a barrier to how involved they are in decision-making... they don't tend to have a voice; they don't tend to vocalise themselves what they're thinking or what's going on in their head. (Adrienne)

A unit wide approach to support nurses in their engagement with end-of-life processes, involved creating forums where raising concerns, and articulating personal knowledge gaps could be done safely.

We have focus days, we have discussion groups every month, and different things that we work on all the time... we're trying to get our nurses more involved in the process of withdrawal of active treatment, and actually have their voices listened to, their concerns listened to... and we've got this new pathway... we have a psychologist and we have people just so that they can open up and ask questions about why we do things differently here and so that their voice can be heard because it is culturally different for everybody. (Adrienne)

In addition, Melissa reported how as a senior nurse she has worked to support nurses within this ICU, to develop experienced understanding within the context of their own cultural perspective.

... I've been doing quite a bit of work with the nurses and I had a breakthrough with one of our more senior [names ethnicity] nurses. I go around and I get them to talk about their experiences with care and what they find hard and what they find easy, and where we can facilitate to help and improve things so that they feel comfortable delivering it. And it was magic, she said, "I am Christian, I go to church every Sunday, and to me when we administer palliative care drugs we are hastening death." But she said, "The patient is dying; I am not killing them, they are dying and it's not about what I believe and so therefore they should be free of pain and they should be free of agitation." (Melissa)

Summary

The theory of '*Experienced Understanding*' explains what is happening in my studies findings. It articulates how these ICU nurses draw on their individual and collective knowledge to influence and manage end-of-life processes. '*Experienced Understanding*' is attained through personal and clinical exposure to death and dying, and is grown by learning from and teaching others. Hospitals are intimidating places with human interaction being the only buffer between patients, families and a faceless healthcare juggernaut. While death is inevitable, it does not need to be a depersonalised experience, simply because it is occurring in a hospital.

Chapter Six: Discussion

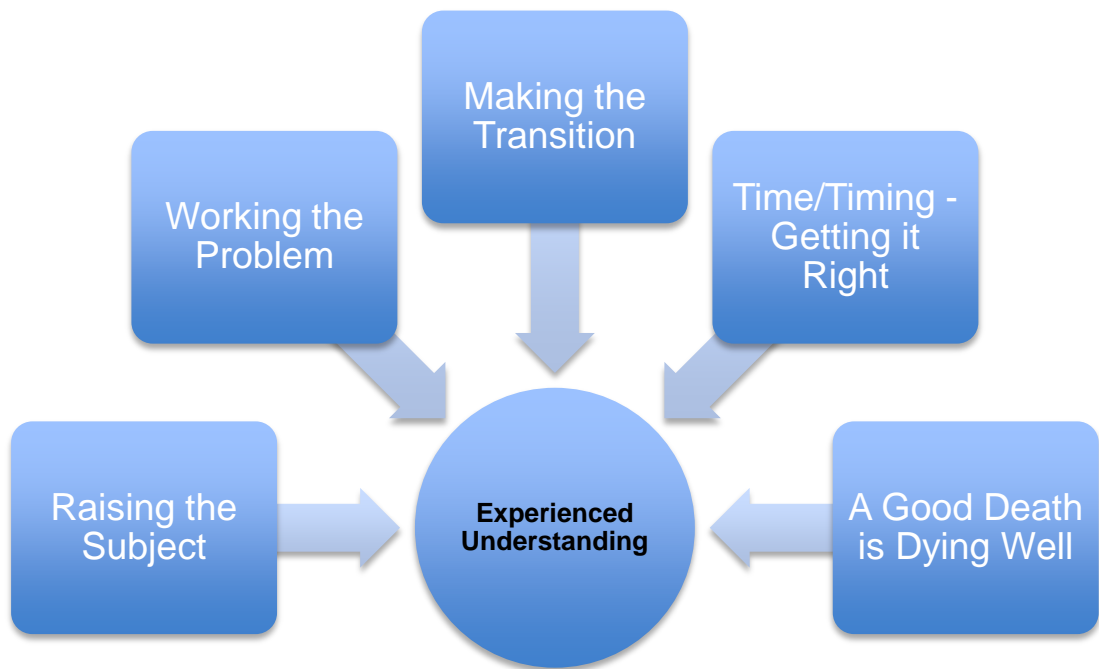


Figure 15: Experienced understanding the core category

Introduction

In this chapter an examination of the findings presented in chapter five will be undertaken. Literature relevant to end-of-life decision-making and care will inform this discussion, along with symbolic interactionism. This discussion draws together the five sub categories, as depicted above in figure 15, and unpacks how they benefit from '*Experienced Understanding*' and how each one assists ICU nurses in attaining this overall skill. Additionally, significant implementations within the ICU this study took place are discussed, limitations and recommendations for future research are outlined and the significance of this study are summarised.

According to Truog et al. (2008) care at the end-of-life is proving to be a significant field of expertise in critical care and therefore requires the same commitment to competence and knowledge acquisition as all other facets of ICU practice. To be in a position to provide both compassionate and effective end-of-life care healthcare professionals need to recognise and be willing to have "the conversation" that death is imminent (Levy, 2001). Like raising the subject, this entails "taking the time to sit down with the patient and/or family to create the proper environment and communicate in an open, genuine manner about the truth of a patient's illness" (p. 34). To be in a position to set out on this journey, Levy highlighted how a nurse for example, needs to feel comfortable with death within themselves and be available to help navigate patients and their families through feelings of pain, suffering and

loss. Nurses and physicians can accomplish this by creating a unit wide understanding around what effective end-of-life processes look like, and facilitate debriefing sessions for the team when a patient has died (Prendergast & Puntillo, 2002).

The Components of Raising the Subject

In this study, raising the subject comprised different conditions, which were impacted by experience, cultural perspectives and personal values. Participants clearly indicated that while overall they perceived their ICU was an environment that fostered speaking up and active participation, they recognised that not all nurses were comfortable with such involvement. Participants also discussed how while their input into raising the subject was possible; the ultimate decision regarding making the transition to palliative care lay with intensivists.

Planting the seed – influencing thinking – initiating the discussion

These strategies; planting the seed, influencing thinking and initiating the discussion were all used by participants to raise the subject around 'where are we going with this patient?' Nurses with more experience and confidence would engage directly with a doctor about their patient, whereas for others running their thoughts via a senior nursing colleague was more within their comfort zone. Within the variety of approaches taken, it was not evident that delays to raising the subject occurred, however during the working the problem and time/timing – getting it right phases time could become fluid and making the transition to end-of-life care varied. One participant explained how initiating the discussion might be doctor initiated, with nurses then being involved in acknowledgment for their valuable insights garnered from a constant bedside presence.

Nurses underestimate their ability to influence a situation by articulating an opinion, or observation, either overtly speaking up, or covertly planting the seed. The conditions of confidence and experience were reported as playing a role, with more senior nurse's being prepared to share their considered opinion with a registrar or intensivist regarding their patients plan of care. Working relationships between doctor's and nurse's defined how a recommendation was received, with a nurse who had a proven 'track record' being more likely to be listened to than one who was still proving themselves. Individual confidence levels may dictate to what extent a nurse feels comfortable raising the subject of moving away from active treatment, and towards palliation, or as discussed above, who they shoulder tap to share their perspective. Nurses held differing perspectives on how valued their input was in this context. Laurie held that in most circumstances the decision is made for nurses, and taken out of their hands. "Normally the decision's made for us; so we just go along with what the consultant wants and the family as well" (Laurie).

At other times if nurses felt strongly that raising the subject needed to happen, then initiating the discussion themselves and influencing the subsequent thinking was undertaken. For Melissa resorting to what she termed as unprofessionalism was sometimes necessary to raise the subject.

... Sometimes you have to resort to unprofessionalism in the form of some snide comments that may be in front of other people, that they pick up on and think, "Right well we have to address this," – close door, let's go. And so then you would have a frank and open discussion and that's all you can do. And you've got to plant the seed... (Melissa)

In both my research and the published literature on intensive care nurses, end-of-life decision-making and end-of-life care in ICU, the concept of planting the seed exists as a non-direct approach to raising the subject. The intention being to float with an intensivist or registrar the idea "what are we doing with this patient"? Planting the seed was a finding in McMillen's (2008) constructivist grounded theory study, where eight ICU nurse's were interviewed. The author describes this as an inductive approach, which incorporates the constant comparative technique a recognisable feature of grounded theory. Two major themes (the use of this term calls into question the claim that this is grounded theory research) were discovered; the nurse's role and perceptions regarding treatment withdrawal. In this research planting the seed was a condition that made up the wider theme of the nurse's role, and referred to nurse's beginning to intimate to their medical colleagues that they needed to consider stopping treatment.

McMillen (2008) also reported that significant characteristics of the critical care nurse's role in end-of-life decision-making comprised "not really a nurse's decision" and "experience counts". The former reflected how all participants reported that the decision to cease active treatment was not theirs to make, it was the responsibility of the consultant anaesthetist. However, there was a sense among these studies participants that nurses ought to have some contribution to this process, and have their insights and perspectives heard given the ratio of time they spend with the patient and their family, compared to any other health professional. As Reen reported below, raising the subject could come about in this particular circumstance, where during ward rounds an intensivist raises the subject, however the bedside nurse can also choose to speak up and offer an opinion. "... On ward rounds they assess the patients, decide whether or not they're going to be able to make progress or whether they're in a holding pattern, or they're just liable to deteriorate..." (Reen).

While my study found that nurses had an opportunity to either raise the subject, or be a part of the process once initiated, it was up to the individual nurses to step in, as being invited to participate did not regularly occur. Gerard however, spoke of the openness of the ICU team and this being a forum for open discussion to occur.

... I think it comes down to the openness of everyone in our team... everyone is quite happy to say, "What's happening here?" and we just discuss it amongst each other, and the medical team may have a valid point in saying, "Well actually, no we're not quite at that point," and we'll all say, "Why?" and we always justify that stance so everyone's on the same page... (Gerard)

The category "experience counts" from McMillen's (2008) study was identified as a key aspect in how nurses responded to the interview questions, with one facet being how senior nurses appeared to be listened to by the consultants. McMillan pointed out such a phenomenon should not come as a surprise, given that senior nurses had greater experience in dealing with end of life decision-making, with consultants being likely to

identify this. Such a finding directly complements my explanatory theory of '*Experienced Understanding*', which ultimately concludes that experience is what critical care nurses draw upon both individually and collectively, when involved in end-of-life decision-making and care. This example from Adrienne underscored the importance of experience, in relation to family members being involved in decision-making.

... When it comes to getting the family involved in the decisions, the doctor very much leads that... But what you will find with your more experienced nurses is they've pre-empted... that these conversations are going to take place... your more senior nurses make sure the family are going into a meeting knowing what the conversation is going to be about... (Adrienne)

In contrast to McMillen (2008), Norton and Bowers (2001) grounded theory study used the term planting seeds as part of their wider finding laying the groundwork. The studies purpose was to "develop a grounded theory of how decisions were negotiated among providers and family members near the end of a patient's life" (p. 260). Planting seeds referred to facilitating future discussions with patients and their families regarding the chances that the former may die. This study interviewed 20 participants comprised of ten nurses, five physicians and five family members. The published document cited here only featured data from the physician and nurse participants, and was part of a wider study.

The process of speaking up

As reported in this study above, for nurses to feel comfortable raising the subject they needed confidence of being listened to by the person they chose to discuss this with, and this also dictated how they would go about doing this. Melissa reported what she does in her role as a charge nurse to support her colleagues when the subject is raised during a ward round.

... So it may be a decision that's made on the ward round and they [the doctors] might say, "Right... this patient is for comfort cares"... Or they'll say, "Right, let's go and have a little bit of a get together"... Then I will facilitate the nurse in the bed space to come so that she's part of that conversation... (Melissa)

As discussed in the methodology section the condition speaking up impacts nurses in a variety of clinical situations, including resuscitations. For individual nurses thrown together as a team in a simulated resuscitation, feelings of inadequacy, being lost, disorganised and not wanting to say anything for fear of being wrong are frequent. Even in the face of seeing chest compressions performed ineffectively, the desire not to challenge is strong. When this observation is raised during the debrief and the participant is asked what prohibited them from 'speaking up' about noticing that chest compressions were poor, the response is usually around self-doubt about what they saw, not knowing how to address the issue without it becoming an argument and fear of being yelled at by the other person. Nurses who tackled such an incident as soon as they recognised it, tended to demonstrate a high level of confidence in the management of collapsed patient's, while also actively engaging with the simulation and seeing it as a learning opportunity. In the debrief their rationale for pointing out that chest compressions were not being performed well, was for the sake of

both the patient and the team. For the former understanding that good quality chest compressions are a key component of surviving a cardiac arrest, and for the latter being aware that a team's success is linked to its members keeping one another safe.

Utilising another person to ask a question of an individual you are not comfortable asking yourself, reminded me of when I was growing up and my sister being too nervous at times to ask our mother a question, she thought the answer would be no to. Instead her solution was to enlist my help, therefore creating a buffer in a situation she found challenging, but within which she still wanted to be heard.

A significant aspect of raising the subject was asking the question 'Is this patient for active treatment, or palliative care' and centred around nurse's feeling safe to have their input heard and acknowledged. Adrienne reported how in her experience some nurses will not speak up, "they'll just carry on and do whatever the senior nurse or the doctor has said and they will not speak up". In contrast to this perspective the excerpts below give different examples that show how this intensive care unit strives to maintain a culture, where nurses are encouraged to impart their knowledge of a patient to an intensivist, registrar, or a senior nurse. "We have ward rounds twice a day... and sometimes at the beginning of the ward round we get asked our opinion as nurse's, "How do you feel the patient's going'?" (Holly).

During the routinely scheduled ward round process, the opinion of the nurse caring for the patient is sought in an ad hoc manner. In this forum do nurses only impart their patient insights if invited to? "I'm quite fortunate with being a charge nurse because obviously in that role and in our environment, our opinion is valued and listened to" (Melissa). Is there not a clear expectation that such an exchange of information takes place regardless of whether it is invited or not? "We have some doctors who you can be very straight out with and just say, 'what are we doing here'?" (Melissa).

A distinction exists here between how the opinion of an associate charge nurse manager is received by intensivists, versus that of a staff nurse. Other communication channels include escalating concerns to an associate charge nurse manager, or a float nurse. "... The ICU team is like no other team I've ever worked with in, in that it's very inclusive of all members of staff... "The nurse certainly has as much input as the medical team I would say..." (Rebecca). She then goes onto discuss her understanding of how this works.

This inclusiveness empowered team members to explicitly communicate with one another, at any stage of a shift. Nurses and doctors, who work alongside one another regularly, developed strategies of anticipatory response that can be difficult for outsiders looking in to understand. While a sense of being included may create an environment where speaking up and being heard are encouraged, what strategies insure that nurses feel safe to do this every day, for any patient they have concerns or questions about?

To say "we just observe patients", casts nurses in a very passive light. While observation is an important skill, it is not the only tool available to nurses in their varied toolkit. What this does convey however, is the ICU staff nurse's role in being the eyes and ears for the team,

utilising knowledge gleaned from hours at a patient's bedside to help guide treatment decisions and direction.

A study conducted by Robichaux and Clark (2006) with 21 critical care nurses working in seven different health centres in the United States, found that speaking for or protecting the patient was a recurrent narrative plot. Using a qualitative study design interview data was analysed through narrative analysis, with the initial objective being to investigate expert critical care nurses practice in end-of-life conflicts. Seven participants produced narratives, which related conceptually to speaking for or protecting the patient, with participants discussing patients they believed were vulnerable because they were intubated, ventilated and unable to speak. The absence of their own voice meant their wishes were at risk of not being heard, prompting these expert nurses to advocate for them. While these nurses were expert practitioners, my study showed how junior nurses were at times allocated the care of dying patients, meaning that any reluctance to speak up may have negatively impacted the patient. This ICUs strategy to support junior nurses caring for dying patients involved insuring that more senior nurses, such as the float one nurse and/or charge nurse regularly checked on them and provided support.

... I'll pop in every hour or so and make sure everyone's ok, make cups of tea, and I think by doing that it shows the nurse well hey here's the charge nurse, she's in here being a part of it, doing these things, I can do this too; sort of leading by example. (Melissa)

Speaking up and being heard according to Garon (2012) are an important part of nurse's practice and significantly impacts on patient safety, their job satisfaction and teamwork. Garon's research, involving 33 registered nurses with at least one year's experience, gathered data from focus groups, and analysed this using thematic content analysis. The study aimed to examine nurse's insights into their ability to speak up in their work setting, and reported that influences, which impacted this were personal and organisational. The former included values, cultural background, education and family history, while the latter comprised managers, peers and administrators. For some nurses they described that something within them imbued them to speak up, which they stated they learned either during nursing training, at home or from colleagues who role modelled this behaviour. Advocating or doing what was right for patients was reported by participants in my study, along with perceived barriers to its achievement. Nurses from different cultures working in this ICU were reported by participants to struggle, with the process of withdrawing treatment, which may in turn have influenced hesitancy in speaking up.

It's been interesting having a lot of nurses from different cultures in the bed space... I found out recently that the [named ethnicity] culture doesn't withdraw treatment and they actively treat right up until the point that the person dies on full treatment. We have quite a large [named ethnicity] workforce and they have huge ethical dilemmas when we withdraw treatment... a lot of them have a religious background as well and they feel that they're aiding and killing and that it's a deadly sin. (Melissa)

Research conducted by Langley, Schmollgruber, Fulbrook, Albarran and Latour (2013) that examined the perceptions pertaining to end-of-life care among South African critical nurses, found that their involvement in discussions and decision-making at the end-of-life were

intermittent, despite their input into the delivery of care. While many of these nurses identified themselves as Protestant, they did not feel their faith was an important factor when making end-of-life decisions. However, when the decision to cease active treatment was being made, respondents felt that the religious views of patient's needed to be taken into consideration. Surveys numbering 149 were sent out, with 100 being returned, resulting in a response rate of 67%. Of those participants, 29% stated they had been involved in end-of-life decision-making, with the researchers reporting improved communication would help address this, and they also observed that of those nurses who reported greater involvement in decision-making, 39% had ICU nursing experience.

The findings of Langley et al. (2013) were supported by Hansen, Goodell, DeHaven and Smith (2009) who found in their study of ICU nurses working in four ICUs at a university medical centre that experience and communication impact the delivery of good quality care at the end-of-life. Information was gathered across two phases using a 30-item tool designed by the researchers, to explore nurses' perceptions of interventions devised to improve end-of-life care. Data collection took place prior to the initiation of phase one and after the commencement of phase two. During analysis the most common response pertained to communication and the need for it to be enhanced, between nurses, doctors and patient's families. The investigators also found that participating nurses, who had more years of experience working in ICU, had higher scores related to ability and knowledge.

These findings continue to highlight the gap that exists between ICU nurses input into decision-making at the end-of-life, while their involvement in care processes is significant. I found a similar weighting of involvement between the two processes, with participants indicating that being heard was often nurse dependent, rather than a given across the entire ICU nursing team. The domain of nursing became apparent once the phase of working the problem was entered into.

I think that once the decision's made, nurses have a huge input because I think we follow that through. We prepare the family as much as we can and make sure that the patient's comfortable and dies with dignity and their end-of-life journey is as good as you would want it for yourself... I think that's our biggest input. We're there at the end. As I say, the doctors might not even put their head in after that [commencing the modified LCP] and so I think it's a big responsibility for the nurses to make sure that all those things are followed through. (Laurie)

The Components of Working the Problem

Working the problem is a key element of experienced understanding and encompasses not only the factors nurses take into account when assessing whether a patient needs to make the transition to end-of-life care, but also impacts on the timing of when this should happen and getting it right. The process, property and dimensional elements that make up this category, all facilitate the right decision being made for the patient whom raising the subject was necessary.

From unpacking the options to collaboration

The forums where working the problem was reported to take place included during ward rounds, handovers and most importantly family meetings where a nurse was always present and the patients family were brought into the process. The conditions of unpacking the options, measuring a life, riding the rollercoaster, a process of elimination, collaboration and refocusing attention would occur in any of these contexts, with junior nursing staff being supported by senior nurses from whom they could learn.

... The doctors won't have a family meeting without the nurse who's actually caring for the patient... If that nurse is very junior then a more senior nurse will also sit in on the meeting because the doctors sometimes use medical jargon. I find our unit are very good; the doctors are actually really good at not doing that. But the occasional time they do a more senior nurse will explain something in a different way or they will take that softly approach. Sometimes when the doctors kind of put their decision into the family's hands, the nurse will then say: Guys, we're not asking you to make this decision; we're going to make this decision together... (Adrienne)

The complexity around reaching a decision that everyone understood and could move forward with necessitated transparency and no hidden agendas, whereby breakdowns in communication caused unnecessary additional pain. It was clear from the findings that working the problem challenged nurses to understand their own feelings when it came to discussing end-of-life care, and having the skills to collate the information they needed to be able to make an informed decision. If they themselves are struggling, then they are not in a strong position to support the patient and their family throughout the dying journey.

Experienced understanding assisted nurses at the bedside in working through problems by providing them with prior knowledge regarding what needed to be accomplished during end-of-life decision-making and care. For junior nurses it was understanding they had the support of their more senior nursing colleagues to call upon, which meant they were never alone when working the problem, or at any stage during the dying process. As participants in this study reported, with most of them being senior nurses, they felt that they shared their experience with junior nurses and provided support to all their colleagues who needed it. Ashleigh discussed how she approached mentoring junior nurses who asked for assistance as the shift from active treatment to making the transition began.

... I think it's to do with having experience of doing that kind of thing... I've had junior nurses ask me to come on the ward round, or come back after to help go through the process with them and take the lead because they're not comfortable with it. (Ashleigh)

As discussed previously bringing the patient and their family into the decision making process, can be a time where the burden of responsibility is at risk of being unintentionally shifted onto these individuals. Making the decision to withdraw or withhold active treatments can be interpreted by patients and families as being very black and white. "Choices between life and death even though such treatments are invasive, painful and not able to help cure, stabilise, improve or alleviate symptoms of the underlying condition" (Hawryluck, Sibbald & Chidwick, 2013, p. 1055). This emphasised the findings of my research around the conditions unpacking the options, and a process of elimination that involved examining, is

there anything else that is appropriate to try, or have we reached the end of the treatment road. These assessments involved looking at the whole person and interpreting both the physical and non-physical feedback. "It's... the trends, and the physiological markers. You're at the bedside and the patient looks very oedematous and clammy and they struggle with any intervention; you'd roll them and they struggle, they've got very little reserve..." (Ashleigh).

By the nature of their consequences decisions to continue undertaking active treatments that sustain, or prolong life will always necessitate a high degree of certainty (Hawryluck et al., 2013). Understanding the consequences, which stem from working the problem, and the process of unpacking the options, needed to be treated with respect and thoroughness. This sometimes resulted in different consultants wanting to move in alternate directions.

We had a patient last week who, the consultant that was on overnight, had decided that they weren't going to intubate, or do any major interventions for, and then the consultant coming on for the day decided that he wanted to try and do something... (Reen)

Unpacking the options was intrinsically linked to the process of measuring a life, another condition related to working the problem, which this writer's research established and found related to the decision to move to making the transition. Cook et al. (2003) observed based on their findings from an 851 patient study-examining physician's decisions to withdraw mechanical ventilation that the strongest clinical determinants associated with this process were not severity of illness, age and organ dysfunction. But, rather the doctor's perception of whether or not the patient would want life support, their predictions of survival and the likelihood of the patient sustaining impaired cognitive function. For the nurses in this researchers study a central aspect of measuring a life, involved gaining an understanding of who they were prior to their admission to ICU. Participants in my study discussed how while age was not a sole determinant, it was a component of "who they were before". This differs from the findings of Baggs and Schmitt (1995) who articulated that when deciding the level of aggressive care in the treatment of ICU patients, differences existed relating to the factors that were deemed influential between nurses and resident doctors. Baggs and Schmitt found that nurses gravitated towards listening to the requests of family members, while residents remained focused on functional status. "... From my reference point it's what they were like before hospitalisation" (Rebecca).

Therefore working with family members to paint a picture of their loved one becomes an important part of end-of-life decision-making, particularly when the patient themselves is not in a position to answer. Gerard reported how he approached this undertaking and how complex it could be.

You can get varying viewpoints from the family and some family may note that if they say they [the patient] don't get out of bed, or they just go round the house... they know that the amount of treatment will probably be limited, and they will say no... he does everything okay. Where in fact... 80% of the time you can look back on previous documentation and they'll have attended... a cardiac clinic, or a diabetes clinic, which will have clear documentation of their functional status, so you have to discuss this with the family. (Gerard)

This aspect of measuring a life required skill and the establishment of trust, so that family members did not feel like they were being interrogated. As Gerard went onto discuss it's about forming a partnership and bringing everything together.

You have to go on a fact-finding mission basically. You have to bring together what the family says and what the family wants and what documentation you have in the system about their pre-hospitalisation care... You have to get the whole picture, before any decision is made. (Gerard)

Gerard's discussion regarding obtaining "the whole picture" highlighted the challenges ICU nurses face when working this particular problem, which mirrors Puntillo et al. (2001) who stated that "gaining consensus about care decisions is difficult for patients, patient's families, and care providers. Consequently, a transition from primarily curative to primarily palliative care may be fraught with tension, conflict, and delay" (p. 217). Holly reported how measuring a life also took place during weekly long-term meetings, held for patients who had been in the unit for a while. "... We have long-term meetings which are held every Tuesday for patients who have been with us long term... and these are not just about their medical presentation; they're about the whole holistic picture..." (Holly).

Working collaboratively with families and patients (even if the latter are unable to participate) is known as shared decision-making and according to Sprung et al. (2014) is a dynamic process involving sharing responsibility for making decisions at the end of life between the patient or their family and the healthcare team. The aim was to achieve a consensus regarding the way forward that acknowledges the patient's beliefs and values, while simultaneously providing support and comfort for family members. These author's stress that the motivation, which drives shared decision making is to move away from unilateral decisions that do not take into account what the patient would want. One participant imparted how for one individual not understanding what was happening regarding her husband's care, led to tension and the nurse at the bedside identified the need to advocate on her behalf.

... We told her we're not going to put the tube back in and something came up and the doctor couldn't talk to her. He was about to go and I said, "Oh no, do you mind? She's got this really important question she wants to talk to you about. She'd like you to re-tube him if he gets unwell..." (Holly).

For nurses and doctors working in ICU gaining expertise in the subtle practice of working alongside families doing their best to act as surrogate decision makers, is worthy of effort, which in conjunction with balanced thinking, patience and empathy will always nurture sound decision-making and good quality palliative care (Siegel, 2009).

The Transition

Making the transition comprised a range of concepts all of which were employed by the nurses in this study, to manage this shift as smoothly as possible. These ranged from changing the physical environment to attaining privacy, which all interlinked to assist in the provision of good end-of-life care. ICU nurses were found to be central to this part of the

dying continuum, taking ownership to do it well, while staying mindful of the barriers that could occur.

Changing the environment to facilitate dying well

Nurses in this study were united in their reporting pertaining to the physical shift, which takes place once a patient has commenced the transition to end-of-life care. The aim of this move was discussed as being two fold; to facilitate privacy, focusing on the patient, an increased and constant presence of family and being mindful of the needs of the rest of the patients in the unit, for whom death was not imminent. These were congruent with Efstathiou and Walker's (2014) findings from their interpretive phenomenological study involving 13 critical care nurses. Efstathiou and Walker reported that nurse's experiences in the provision of care at the end-of-life were comprised of four master themes, namely providing and encouraging presence, dealing with emotions and ambiguity, caring for the dying patient and their family and reconnecting the patient and their family. Of particular resonance to this author's study, was the correlation between changing the physical environment and these themes. Providing an encouraging presence was focused on nurses' belief that a patient should not die alone, and that someone should be at the bedside all the time. If family could not always undertake this, then it became the nurse's responsibility. In the ICU my study took place, a 1:1 nurse patient ratio ensured that the latter was never alone. To ensure a family presence Efstathiou and Walker suggested that at times withdrawal of treatment was delayed, until people arrived and while a similar phenomenon was found in my study and became a key dimension of timing, this related to family either wanting to buy time to come to terms with what was happening, or so that other family members had time to arrive.

Participants in my study reported that moving a dying patient and their family into a private space facilitated the establishment of an environment where family members could remain ever present and in greater numbers. This reflected a unit wide understanding that for the dying, restrictions around visiting hours and visitor numbers would be relaxed, to support family coming together. Reconnecting the patient and their family was described by Efstathiou and Walker (2014) as an important strategy to address possible barriers created by the technological nature of the ICU environment, and involved removing equipment that promoted this sense and engaging family in the care of their loved one. Switching off or turning away vital sign monitors was seen in my findings as a way to remind family members that their focus needed to be with the patient, and experience informed these nurses that attention became fractured if this was not tackled. "Often they [family] are keeping an eye on the monitor... so we'll turn off the monitor so that people are not focusing on the numbers but focusing on the patient" (Rebecca). Laurie reported the same perception.

You give them the opportunity to spend those last moments with their relative. But I don't necessarily think that we need to have the monitors on to be seen by the family; they take away from the whole dying process and relatives being together. (Laurie)

The amount of technology present in ICUs can also be overwhelming for nurses. In a profile piece that focused on nurses working in Christchurch hospital's ICU, one nurse commented

that she felt daunted by the monitors and multiple infusions when she first started. “I had to break down the machinery into manageable pieces and take every infusion one at a time. But after about six months, my focus was more on the patient...and now I don’t focus on the machinery nearly as much” (O’Connor, 2010, p. 15).

Making the transition also marked a shift away from active treatment and saw the withdrawal process commence and a focus on palliative care begin. Key interventions reported as part of my study that characterised this shift, were the withdrawal of mechanical ventilation and the administration of pain relief. Ceasing ventilatory support and/or extubation saw participants informing their thinking by drawing on previous experiences of this action, which were both good and bad, with the goal then being to prepare families to understand the changes that would occur during and after cessation, and ascertaining the part, if any, they wished to play during this transition. For Adrienne managing this required experience.

The actual withdrawal of things like ETTs and blood pressure support, need to be managed by I would say senior nurses rather than junior nurses who haven’t seen a million times what to expect and haven’t prepared the family, because that can change somebody’s experience for life... (Adrienne)

This was a common aspect of making the transition whereby participants reported how important it was that extubation be well planned and family well prepared. Managing this well then became an extension in the provision of a good death. Norton and Bowers (2001) described this aspect of end-of-life care as changing the value of treatment options, reframing them to accentuate the value of palliative care and that it by no means meant that anyone was settling for second best. Norton and Bowers reported that active treatment interventions were de-emphasised, with their negative aspects being highlighted along with their ability to prolong suffering. Ceasing this life sustaining intervention was also interwoven with the category of timing and getting this right, with nurses advocating for patients when their dignity may have been compromised, if letting them die became prolonged due to family negotiating for more time. This will be discussed in greater detail in the next section of this chapter.

Analgesia and the intent behind its administration featured in the sub categories making the transition and a good death is dying well. Experience and personal and cultural beliefs influenced the nurses in my study’s perceptions around the administration of adequate pain relief. In an effort to provide health professionals with reassurance, White (2014) described the principle of double effect, which differentiates between intended effects and those that are anticipated although unintended, when pain relief is prescribed and administered. Many of the nurses in my study reported the impact the administration of morphine had on some of their colleagues, when given in doses they believed would hasten death. Some of them spoke about their experiences as senior nurses and having to step up and take on this responsibility for nurses where giving morphine boluses was too challenging. Not all however, were unconditionally supportive of such a stance, and felt nurses whose beliefs were challenged by the role of pain relief in comfort care, needed to come to terms with how

this process is managed in New Zealand ICUs, even if they have to distance themselves from involvement.

It is part and parcel of working in ICU and its part and parcel of being in New Zealand, where we do have end-of-life care, and we do withdraw treatment. I'm not saying that they have to be involved or agree with the decisions, but they need to understand why we make certain decisions and at least be accepting of that, otherwise you have to question if they're working in the right environment... (Adrienne)

Time and Timing – Getting Them Right

Nurses are constantly faced with having to manage time in some way. The drivers behind this can include managing six patients in a ward environment; being faced with the arrival of a status one patient into the emergency department, or planning a complex patient's discharge so they can return home. Finding the balance between the best outcomes for the patient, the needs of family members, and the needs of the nurse, require a degree of compromise, to reach an equitable conclusion. In the context of managing end-of-life decisions and care in ICU, nurses co-ordinate making the transition, aspects of working the problem, making the judgement to raise the subject and pulling these elements together to facilitate a good death. The findings from my study show that time is an important aspect regarding nurses' influence on end-of-life processes and how gaining experienced understanding assists in harmonising the processes, properties and dimensions that make up this category. To recap, these are: Buying time, how long will death take, negotiating, what happens while we wait and finding the balance.

Buying time is about nurses and families working together to create a period of time for the latter, and their loved one to adjust to what is happening. Upon making the transition to the side room, the focus for nurses became about family gathering together and maximising their time with the patient. However, as Rachel reported this was not always a smooth journey.

We have had [names ethnicity] patients... and I remember them so clearly... the doctor's made a decision and we are going to extubate and nobody's [the family] happy. Can we have some more time? We have had families given 72 hours to come to terms with extubation... at the end of the day they agree but I can definitely see the cultural difference. (Rachel)

Building trust with families and understanding their cultural needs was a key facet of negotiating withdrawal of active treatment, while also being an integral component of dying well. This is congruent with findings reported by Pattison et al. (2013) who suggested that timeliness contributed to staff and families feeling that a good death had been achieved. This pertained to nurses being able to direct withdrawal of active treatment, and foresee when a patient's death was pending and provided support to the family. Pattison et al. also observed that some nurses reported being hesitant about the practicalities associated with treatment withdrawal, with this being attributed to feelings of experience and confidence.

How long a patient took to die was another condition that correlated with the provision of a good death, once again linking these two categories. Pattison et al. (2013) found that to die

well, dying had to not take too long, but also not be too fast. As Holly reported taking too long to die might mean being transferred out of the unit and onto a ward.

... You can't say how long it will take. If we think it may take a while then we might look at the benefits of moving them to a ward, or home, or wherever the family want them to be. But it's not something that I see encouraged, which to be honest I don't understand... (Holly)

Laurie reported that being short of beds also had an effect on the pacing of making the transition and the provision of end-of life care. "... When you're short of beds I think that a lot of people are fast tracked... we need to palliate them quicker. And I think that can be quite impersonal but it's just the nature of the hospital..." (Laurie).

This raises the wider issue of resourcing and the consideration that for some patient's, ICU may not be the best place for them to die. It is worth considering here that providing palliative care to patients who are dying is complex, as well as being both distressing and stressful for nurses, who will take on much of this responsibility, because in most Western countries people who are dying are cared for in acute hospitals (Gagnon & Duggleby, 2013). In addition, for many dying patients being at home to die is not considered important, but as too overwhelming, when having skilled people present to offer support and symptom management seems a more attractive option (Eues, 2007). For families the experience and skill of the nurses caring for their loved one makes a difference, because "losing a loved one in the ICU is one of the most stressful events that a person can experience. It is a "life-changing" event and it will be remembered by the close relatives forever" (Fridh, 2014, p. 308).

The ICU is a unique environment in which to die, due to the fact that unlike in any other hospital setting, time can be manipulated and controlled. As reported by Gerard below, time existed as something that could be shortened.

There's always been one situation that's never sat comfortably with me. We had a patient who was in status epilepticus and was not going to survive, and this was when I was relatively new; I couldn't quite fathom the situation and the consultant at the time said to us... "We're going to give them some midazolam and blunt off their respiratory functions so they can pass away peacefully", and at the time I was like, "Well it's futile." That's fine but you always get situations that I think hold a little bit of a tweak in the back of your mind and you always think morally and you think, "Was that the right decision at the time," because you know euthanasia is technically illegal, and what have we done there, we've sped up that person's death basically... I think you will always have people who have tweaks in the back of their mind that people carry around like that. (Gerard)

The question of how long a person can live for once treatment is withdrawn, is also linked to the way in which palliative care is managed. The parameters around the use of such medications as morphine are governed by the intent behind its use, and the frequency and amounts in which it is prescribed. While morphine may hasten a person's death, if the intent it is being used for is to reduce the pain and suffering associated with dying, and not to purposefully end a life, then the fact that death may result, is a by-product of the primary intention. This phenomenon known as the double effect was discussed above. Gerard's vivid retention of an experience earlier in his career that involved the use of midazolam at

the end-of-life, underscores how nurses can inform their current practice by drawing on their own historical decision-making, or those they were involved in as part of a team.

Having experienced the death of a loved one, whom during the process of dying you want to be as pain free as possible, while at the same time seeking every opportunity to extend the time you can spend with them. Logically it can be understood that death could and should not be held at bay indefinitely, however emotionally the temptation to forge ahead with heroic measures is very strong.

Achieving A Good Death

Being pain free/maintaining dignity

Understanding how to maintain adequate analgesia levels and using which drugs requires a knowledge base gained through learning, and refined over time. Death and its association with pain have long proved to be a challenge for nurses, along with how to mitigate it from ruling the dying process. In critical care strong intravenous analgesics administered in conjunction with hypnotics, mean that pain can realistically be kept at bay. The trade off to achieve this however, can mean that a patient has to forgo lucidity, or consciousness in order to be liberated from the pain they are experiencing. Nurses are the advocates who are in a position to ensure the pain management plan is comprehensive and achievable, and that it meets the patients' needs from both a physiological and socio-cultural perspective. To be effective in doing this, finding out from family members, or if possible the patient themselves, what their wishes are as they enter the final stage of their life, is important. "... As long as the patient's comfortable and there are family members around, they're on adequate sedation or morphine and midazolam... and they're just supported with dignity really and pain relief" (Laurie).

Laurie identified that for her comfort; dignity and not being alone are important elements of a good death. This suggests that in the absence of these conditions it may not be possible for a person to die well. Making these circumstances possible is facilitated in the work environment of these participants, by moving the patient into a side room, creating a private space where additional family and friends can remain present for more sustained periods of time. This change in physical environment occurs as part of making the transition, and marks the patient's passage from cure to palliative care. This transition comprises the dimensions of the death and dying room, increased privacy, flexible visiting hours, increased visitor numbers and withdrawing treatment.

Schenck and Roscoe (2009) observed that, "dying is a personal and a public act that is constrained by experiences, expectations and access to resources determined by history, circumstances, and social context" (p. 63). For patients and their loved ones Schenck and Roscoe ruminated on how dying has become fraught with the need to make difficult decisions, which has the potential to detract from spending time on those activities that will aid coming to terms with what's ahead. The interview excerpts discussed below demonstrate that the nurses, who participated in this research, have a clear understanding

of what a good death should look like. The challenge then becomes about how to put this into practice. Ensuring a good death is something critical care nurses are in a strong position to facilitate, even within the potential constraints of the inpatient setting.

... If we're going to palliate them basically, they end up in a side room cause we think it will happen reasonably quickly. We had one patient that came back to us. She'd gone over to another ward. It was a really awful case because there was query an accident with insulin administration or something because she was hypoglycaemic and there was damage that was irreversible... (Holly)

This interview excerpt relates to a good death, but also has links to two other categories, those of time/timing and making the transition. While ICU may not be seen as a place where people go to die, the situation above demonstrates that for patients with complex health needs, being cared for in ICU as the most appropriate place for their needs to be met, is an important consideration whether they are dying or not. Part of a good death is being able to die in a place where the expertise exists to ensure the dying process is handled well. Dying involves a unique level of complexity (pain and secretion management), which means that in the absence of appropriate infrastructure being mobilised, such as palliative care teams or district nursing, discharge from ICU to either a ward or the patient's home, may not be suitable. Wilson, Gott and Ingleton (2011) observed that a deficiency in resources or interventions to support cares, impacted on making decisions for patients to be transferred home to die. Coombs, Long-Sutehall, Darlington and Richardson (2015) found that while patients dying in ICU had a preference to die in their homes, and health care professionals supported this, the feasibility of facilitating this in every situation remains limited. Coombs et al. concluded therefore that it remains debatable whether or not this will become an accepted component of end-of-life processes, due to the diversity of patient needs, the complexity of transferring to community based services and the length of time a patient may take to die.

A good death is a death where the patient is free of pain, discomfort and agitation, they're surrounded by things that are special to them, so music playing, they're surrounded by their family and loved ones... sharing stories, reminiscing about the person, joking, having a laugh. You know taking the focus away from the fact that they're dying and putting the focus on the fact that they're a person who is leaving us and this is our opportunity to share with them and say goodbye... (Melissa)

Gaining an understanding of what critical care nurses perceived as contributing to a good death provided an indicator to what extent this impacts on the end-of-life process. Through enabling family members to be active participants in their loved ones last hours, nurses are influential agents through the building and maintenance of functional relationships. Melissa's assertion that sharing and saying goodbye are important aspects of a good death; reflect the findings of Kehl (2006) who identified attributes of a good death, including recognition of death being imminent, values and beliefs being upheld, the optimisation of relationships and family care. These conditions move beyond the tenets of being comfortable and pain free, that encapsulates the physical attributes of dying well.

I think a good death has quite a few facets to it. For me, one of those is that all the family members are aware and are in agreement; they may not be personally present but that there's cohesion within the family... (Rebecca)

Rebecca suggests here that family cohesion is a contributing factor to a good death. To assist in achieving this, participants reported that family meetings are held regularly, allowing for updates regarding the patient's status to be discussed, questions from family members to be answered and decisions regarding whether to continue treatment to be initiated. However, as reported in the findings chapter (p. 75) one case occurred where this did not happen, where the conditions of poor communication, language barriers and fractured family dynamics resulted in a close relative not being included in family meetings and update sessions. Dying fighting a battle that cannot be won and potentially suffering in the process is the hallmark of a bad death. Pain and suffering are both considered tenets of a bad death, and are not exclusively related to pain, but include emotional anguish, spiritual distress and mental illness (De Jong & Clarke, 2009). Heyland et al. (2015) reported in their study conducted with over 500 family members of relatives over 80 years of age admitted to ICU, how important effective communication was in determining a good death trajectory. Incongruity was found to exist between what families preferences were regarding end-of-life care, and the care their loved ones ultimately received. Heyland et al. found that poor decision-making and communication could result in patients receiving life-prolonging interventions that were not wanted, with families reporting that prolonging life at any cost was their least important priority. The competency and skill of the nurses caring for their relative was cited by families as being the aspect of admission they were most satisfied with, which is congruent with this authors explanatory theory of *'Experienced Understanding'*.

... When I first started working in ICU I was blown away by the sheer technicality of it that I probably didn't appreciate how much you can do in end of life care, but as my time has gone on and especially with the introduction of the LCP... It's given me a bit more insight into it. It becomes one of the most rewarding things when you can let people die with dignity, more than saving lives, is to give them that sort of process through to death that's comfortable, and the family are comfortable with it... When they say, "Thank you for doing that, that was really nice," it puts a gleam on your day and it makes things so much better. (Gerard)

This perspective highlighted some of the stages through which participants progressed to attain experienced understanding. These stages included, time spent working in ICU, learning how to use and integrate technology into care and developing an understanding of what it means to facilitate dying with dignity. As Truog et al. (2001) observed, within the ICU setting, advances in both knowledge and technological capability have not only improved our capacity to restore health, but to provide patients with a pain free and dignified death. Gerard concentrated on looking beyond a cure, to see that death is not a failure, but the end of one journey and the beginning of another (Bhatnagar & Joshi, 2012). Appreciating this on a philosophical level without having any actual experience of death, either personally or professionally may render this insight hollow when it comes to forming meaningful relationships with a patient and their family. A stronger degree of empathy is achieved through having shared the lived experience of others, at some stage. Gerard explains that when he was a nurse new to the ICU, learning about the capabilities of the technology available in this environment, meant developing an idea of how nurses can affect end-of-life care took longer to consolidate. Once a decision is made that a person is now for end-of-life care, making this transition along with the effort to ensure a good death may equal or

surpass the original endeavours to treat (Beuks et al., 2006). “A good death means that the family have all come to terms with the situation, they’ve all decided. They’ve said: Okay, we’re ready” (Adrienne).

Like Rebecca, Adrienne sees a component of a good death as family members being on the same page regarding what is happening and that they feel ready. Dying a dignified, comfortable death is consistent with the findings of a 15 respondent study conducted by De Jong and Clarke (2009), in their paper ‘what is a good death stories from palliative care’. De Jong and Clarke contend that what constitutes a good or a bad death, has not been well explained in the literature, and set out to remedy this by undertaking research in the area of palliative care. Interviews were conducted, with thematic narrative analysis being performed on the resulting transcripts. The resulting themes were categorised under either a good or a bad death, and included having the chance to be prepared for death, having the chance to say good by to loved ones and being free from pain and suffering. Loss of control, being dependent on others, not being heard and dying alone were reported as constituting a bad death.

“A Good death I believe is pain free” (Rachel). Rachel’s description of a good death also correlated with De Jong and Clarke’s (2009) findings, and focused on a patient being pain free, with this being achieved through a combination of analgesia and sedation. A challenge with sedating someone as part of a pain management strategy, is if they had the option, would the patient choose to be kept unconscious, or free of pain but lucid? Intubation does not routinely necessitate complete sedation for the duration it’s in place. Therefore a patient who is dying needs to have the choice of remaining conscious, without fearing that pain relief will be inadequate. A nurse’s ability to explain to family members what is taking place during the dying process, as well as provide guidance around what to expect once making the transition commences, I believe is an important skill when caring for the dying. A skill that is informed and deepened by the cumulative attainment of experienced understanding.

The patient themselves is comfortable and the family can see that their loved one is comfortable - they know what’s going on... what the story is. Everybody’s comfortable, understands and feels supported; the patient especially. You want the patient to be comfortable. If they look like they’re uncomfortable; anxious, that’s not a good death. (Reen)

Reen picks up where the discussion left off in the previous section, regarding the importance of family members feeling included and aware of what is going on. For the patient, authors indicate maintaining a sense of control as a key element in designing a good death. Having significant control over issues pertaining to dying, is cited by Leung, Liu, Cheng, Chiu and Chen (2009), under the broader category of “autonomy and preference” (p. 695) as a major constituent in contributing to dying well, which the authors highlight is supported by the existing body of literature relevant to this subject. Interestingly, the findings of Leung et al. contrast some of the findings presented in this thesis, which correlate a good death with being free from pain, even if achieving this means a patient has an altered level of consciousness. Who then, is this altered state preferable for? The patient, their family or

the nurses providing care? According to Leung et al. finding a balance based upon a patients individual requirements, needs to be the foundation from which care is planned and their five stage process developed with the aim of facilitating a good death aims to achieve such an equilibrium. One of the keys to this is, they suggest reducing a patients pain to a level that is acceptable for them, whereby the other four stages; autonomy, acceptance of death and spiritual inspiration and sublimation can all be progressed through.

Summary

In this chapter a discussion has taken place based around the findings presented in chapter five of this document. End-of-life decision-making and care in intensive care are complex processes, requiring nurses to draw on their own '*Experienced Understanding*', or that of their colleagues if this is still developing. The sub categories; raising the subject, working the problem, making the transition, time/timing – getting it right and a good death is dying well, are all supported by the existing body of knowledge, and their symbiosis gave them strength as they formed the explanatory theory of '*Experienced Understanding*', as represented in figure 16 below.

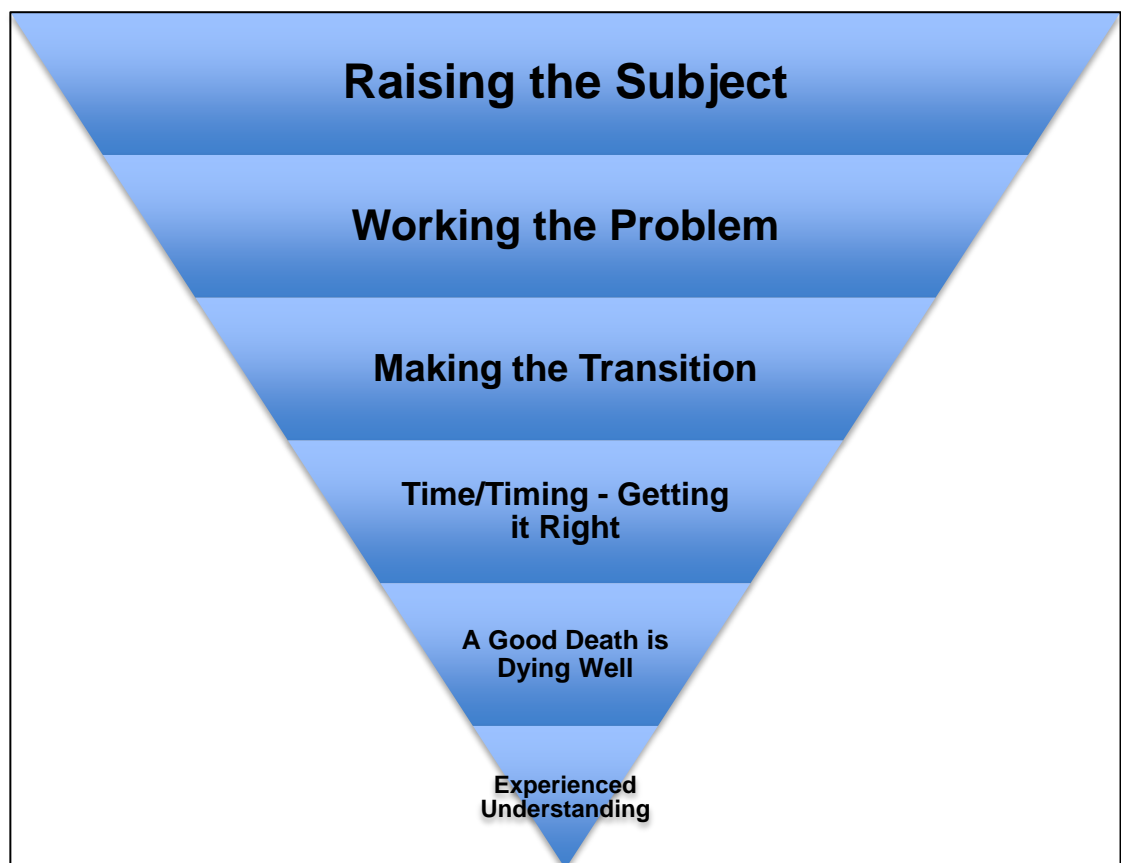


Figure 16: Drilling down to the theory of experienced understanding

Significant Implementations

The ICU in which this study took place has, in this researchers opinion, implemented two key initiatives that have been instrumental in supporting nurses to better engage in and manage

end-of-life decision-making and care. The first was the integration of a modified LCP, which was adapted to meet the unique spiritual and cultural needs of the patient population. The second was an insitu (in the clinical environment) simulation programme that has facilitated the development of communication skills and forged stronger links between nurses and doctors. Both initiatives had been initiated prior to the commencement of this study.

A modified LCP

As documented in my findings chapter the LCP was introduced into this unit, with a senior nurse as its proponent. However, due to a lack of flexibility in its generic form, a modified version was created in 2013 that better fits the unit's needs. Its significance rests with how it has created a common language and provided the steps to follow when particular events occur, including conversational prompts and drug administration. Melissa who has been instrumental in bringing about this change commented during her interview that it "didn't work for us, just purely because it wasn't individualised enough. We've got very unique spiritual and cultural needs and they weren't met by that" (Melissa). She went on to discuss how a piece of positive feedback regarding the adapted pathway was "that people are feeling more comfortable to speak up to the families, they some families cross boundaries and they don't know how to deal with that" (Melissa). Clear and effective communication around speaking up, providing regular updates, what to expect and facilitating all parties to understand the plan, are all things a care pathway can support.

With the new pathway that I've written we encourage the nurses to speak to the families and find out what their expectations are of us as a hospital and of that person as a nurse, and also let them know these are our boundaries and this is what we expect from you. (Melissa)

The decision to commence a patient on this pathway occurs after all possible causes for the patient's condition have been considered, a decision pathway has been completed and all family meetings documented. The findings from my research support that a level of '*Experienced Understanding*' supported ICU nurses in initiating and managing this process.

Building a culture of safety

Additionally, the inception and integration of an insitu simulation programme that encourages ICU nurses and doctors to work together as a team, has had a positive impact on collaboration, effective communication and speaking up within this ICU (C.H, personal communication, December 18, 2014). The motivation behind this approach was to embed human factors and teamwork principles into everyday clinical practice. These are: Sharing a mental model, role clarity, clear communication, resilience, speaking up and psychosocial safety. As my study has demonstrated, speaking up and clear communication are key elements of '*Experienced Understanding*', and are honed over time, through experiential learning and life experience. This simulation programme provides nurses with an opportunity to develop these skills in a safe environment; alongside the people they work with every day. Effective teamwork and communication are fundamental to the provision of safe, high quality patient care (Leonard, Graham & Bonacum, 2004) including at the end-of-

life. Simulation supports nurses to “enact their knowledge of the natural and human sciences, technology, and ethics... to transform this knowledge into the capacity to perceive and act in a given situation” (Benner, Sutphen, Leonard & Day, 2012, p. 178). In recent years nurse driven research in critical care has increased, with the resulting challenge being to ensure this information is disseminated internationally, to benefit continued knowledge acquisition and to position ICU nurses to be better prepared to meet future care needs, including those at the end-of-life (Pirret, 2011).

Limitations of the Study and Recommendations for Future Research

This study has a number of limitations, all of which stemmed from it being conducted as part of a Master's Degree. These included a small sample recruited from one ICU. Participants were only interviewed once and no observation was undertaken. For researchers interested in building on this field of study, I would recommend being in a position to recruit a larger number of participants, including intensivists. Expanding to include multiple ICUs would add the opportunity to compare similarities and differences that may exist from hospital to hospital. Re interviewing participants to clarify points of significance and test emerging concepts would also be valuable, along with observing participants working in the ICU environment. Since conducting the research that has been reported in this thesis I have developed an even stronger conviction that qualitative methodologies provide a good opportunity to gain rich data on the complex processes that comprise end-of-life decision-making and care.

Significance of the Study

A summary of what this research has found

A nurse's level of engagement when caring for a dying patient, to an extent rests with them. For some nurses, a talent is tapped into that enables the nurse to walk the end-of-life path alongside those on this journey, but for others it can be more of a challenge. Starting the conversation around whether intensive treatment is the right approach for some patients is where the process of end-of-life decision-making begins.

Raising the subject necessitates a team approach and requires every team member to have his or her voice heard. Family members and the patient themselves, where practical, are advised soon after admission that discussions pertaining to the level of intensity and the benefit of treatment options would be ongoing. Once the decision to cease active treatment has been made, the transition to palliative care begins.

A condition of this focal shift involves making the transition, moving the patient and their loved ones from an open plan setting in the main critical care unit, to a side room where privacy is more prominent. The physical relocation underscores the gravity that underpins the change-taking place here and the recalibration the nurse caring for the patient undergoes, in preparation for the responsibilities to come. Wellness and recovery are no

longer the goals here, but rather, it is a good death, nuanced by an '*Experienced Understanding*' imbedded in the nursing team of how to achieve the new objective. End-of-life care is the nurse's domain, from facilitating the physical changes; switching off monitors and discontinuing infusions, to interacting with patients and their families and ensuring they are included every step along the way.

Interwoven throughout this process is the influence exerted by time and timing. When is the right time to raise the subject, make the transition, enter into discussions with family and negotiate when death is likely to occur? Preparing a patient and their loved ones for what to expect during the dying process, plays a central part in humanising this experience. Discussion's involving what takes place physically when a person is dying creates a partnership between family members and the nursing team that further cements how important it is to have the skills to balance clinical acumen with an understanding of human factors, and how these impact on dying in ICU. Critical care nurses are well placed to deliver a high standard of care at the end of life, with '*Experienced Understanding*' providing an explanation for how this is achieved.

New Zealand is a unique place in which to die, due to a strong focus on having family and friends present, during and after the dying journey. The ICU in which this study took place embraced strategies that enabled visiting parameters to be relaxed, as part of a patients dying trajectory. Critical care nurses ongoing acquisition of '*Experienced Understanding*' will keep them well prepared to adapt to an ever changing patient population, whose needs are constantly adjusting. Singing and family members keeping vigil were both considered hallmarks of a good death, as reported in this study. During a conversation with my supervisor regarding this finding, she discussed how she had experienced this while spending time in another ICU, which indicated that this aspect of dying well is supported elsewhere within this environment in New Zealand (B. McKenzie-Green, personal communication, April 20, 2015).

Conclusion

In this thesis critical care nurse's influence on end-of-life decision-making has been explored and discussed. Nine ICU nurse's provided the data for an explanatory theory of '*Experienced Understanding*' to be formulated, using grounded theory. This theory stands on a strong foundation built from five interlinked sub categories, comprised of Raising the Subject, Working the Problem, Making the Transition, Time/Timing – Getting it Right and A Good Death is Dying Well. '*Experienced Understanding*' brings together and contextualises what was happening, throughout the processes of end-of-life decision-making and care. This study has reinforced how ICU nurses constant bedside presence; make them a key asset throughout the end-of-life continuum. For less experienced ICU nurse's and junior RNs a strong support network of senior nurse's, using their '*Experienced Understanding*' came alongside them to mentor and lead by example, in an effort to overcome barriers to speaking up, maintaining dignity and being instrumental in the provision of a good death. While ICUs are not traditionally seen as optimal environments in which to die, this study has

found that as long as nurses '*Experienced Understanding*' is developed, they are equipped to manage this challenge.

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Appendices

Appendix 1: Example of a Memo

Date Memo Started: 23/02/2014

Nurse 04

In ICU, especially our one, it's quite open and we can say, "I think this is futile; what are we doing?" Sometimes that necessarily may not be right in circumstances and majority of the times it is, and you find a day or two later things got worse and then you move onto the palliation and comfort side of things.

Code: Speaking Up/Speaking your Mind (14/02/2014).

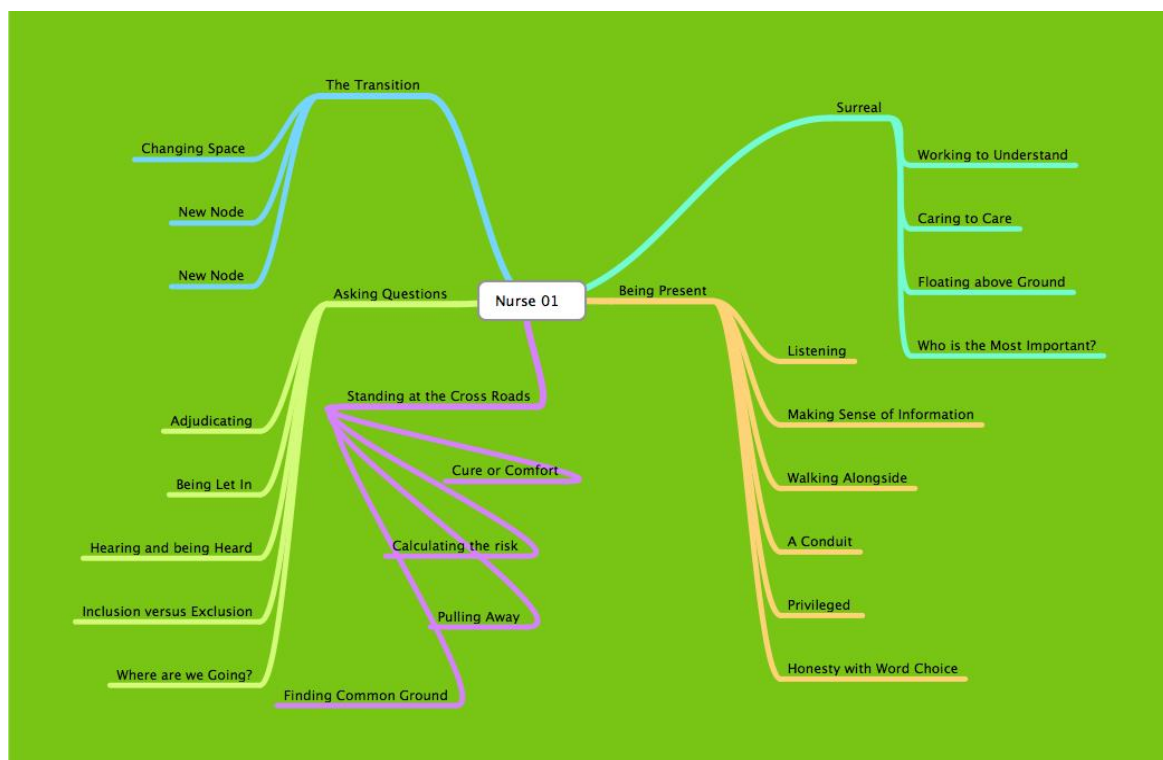
Memo:

In this passage the concept of speaking up comes to the fore. For nurses feeling safe to verbalise an opinion, in particular with senior colleagues can be a difficult hurdle to navigate. A number of reasons can account for this: personal confidence, years of experience, putting patient needs first, and working in an environment that values everyone's input. When a team is clear that each and every member's perspective is useful, this not only facilitates a broader level of knowledge being made available to aid decision-making, but also means key items of consideration are less likely to be missed.

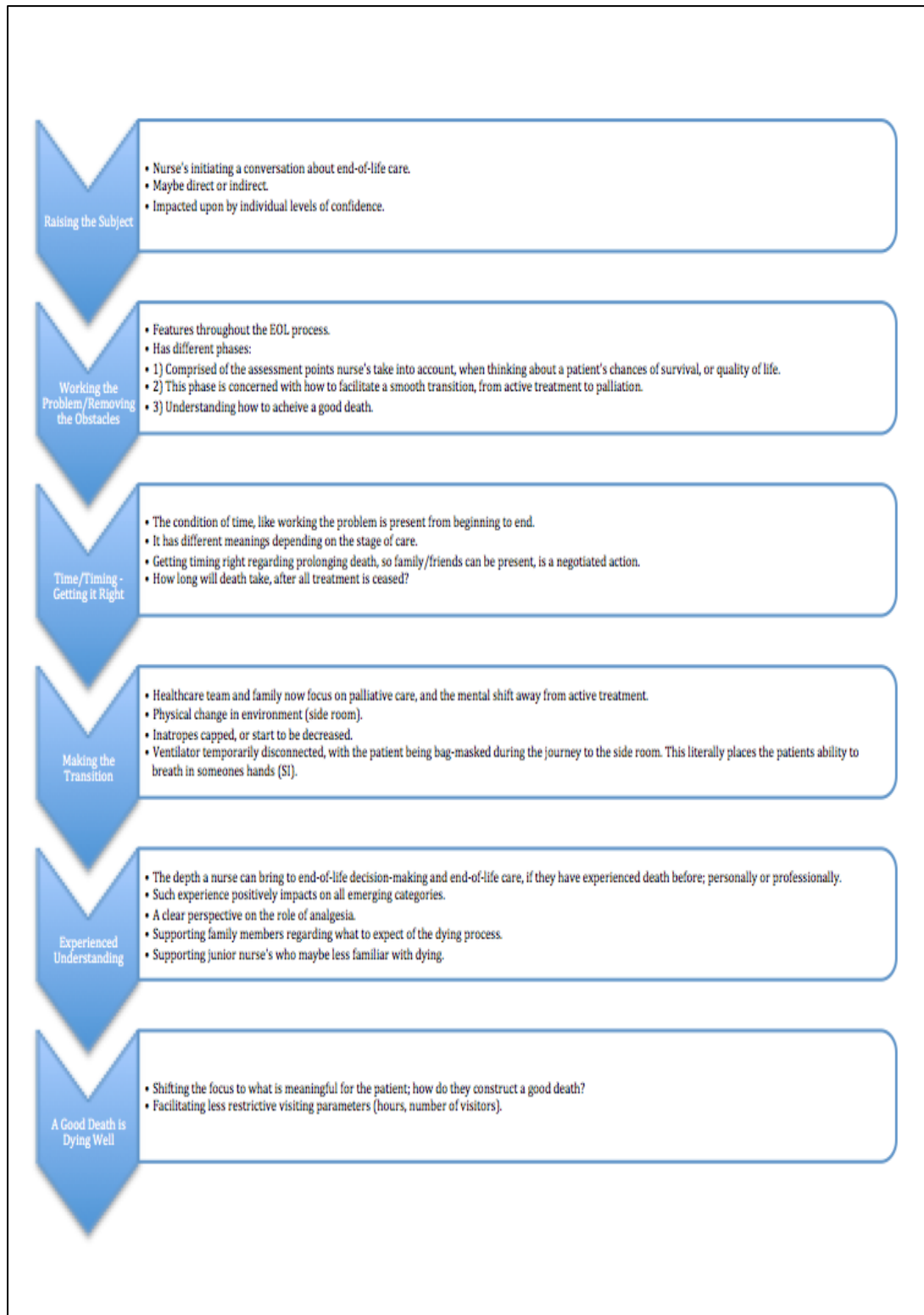
The assertion here is that if a nurse asks the question "I think this is futile; what are we doing?" with regards to particular patients the outcome is often that the person in question is going to die. Therefore, the nurse's constant bedside presence enables them to be ever vigilant and to develop a level of sensitivity to changes in condition as to place them in a position of being 'the first to know.'

There is the suggestion here that if the transition to end-of-life care was made earlier, then perhaps any suffering experienced as a result of this delay could be avoided. Interwoven throughout a patient's time in critical care is the notion who is the primary beneficiary of asking "I think this is futile; what are we doing?" The ideal answer is the patient and their family. Conversely for some nurses not speaking up and initiating this discussion may also be seen as having a patient's interests at its heart. By advocating that a patient should explore every option, give treatments time to work and not discuss what happens if interventions don't work, then death isn't being hastened by changing focus from active treatment to end-of-life care.

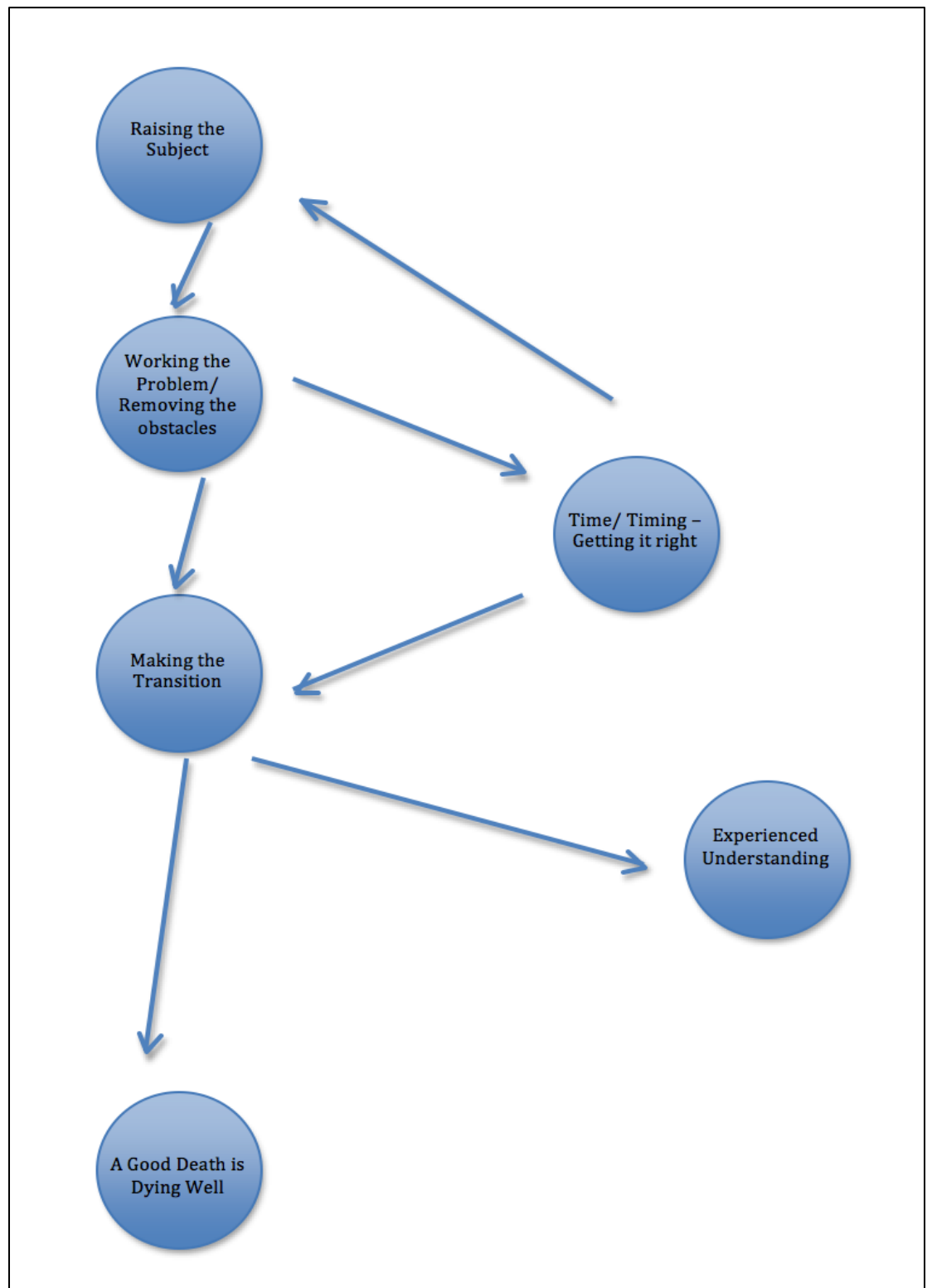
Appendix 2: Open Codes for Nurse 01



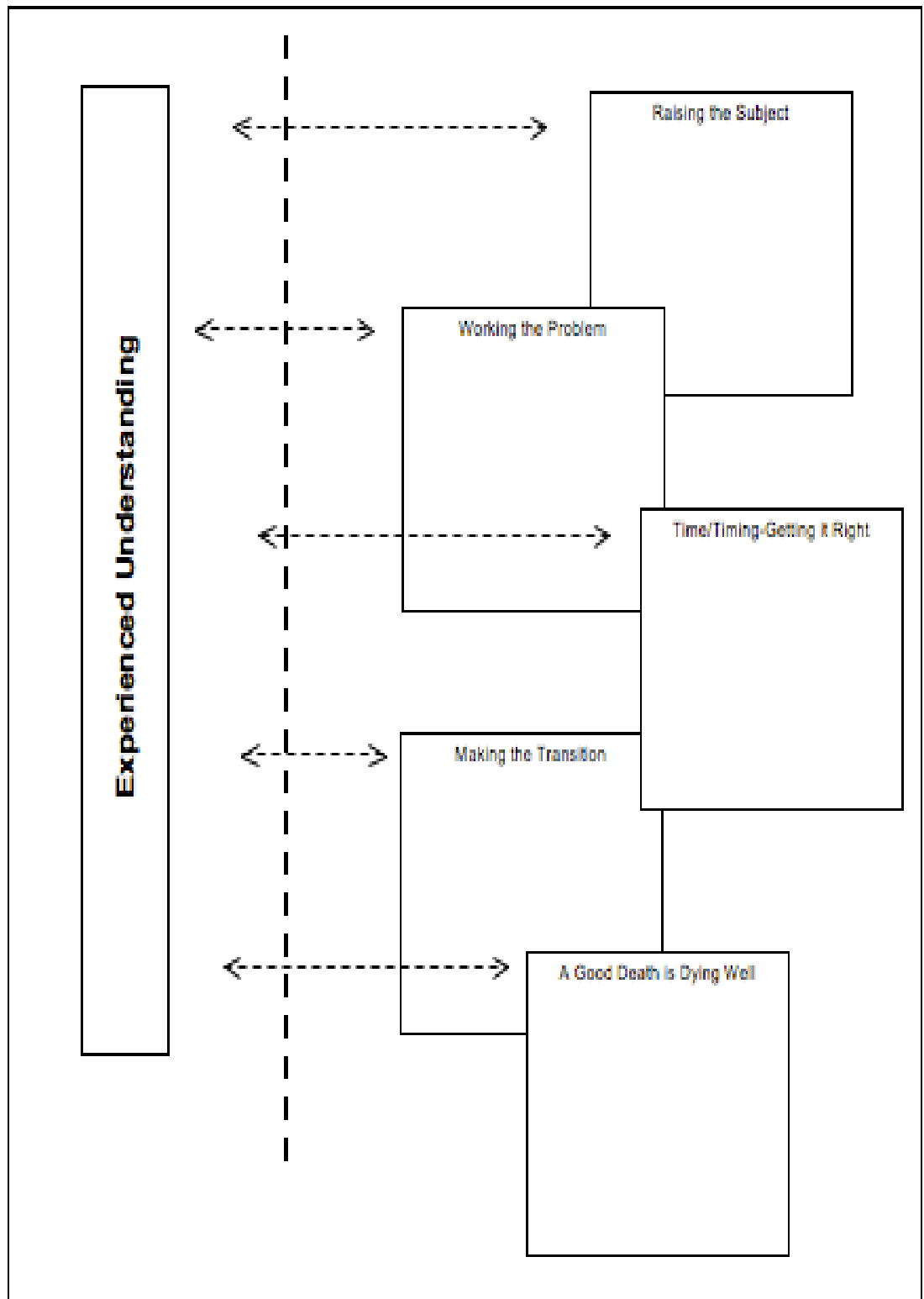
Appendix 3: Initial Category Diagram



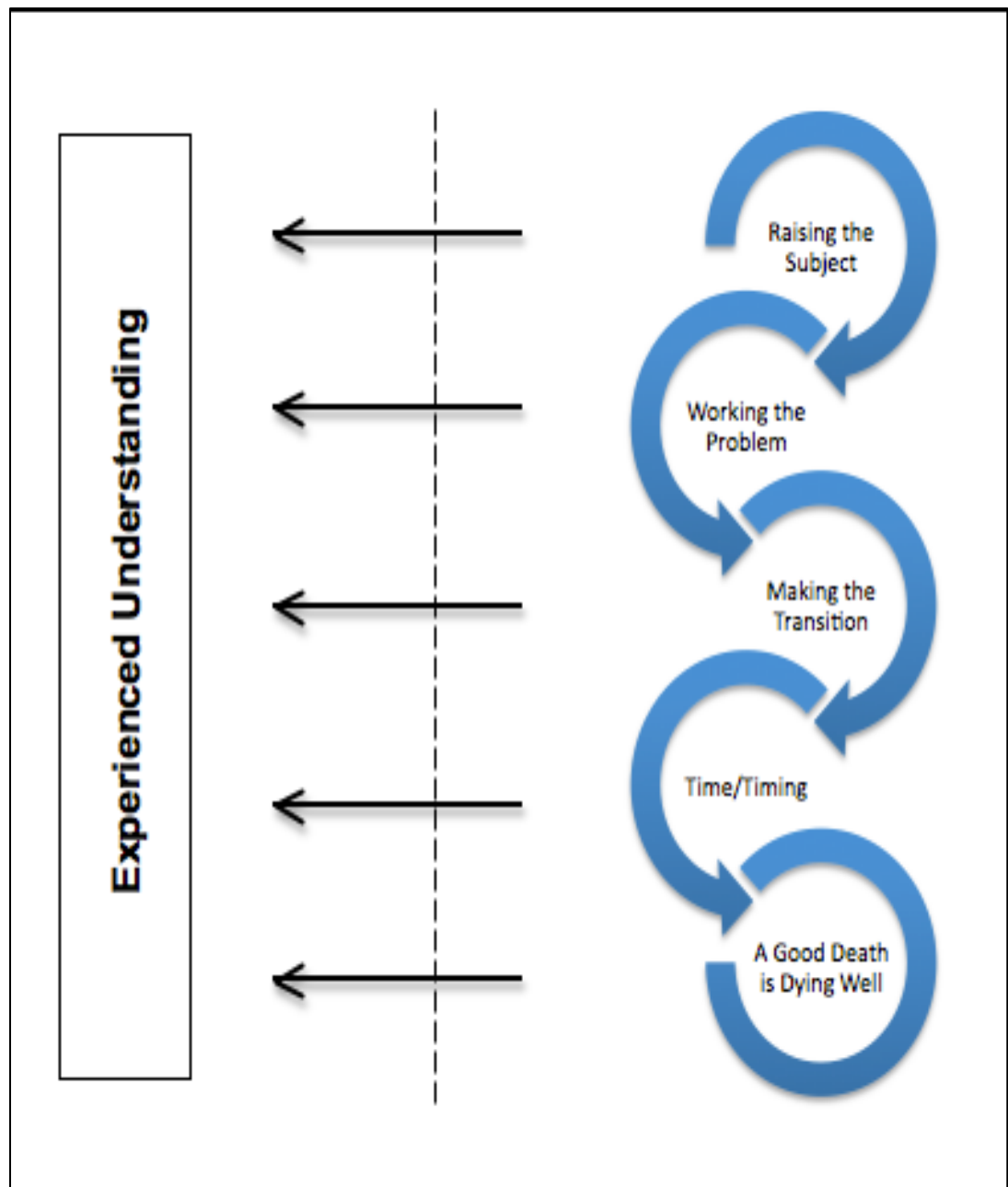
Appendix 4: First Theory Diagram



Appendix 5: Second Theory Diagram



Appendix 6: Third Theory Diagram



Appendix 7: Letter of Invitation

Greetings,

This is an invitation to assist me in exploring critical care nurse's input into end-of-life decision making processes. I am conducting this study as part of a Masters in Health Science through Auckland University of Technology. Through this research I am hoping to shed light on and increase understanding of what is involved in this process. If you are interested in participating in this study after reading the accompanying information sheet, please don't hesitate to get in contact with me.

Warm regards

Tristan

Appendix 8: Participant Information Sheet

Participant Information Sheet



Date Information Sheet Produced:

6th May 2013

Project Title

Critical care nurses' input into end-of-life decision making processes: A grounded theory study.

An Invitation from Tristan Tully

My name is Tristan Tully and you are invited to join me on my endeavour to better understand the input that critical care nurses' have into end-of-life decision making. Participation is completely voluntary and you will retain the option of withdrawing from the study at any time, without any negative consequences to yourself or your work.

I have been a registered nurse since 2001 and gained experience working in the areas of General Medicine, Orthopaedics, Renal and Respiratory Medicine, Emergency Care and Telenursing. I am currently employed as a Resuscitation Education Facilitator, where I am responsible for educating health professionals in a variety of resuscitation skills, emergency responses and crisis management.

What is the purpose of this research?

The purpose of this study is to explore the input critical care nurses have into end-of-life decision-making. I am undertaking this research as part of a Masters in Health Science degree and will be submitting my findings for publication in an as yet to be decided professional journal. The findings may also be presented at a conference.

How was I identified and why am I being invited to participate in this research?

You have been identified and subsequently invited to participate in this research because you are a registered nurse who has been working in critical care for a minimum of one year. You have contacted me in response to an advertisement I placed in the critical care unit and your internal mail "pigeon hole". Due to the research methodology I am using in this study (grounded theory) I may not need all those who are willing to participate.

This is because in grounded theory once the interview process has commenced data analysis commences. The data analysis then provides a guide to how I conduct further interviews and how often. Once I reach what

is termed data saturation whereby similar or identical information begins to come through in interviews, I will draw this process to a close.

What will happen in this research?

If you opt to take part in this study, you will participate in a face-to-face 60 to 90 minute interview about your experiences regarding end-of-life decisions and withdrawal of treatment. This interview will be recorded using two digital audio Dictaphones. It will then be transcribed verbatim by a professional transcriptionist who has signed a confidentiality agreement.

What are the discomforts and risks?

The decisions made at the end-of-life are complex. Therefore it is possible that in talking about this process you may raise memories that you find uncomfortable or painful.

How will these discomforts and risks be alleviated?

If at any stage during the interview you wish not to discuss anything you find distressing, simply advise me of this and we will move on. If you wish to stop the interview completely this is also your right. Counselling services will be made available through AUT if you require them. These can be accessed in the following manner: Via the city campus on 09) 921 9992 or the north shore campus on 09) 921 9998. You will need to advise the receptionist that you are a research participant, and provide them with my contact details to confirm this. You can also access the following website for more information:

http://www.aut.ac/students/student_services/health_counselling_and_wellbeing

What are the benefits?

There are no immediate benefits for you participating in this project. You will however be imparting information that will assist greater understanding of the role critical care nurses play in end-of-life decision making processes, which may lead to more support being available to inform practice in the future.

How will my privacy be protected?

Only my two supervisors and I will have access to the information you provide from interviews. Your identity will not be made available to anyone other than myself. Any descriptions which may come up as part of the interview process that could identify you will be excluded from the completed thesis. All the information gathered as part of the study will be kept in a secure location, and destroyed after six years.

What are the costs of participating in this research?

Time and transportation. An interview of 60 to 90 minutes duration will be undertaken with me in a private space at Ko Awatea; a location that is both comfortable and convenient.

What opportunity do I have to consider this invitation?

If you choose to be involved you can get in contact with me using the contact details provided below. If you have any questions my supervisor Barbara McKenzie-Green or I would be happy to discuss these with you.

How do I agree to participate in this research?

If you are willing to participate in this research it would be appreciated if you specify this within two weeks of receiving this information. Complete the informed consent form, which you received with this information sheet, and return to me as part of your wish to participate response using the contact details provided below.

Will I receive feedback on the results of this research?

You will. I plan to present the findings of the study to the critical care complex on completion of my thesis. If you wish, you will also be able to read my thesis once it has been graded.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor.

Concerns regarding the conduct of the research should be notified to the Executive Secretary of ATEC, Kate O'Connor, ethics@aut.ac.nz, 921 9999 ext 6038.

Whom do I contact for further information about this research?***Researcher Contact Details:***

Tristan Tully, pumpkin1979@hotmail.com Mobile 021 1193 781

Project Supervisor Contact Details:

Dr Barbara McKenzie-Green, bmckenzi@aut.ac.nz, 921 9999 ext 7352

Approved by the Auckland University of Technology Ethics Committee on the 11th of July 2013, ATEC Reference number 13/130.

Appendix 9: Participant Consent Form

Consent Form



Project title: Critical care nurse's input into end-of-life decision making
processes: A grounded theory study

Project Supervisor: Barbara McKenzie-Green and Rosemary Godbold

Researcher: Tristan Tully

- ☐ I have read and understood the information provided about this research project in the Information Sheet dated 06 May 2013.
- ☐ I have had an opportunity to ask questions and to have them answered.
- ☐ I understand that notes will be taken during the interviews and that they will also be audio-taped and transcribed.
- ☐ I understand that I may withdraw myself or any information that I have provided for this project at any time prior to completion of data collection, without being disadvantaged in any way.
- ☐ If I withdraw, I understand that all relevant information including tapes and transcripts, or parts thereof, will be destroyed.
- ☐ I agree to take part in this research.
- ☐ I wish to receive a copy of the report from the research (please tick one): Yes ☐ No ☐

Participant's signature:

Participant's name:

Participant's Contact Details (if appropriate):

.....
.....
.....
.....

Date:

Approved by the Auckland University of Technology Ethics Committee on the 11th of July 2013, AUTEK Reference number 13/130

Note: The Participant should retain a copy of this form.

Appendix 10: Ethics Approval



AUTEC
SECRETARIAT

11 July 2013

Barbara McKenzie-Green
Faculty of Health and Environmental Sciences

Dear Barbara

Re Ethics Application: **13/130 Critical care nurses' input into end-of-life decision making processes: A grounded theory study.**

Thank you for providing evidence as requested, which satisfies the points raised by the AUT University Ethics Committee (AUTC).

Your ethics application has been approved for three years until 11 July 2016.

As part of the ethics approval process, you are required to submit the following to AUTC:

- A brief annual progress report using form EA2, which is available online through <http://www.aut.ac.nz/researchethics>. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 11 July 2016;
- A brief report on the status of the project using form EA3, which is available online through <http://www.aut.ac.nz/researchethics>. This report is to be submitted either when the approval expires on 11 July 2016 or on completion of the project.

It is a condition of approval that AUTC is notified of any adverse events or if the research does not commence. AUTC approval needs to be sought for any alteration to the research, including any alteration of or addition to any documents that are provided to participants. You are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

AUTC grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to obtain this. If your research is undertaken within a jurisdiction outside New Zealand, you will need to make the arrangements necessary to meet the legal and ethical requirements that apply there.

To enable us to provide you with efficient service, please use the application number and study title in all correspondence with us. If you have any enquiries about this application, or anything else, please do contact us at ethics@aut.ac.nz.

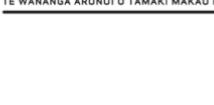
All the very best with your research,

A handwritten signature in black ink, appearing to read 'K O'Connor'.

Kate O'Connor
Executive Secretary
Auckland University of Technology Ethics Committee

Cc: Tristan Tully ttully@slingshot.co.nz

Confidentiality Agreement



AUT
UNIVERSITY
TE WĀNANGA ARONUI O TAMAKI MAKAU RAU

Project title:

Project Supervisor:

Researcher:

*Critical care nurse's input into end-of-life decision making processes:
A grounded theory study*

Barbara McKenzie-Green and Rosemary Godbold

Tristan Tully

☐ I understand that all the material I will be asked to transcribe is confidential.

☐ I understand that the contents of the tapes or recordings can only be discussed with the researchers.

☐ I will not keep any copies of the transcripts nor allow third parties access to them.

Transcriber's signature:

Transcriber's name:

Transcriber's Contact Details (if appropriate):
.....
.....
.....
.....

Date:

Project Supervisor's Contact Details (if appropriate):
.....
.....
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**Approved by the Auckland University of Technology Ethics Committee on the 11th of July 2013,
AUTEK Reference number 13/13**

Appendix 12: Counties Manukau Health Ethics Approval



Ko Awatea Research Office
Counties Manukau DHB
Clinical Support Building
Room 253, Level 2
Middlemore Hospital

02 September 2013

Dear Tristan

Thank you for the information you supplied to the Ko Awatea Research Office regarding your research proposal:

Research Registration Number: 1473

Ethics Reference Number: 13/130 (AUTEC)

Research Project Title: **Critical Care Nurses' Input Into End-of-Life Decision Making Processes: A Grounded Theory Study**

I am pleased to inform you that the CMDHB Research Committee and Director of Hospital Services have approved this research with you as the CMDHB Co-ordinating Investigator.

Your study is approved until 31 March 2014.

Amendments:

- All amendments to your study must be submitted to the Research Office for review.
- Any substantial amendment (as defined in the *Standard Operating Procedures for HDECs*, May 2012) must also be submitted to the Ethics Committee for approval.

All external reporting requirements must be adhered to.

Please note that failure to submit amendments and external reports may result in the withdrawal of Ethical and CMDHB Organisational approval.

We wish you well in your project. Please inform the Research Office when you have completed your study (including when a study is terminated early) and provide us with a brief final report (1-2 pages) which we will disseminate locally.

Yours sincerely

A handwritten signature in black ink, appearing to read "S. Everitt".

Dr Samantha Everitt

Manager Research Office

Counties Manukau District Health Board

Under delegated authority from CMDHB Research Committee and Director of Hospital Services

Appendix 13: Support for Research Participants



MEMORANDUM

TO Tristan Tully

FROM Kevin Baker

SUBJECT Psychological support for research participants

DATE 10th May 2013

Dear Tristan

I would like to confirm that Health, Counselling and Wellbeing are able to offer confidential counselling support for the participants in your AUT research project entitled:

Critical care nurses' input into end-of-life decision making processes: A grounded theory study.

The free counselling will be provided by our professional counsellors for a maximum of **three** sessions and must be in relation to issues arising from their participation in your research project.

Please inform your participants:

- They will need to contact our centres at WB219 or AS104 or phone **09 921 9992 City Campus** or **09 921 9998 North Shore campus** to make an appointment
- They will need to let the receptionist know that they are a research participant
- They will need to provide your contact details to confirm this
- They can find out more information about our counsellors on our website: http://www.aut.ac.nz/students/student_services/health_counselling_and_wellbeing

Yours sincerely

Kevin Baker
Head of Counselling
Health, Counselling and Wellbeing

Health, Counselling & Wellbeing
Private Bag 92006, Auckland 1020
55 Wellesley Street, Auckland.

Tel: 09 921 9992