INTENSIVE CARE NURSES’ PERCEPTIONS OF ‘GOOD’ END-OF-LIFE CARE FOR THE ADULT PATIENT WHO HAS HAD TREATMENT WITHDRAWN OR WITHHELD.

A North Island non-metropolitan ICU nursing study.

A thesis presented in partial fulfilment of the requirements for the degree of Master of Nursing at the Eastern Institute of Technology Taradale, New Zealand.

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Abstract

End-of-life care in the ICU for the adult patient who has had treatment withdrawn or withheld.

Intensive care is a place for the critically ill. It is a place of advanced technology where alarms, lights and noise are plentiful and where privacy and dignity are not always able to be given the highest priority. ICUs are places catering for the most acutely unwell patients, a number of these patients do not recover. A percentage of those patients who die, do so after extensive discussions, when treatment is withdrawn or withheld. The focus turns from cure to comfort for the patient and their family. Providing a ‘good’ death for the adult patient who has had treatment withdrawn or withheld is a challenge in an environment where the emphasis in on cure.

I designed a questionnaire to investigate nurse’s perceptions of ‘good’ end-of-life care. Nurses in eight ICUs who worked at the bedside were requested to numerically rank 10 important end-of-life issues as they perceived to be most important for the patient, family and themselves. The nurses were then asked to rank those same issues for how well the unit they work in performs. Some open-ended questions were also asked to combine the qualitative approach with the quantitative, to add richness to data.

Results showed the top four issues nurses perceived to be most important when providing ‘good’ end-of-life care was the administration of medication for analgesia and symptom relief, preservation of the patient’s dignity, maintaining open communication channels for the patient, family and health care team and unlimited family visiting. Featuring consistently last was the documentation of an alternative care plan based on maximising patient comfort and attention to environmental issues.

It appears generally end-of-life care in non-metropolitan ICUs is done reasonably well. Barriers to providing ‘good’ end-of-life care documented by nurses in this study are similar to results from nurses who have studied similar themes overseas.
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Chapter One

Introduction

When intensive care turns palliative

“Medical therapy is often stopped once its efficacy becomes apparent. If a treatment works, it may no longer be needed; if it does not work, there rarely is any point in continuing it” (Prendergast, 2000, p. 1).

Perspectives

Consider these two fictional scenarios:

An elderly lady is admitted to intensive care with multi-organ failure, a long list of chronic medical problems and an incidental finding of an undiagnosed large breast lump found on routine examination. After three weeks of aggressive treatment (inotropes, mechanical ventilation via a tracheostomy tube and continuous renal replacement therapy) progress has ceased. With no sedation for days her family voice concerns to nursing staff repeatedly about how they think she is suffering and how she appears to have stopped interacting with them. Whenever staff approach the patient she distressingly repeatedly closes her eyes and shakes her head from side to side until she is left alone.

Would we let a member of our family endure this? Do nurses question the aggressiveness of treatment? Do nurses advocate for the patient and their family?

Even though fictional, there is a familiarity in this scenario to real life situations we, as nurses come across when working in intensive care. Nurses are often advocates for patients and families, we often question the aggressiveness of treatment for patients when we believe there is little or no chance of recovery. We verbalise terms such as “flogging” and “suffering” to describe patients who we believe should be receiving compassionate care.

For the lady described the course of treatment changes. Medical staff are informed by the nursing staff how the family feel on the morning consultancy round. A meeting is set up with the family. The intensivist discusses the care of the patient with colleagues after meeting with the family and a decision is made to withdraw treatment. The patient is moved to a side room, sedation is recommenced and the family are given unlimited access.

It is situations like this that has led the researcher to become interested in how patients die in intensive care. As technology improves and we become better at looking after people, they live
longer and with age, long lists of medical problems may ensue. This is the changing population of acute care. People are presenting sicker, older and with a host of chronic medical conditions. When the continuation of aggressive medical care proves futile as in the scenario of the elderly lady in the previously mentioned text, treatment, after discussion with the family, may be withdrawn.

Second patient scenario:
A very elderly man with complex medical problems is admitted to intensive care with sepsis secondary to cellulitis from chronic leg ulcers. His condition deteriorates and he develops acute on chronic renal failure. A family meeting is held with the medical staff. During the nursing handover at change of shift the nurse taking over the patient’s care is told by the preceding nurse “Mr. Z is for comfort cares now”. When the nurse goes to assess the patient, the patient has had no pain relief, is breathing in a distressing way, is semi-comatose, is still on high doses of inotropes, an orderly arrives to escort the patient for a scan and the family ask the nurse “is he getting better”?

Is this good care? Is this the norm in intensive care? Is this what we regard as “comfort cares”? This scenario is an example of the withholding of treatment (in this patient, renal replacement therapy) and how death in the intensive care unit (ICU) should not be. Don’t get me wrong, as a clinical nurse, the challenge of caring for an acute trauma, bleeder, obstetric emergency or septic shock provides a great deal of job satisfaction. But with age comes experience and maturity, it is the attention to detail that is important in the ICU. We do not stop caring when the goalpost has shifted, the same attention to detail should occur with the dying patient as it does when caring for the patient attached to the most technologically advanced equipment. When intensive care turns palliative, death is generally imminent.

Two fictional scenarios have been provided to demonstrate why this topic has become the focus of this thesis. The major aim of the thesis is to provide a New Zealand (NZ) perspective regarding what nurses’ perceive to be ‘good’ end-of-life care in our ICUs and more specifically issues revolving around a ‘good’ death for the patient who has had treatment withdrawn or withheld. In this chapter the author will provide a definition of terms, provide evidence of why this topic is relevant to intensive care nursing and how end-of-life care is becoming increasingly important when caring for patients in our intensive care units. The legalities behind the withdrawal or withholding of treatment will be referred to as well as a short discussion about the withdrawal of treatment and palliative care in the ICU.
**Background to the thesis**

The researcher believes ICUs contain two types of patients, those who have an acute sudden illness or a traumatic event, for example, a traumatic severe head injury patient or those who have acute exacerbations of chronic illness precipitated by a stressor, for example, a chronic obstructive respiratory diseased patient who develops severe community acquired pneumonia.

Miller, Forbes and Boyle (2001) discuss how the biomedical model has dramatically changed how we view aging and dying and dramatic advances in medicine now decide when, how and where people die. Death, 100 years ago was a ritual or routine and clearly recognisable (Miller et al.). Death now is a disease to be treated and conquered. Nowadays people live for many years with multiple chronic illnesses experiencing many acute exacerbations only to be rescued from the brink of death by sophisticated technological interventions, providing a challenge for those who work in the ICU. Providers of health care are reluctant to label a patient as terminal and there appears to be a “vanishing line between life and death” (Miller et al., p. 232). Now death is ‘medicalised’ as advances in technology allow the prolonging of life, the frightening reality is that death is also prolonged (Kyba, 2002). Patients who in the past may have died are now maintained with life support systems with little or no chance of recovery or a reasonable quality of life; hence decisions concerning the withdrawal of life-support are increasingly being faced by health care professionals.

**The development of ICUs and intensive care nursing practice**

ICUs evolved from the recognition that patients with acute life-threatening illnesses or injury could be better looked after if they were grouped together in a dedicated area of a hospital (Urden, Stacy & Lough, 2002). Intensive care nursing was organised into a specialty more than 30 years ago and evolved from the recognition that the monitoring and observation of critically ill patients was important with technological advancements and the development of new medical interventions (Urden et al.).

In NZ the first stand-alone ICU, with its own dedicated nurses and doctors was established in 1962 at Auckland hospital (Trubuhovich & Judson, 2001). The founding director of the Auckland Central Respiratory Unit, Matt Spence, believed what was essential for respiratory therapy to be successful was the availability of experienced trained nursing staff to attend to the patients and operate the equipment (Wiles & Daffurn, 2002). Throughout the 1960s other units in hospitals were developed. As of the year 2000 there were 31 ICUs identified in NZ (Trubuhovich & Judson, 2001). Ideally units should be staffed by a qualified intensive care consultant (intensivist) and specialised trained nursing personnel (Trubuhovich & Judson).
Many nurses believe the ultimate achievement in a career is to become an intensive care nurse. Intensive care nurses have always been regarded as quick, knowledgeable, technically competent and incredibly efficient – saving lives in a flurry of codes and orders at a frenetic pace. The researcher has worked in intensive care for a long time and hopefully wisdom has accompanied age and experience. As previously mentioned attention to detail is the most important aspect when caring for patients and families and critical care nurses are able to achieve this through one to one contact. Intensive care nurses need to meticulously attend to the reality of caring for critically ill patients and families; whether it’s detecting the flash of horror on a relative’s face when they see their loved one for the first time, or connecting with the relative who sits quietly at the bedside for every allowable visiting minute, or recognising the anguish and fear in a weaning (ventilator) patient’s eyes. Attention to detail is paramount.

**Definition of terms**

Pattison (2004) refers to intensive or critical care as care provided for patients who have a potentially reversible condition but require a greater level of medical and nursing dependency.

Palliative care is defined by Clark and Seymour (cited in Pattison, 2004, p. 132) and refers to the “alleviation of symptoms that accompany end-of-life, using ‘low-tech’ options, such as morphine for dyspnoea (rather than increasing or aggressive respiratory support) for treatment of people dying with advanced disease”. Pattison discusses how the intensive care philosophy is based on life-saving technical skills and the palliative philosophy is more patient focused and holistic.

Prendergast (2000, p. 1) defines the withdrawal of life-sustaining therapy, “The cessation and removal of any medical treatment with the explicit intent not to substitute an equivalent alternative treatment. It is fully anticipated the patient will die as a result of the change of therapy”.

The withholding of life-sustaining therapy is also defined by Prendergast (2000, p. 1). “The considered decision not to institute a medical appropriate and possible beneficial therapy. It is fully anticipated that the patient will die without initiation of the therapy in question”.

Withdrawing treatment may occur as a single entity or it may occur over time as different treatments are gradually discontinued. Prendergast and Puntillo (2002) proclaim the most frequently withdrawn therapies (in order) are blood products, haemodialysis, vasopressors, mechanical ventilation, total parenteral nutrition, antibiotics, intravenous fluids and enteral nutrition. Randall Curtis and Rubenfeld (2001) mention how different doctors vary in their
practice of withdrawal, depending on invasiveness, cost and familiarity. From a medical and legal view there is no difference between mechanical ventilation, enteral nutrition, antibiotics, blood transfusions, or intravenous fluids; all medical treatments in the appropriate setting can be stopped legally and ethically in a compassionate manner (Randall Curtis & Rubenfeld). There is nothing to distinguish between the withdrawal and withholding of life support and all the literature supports this. For the purposes of the following text, the two concepts will be referred to as one.

Futile care refers to those “life-sustaining interventions and treatments that have no medical benefit for a patient because the intervention and treatments cannot end dependence on intensive medical care” (Meltzer & Huckabay, 2004, p. 203).

The term ‘death with dignity’ is interpreted differently for everybody. This is how Benner (2001, p. 255) describes the concept “for some people it means the absence of unnecessary heroic measures for a person who is dying … for others it means not prolonging life that is deteriorating in quality and continuity.”

Comfort measures are defined as “… the administration of drugs such as narcotics and sedatives to prevent and treat symptomatic discomfort during the dying process” (Hall, Rocker & Murray, 2004, p.633).

**Legal and historical background of the withdrawal and withholding of treatment**

When referring to the withdrawal or withholding of patient treatment, the primary reason for doing this is because the continuation of treatment is futile. The central issue is whether the continuation of aggressive medical interventions offers a realistic hope of recovery and if not, is it appropriate to allow the patient to die? (Prendergast & Puntillo, 2002). Oh (2003) discusses how the withholding or withdrawal of treatment is not euthanasia. Euthanasia is a term that may be confusing when discussing this topic. The use of narcotics intentionally is to relieve pain and discomfort at the end-of-life, not primarily to kill (Oh). Randall Curtis and Rubenfeld (2001, p. 128) state there is no doubt the withdrawal of life-support will hasten death; ethicists have differentiated between the withdrawal of life-support “when the expected but unintended effect is to hasten death and providing a treatment with the sole intent of hastening death.” The concept of withdrawing or withholding treatment is complicated and fraught with difficulties. Generally doctors will use mortality and morbidity scores to predict patient outcomes and collaborate extensively with colleagues before a decision to approach the family is reached.
An important concept to remember is that not all patients die after treatment withdrawal. This creates an ethical dilemma for the medical team, and it is important at the time to ensure families are aware the timing of the death is out of their control. Randall Curtis and Rubenfeld (2001) suggest that from available datum, prolonged survival after treatment has been withdrawn is uncommon. It may be appropriate now to mention also that the withdrawal of treatment does not include those patients who are brain dead. Discussions concerning the withdrawal of treatment for this group are senseless, as those patients who are declared brain dead are legally dead and to continue treatment is pointless (Oh, 2003).

Interestingly enough the practice of withdrawing treatment in the ICU has only evolved over the last 20 years. Before 1983, when initial recommendations for the withdrawal of ventilator support were published, the practice was rare (Faber-Langendoen & Lanken, 2000).

End-of-life decision making is complex; much controversy has surrounded legal and medical issues with reference to the withholding or withdrawal of life-sustaining treatments. Prendergast (2000, p. 1) states: “The path from the 1960s to current practice was one of soul-searching, debate, and controversy, not only within the medical profession but within society and the courts.” There have been many publicized disputes over the years, sensationalised by the media, triggering widespread international public debate and discussion concerning the withdrawal of treatment. To name but a few; the case of Karen Anne Quinlan, 1975, in the United States (Angell, 1994); Tony Bland, 1993, in the United Kingdom (Jennett, 1999); and Helga Wanglie, 1991, also in the United States (Angell, 1991) come to mind. Perhaps the most famous of these is the case of Karen Anne Quinlan in 1973 described by Prendergast and Puntillo (2002). Karen Anne Quinlan lay in a persistent vegetative state for nine months before her parents asked that her ventilatory support be withdrawn. This request was supported by the family physician but not by most professional medical societies. The parents sued and won a landmark ruling with the State Supreme Court permitting their daughter’s extubation. Such a decision sparked fifteen years of intense debate regarding the appropriate use of life support (Prendergast & Puntillo). In 1997, in North America when the courts reviewed such deaths, the legal system acknowledged patients who die following the withdrawal or withholding of life support, die from the underlying disease process and are therefore neither assisted suicide nor euthanasia (Prendergast, 2000). This was established after a committee of physicians, nurses, bioethicists, lawyers and members of the public reached a broad consensus that decisions to withdraw life support is appropriate in many clinical situations (Prendergast & Puntillo, 2002). There is however a variation amongst countries. The main difference between America and the United Kingdom is in the United Kingdom, there is no legal right to surrogacy and therefore clinicians do not need to consult with a designated person before making treatment decisions. (Seymour,
End-of-life care in the ICU

Why is end-of-life care so important in the ICU? Unfortunately a patient dying in the ICU is not uncommon. Despite technological advances and the efforts to prolong life, patients still die. When reviewing past records of a regional hospital in NZ where the author is currently working clinically as a staff nurse, approximately one in ten patients admitted will die. To the best of the author’s knowledge, this figure is comparable to other NZ centres. Because of the severity of the illness or injury, patient mortality is high in ICU’s and because of this, it is appropriate to focus on improving the quality of end-of-life care for patients who are dying in the ICU. Care of the dying is a big part of what intensive care nurses do. International literature reports figures as high as one in three patients die in ICUs’ in the United Kingdom (Pattison, 2004); in the United States ICU mortality figures of 20 percent (%) are reported (Meadow et al., 2003; Nelson-Marten, Braaten & English, 2001; Rocker & Randall Curtis, 2003). Many deaths are due to treatment withdrawal. Australasian statistics regarding mortality figures in the ICU when treatment is withdrawn or withheld were unable to be accessed.

Intensive care is a place where many discussions between family and staff occur when considering whether to continue to attempt to cure disease and prolong life for the patient or to make the transition to comfort and allow death with dignity (Randall Curtis & Rubenfeld, 2001). Dracup and Bryan-Brown (2005) believe end-of-life issues are one of the most serious problems facing critical care nursing and medical staff today. When patients’ who are actively being treated die in intensive care, death is often abrupt and traumatic. However, when the continuation of treatment on a patient is futile, delaying an inevitable death and prolonging suffering, patient treatment, after discussion with family may be withdrawn or withheld. When this occurs death is generally imminent. Randall Curtis and Rubenfeld (2001) comment, when considering the withdrawal of therapy, there should be a consensus amongst the medical team. Rarely is the decision urgent, and the same meticulous attention should be made to the quality of this decision as to the most difficult of technological skills needed by the intensive care consultant when performing a difficult procedure. The majority of deaths in intensive care occur due to the withholding or withdrawing of life support measures (Prendergast, 2000; Rocker & Randall Curtis, 2003; Rocker et al., 2004; Treece et al., 2004). This trend is expected to increase as a population with chronic health problems live longer and we improve our techniques for caring for them using life-prolonging technology. Randall Curtis and Rubenfeld (2001) discuss how unless elderly patients are willing to forego life-prolonging treatments, decisions to shift
from cure to comfort will increasingly be faced. Brenner (2002, p. 11) states: “Approximately 40% of patients in an ICU die after care is withdrawn”. Winter and Cohen (cited in Allen-Smyth, 2001) provide a figure of 70% of deaths in ICUs occur after treatment withdrawal. One survey reported from The United States found 90% of patients who die in the ICU now do so after the decision to limit therapy (Truog et al., 2001). It is now well recognised the withdrawal of life support and end-of-life care is an important aspect in the overall quality of medical and nursing care. Now the care should revolve around the provision of a ‘good’ death. End-of-life care, including pain management and comfort measures, are no less important than when care revolves around the patient receiving life-saving treatment. Practices which were once controversial are now becoming acceptable when patients remain hopelessly ill, with increased suffering or when continued medical treatment becomes futile (Holzapfel, Demingeon, Piralla, Biot & Nallet, 2002).

When intensive care turns palliative
Chronic disease has emerged as a leading cause of death (Thompson, McClement & Daeninck, 2006). Technological advances challenge the chronically diseased patient and their family to make choices around terminating treatment when cure is no longer a possibility. This is one of the contributing factors for hospital based dying. The challenge now is to focus on a ‘good’ death changing lanes to a palliative approach. Comfort vs. cure is the fundamental difference between palliative care and intensive care (Truog et al., 2001). The traditional paradigm that once existed between the two disciplines no longer exists. The palliative or holistic approach to care includes the physical, psychosocial and spiritual domains of comprehensive care (Kirchhoff, 2002). When treatment has been withdrawn or withheld, the caring focus now becomes palliative, with pain, sedation and symptom control for the patient and ongoing support for the family. Nurses are in the unique position to provide care revolving around respect and dignity for the dying patient and their family and ensuring this is maintained. How patients die with attention to symptom control is becoming increasingly important. Nurses must be alert to assessing and managing symptoms such as pain, agitation and anxiety. The goal of patient care now revolves around the alleviation of symptoms. For those patients who stay in the unit to die, we need to develop a supportive environment (Kirchhoff).

Brody, Campbell, Faber-Langendoen and Ogle (1997) recommend the following points for compassionate clinical management:

- Pain and discomfort require prompt attention. Signs of distress such as moaning, restlessness and agitation may signify the requirement of a better pain management plan.
Routine interventions such as laboratory tests, radiographic examinations, frequent recording of vital signs and pulmonary hygiene can now all be overlooked as frequently these interventions cause discomfort.

There is ample justification for the use of opioid and sedative administration. Opioids are well known to cause respiratory depression. Studies have shown patients who have had life-support withdrawn and given large doses of opioids for comfort live the same length of time as patients not given opioids, suggesting the underlying disease process not the medication, determines the time of death.

Patient goals should determine the sequence of treatment withdrawal. The effect on the patient must be what determines treatment withdrawal, not the cost, scarcity or invasiveness.

Despite belief, there is no evidence to suggest continuing artificial nutrition and hydration improves patient comfort. The assumption that these therapies extend life and are palliative is unwarranted. Often to continue these treatments causes unwanted nausea, vomiting, abdominal discomfort and fluid overload.

Emotional support for families is mandatory. Allowing the family unlimited access to their loved one and having space for rest and nourishment is advisory. Communication and a commitment to individualize treatment, titrating medications according to patient symptoms prevents the perception that the patient is being abandoned. Nurses must be frequently seen to be at the bedside and we are in the unique position as intensive care nurses, where the patient-nurse ratio is high to be able to achieve this.

Attention should also be made to the environment; alarms, lighting, noise, monitoring, privacy and the removal of unnecessary equipment. Modification to all these should be encouraged to promote calmness and dignity for the patient and family alike.

Last of all look after ourselves. It is not uncommon for staff members to extend themselves beyond caring for the patient. Caring for the dying patient and their family takes its toll; feelings of loss and frustration are not signs of weakness, but predictable results from difficult work.

Palliative care in the ICU is becoming increasingly important. Changing patterns in treatments of chronic illnesses means that people are living longer (Skilbeck & Payne, 2005). If an ICU has no criteria for patient admission, a percentage of these people may end up in the ICU as patients. Opportunities exist for reforming end-of-life care practices in the ICU as long as staff recognise their own unit’s deficiencies and want to make the change. There are some model examples of optimal end-of-life care but dying well is still not a universal expectation (Campbell, 2002). There are still many obstacles to providing ‘good’ end-of-life care and some of these will become apparent in the following chapter. For the researcher, the big question is,
can we do better? The answer is, yes, we can always do better. The irony is just because we see death all the time; it does not mean that we are good at it (Levy, 2001).

**Research topic**
Traumatic deaths occur in the ICU; they may occur suddenly, or the process may take days or weeks when aggressive medical interventions are persisted with, only for the patient to die an undignified death. Bed spaces, faces and names are remembered by the death they endured. However, for the patient who has had treatment withdrawn or withheld, nurses can achieve a dignified death, it is our chance to ‘do death well’.

Dracup and Bryan-Brown (2005) comment on how in the perfect world, patients, families and caregivers would all understand the inevitability of dying and at some point the continuation of care becomes futile. However, unfortunately ICUs are full of examples of members of the health care team, patients and / or families who falter in their decisions of when to stop aggressive medical therapy and accept death (Dracup & Bryan-Brown). Badger (2005, p. 513) states nurses who work “in ICUs and hospices are more likely to experience death or dying on a regular basis than are nurses working in any other area of patients’ care”.

This thesis is about what intensive care nurses perceive to be ‘good’ end-of-life care for adult patients who have had treatment withdrawn or withheld and are expected to die. The study encompasses nurses who work in non-metropolitan North Island ICUs. The reader will discover in the following chapter there is an abundance of international literature written on the subject, however very little was found from NZ. The purpose of this research is to provide a NZ perspective about end-of-life care in our ICUs.

**Research aims**
a) To identify what the intensive care nurse perceives to be important for the patient, family and themselves when providing ‘good’ end-of-life care for the adult patient who has had treatment withdrawn or withheld.
b) To identify participating units’ (collective) strengths and weaknesses when providing end-of-life care.
c) To provide NZ evidence on a subject widely researched overseas.

**Thesis direction**
This first chapter has provided the reader with an introduction to the withdrawal of therapy in the ICU and how this may progress to end-of-life for the intensive care patient. Chapter One has also provided statistical evidence from international literature regarding how significant this
subject is for the nurse working in intensive care. Chapter Two will briefly review what the literature has to say about the withdrawal or withholding of life-sustaining therapies. However, in general it will concentrate on the international literature and what it has to say about what nurses perceive to be a ‘good’ death for the intensive care patient who has had treatment limitation. A questionnaire was developed by the researcher and this will be discussed in the methodology (Chapter Three). Chapter Four will present and discuss the findings from the questionnaire and the final chapter (Chapter Five) will focus on recommendations for end-of-life care for patients dying in NZ ICUs based on the results of the survey.
Negotiating a ‘good’ death for patients who have had treatment withdrawn or withheld in our intensive care units.

“The best care, which is in the patient’s best interests, should be what drives decision-making” (Pattison, 2004, p. 134).

Introduction

Patients in intensive care die in one of two ways; traumatically, while receiving advanced technological support, or, as a result of what is one of the many ethical dilemmas of intensive care, when life sustaining support is withdrawn after consultation and discussion with family members due to medical futility. When intensive care turns to palliative care, death is imminent. To achieve a ‘peaceful’ death is challenging in a technologically advanced environment where the emphasis is on cure. ‘Good’ end-of-life care for patients who have had treatment withdrawn or withheld is attainable. Nurses have the unique opportunity to achieve this for the patient who is dying and their family in the ICU.

Patients are not transferred to ICUs to die. ICUs are designed to save patients’ lives using maximal monitoring with advanced technology. The ICUs emphasis is on cure and to prevent death. Many treatment options are available for the critically ill. Providers, patients and families must decide on the best treatment options from a continuum where maximum aggressive treatment lies at one end while at the other is comfort care. Technological advances prolong life for patients and patients may linger in ICUs with no hope of recovery. Aggressive therapies must be weighed against the potential for causing a patient and his or her family unnecessary suffering and prolongation of dying. Decisions regarding the withdrawal of life-supporting therapies are increasingly being faced. It is the responsibility of the nurses who work in intensive care units to provide excellent care even when the goals have shifted.

In the following text, what nurses have to say about dying a ‘good’ death will be reviewed. In particular, a landmark American study will be referred to when discussing end-of-life care for patients dying in hospitals. Shortcomings found with this study will be discussed in the context of the intensive care environment. It may be difficult not to immediately think of legalities and medical ethics when discussing such a sensitive topic. The researcher has referred briefly to legality issues in the introductory chapter. For the purpose of the literature review medical
ethics and legal issues will not be alluded to. However, it is difficult to avoid moral and ethical dilemmas for nurses when discussing this subject and these will be referred to later in the text.

**Search strategy**

A search was conducted with a variety of terms such as end-of-life, withdrawal of treatment, intensive / critical care and ‘good’ death. A range of key words was used to assure no pertinent material was excluded. The search was confined to adults and the time frame was limited to 1998 – 2005. The Cumulative Index to Nursing and Allied Health Literature (CINAHL), ProQuest, A to Z journals and PubMed were accessed facilitating journal searching. Through interloan services available locally, national and international literature was able to be retrieved. Further information was accessed via work colleagues.

**End-of-life decision making and the withdrawal or withholding of patient treatment**

End-of-life decisions are gaining increasing national and international attention heightened by

a) the right of individuals to make health care decisions;

b) an aging population with chronic health problems; and


There is an abundance of international literature regarding end-of-life issues in critical or ICUs. Most of the literature appears to originate from the United States of America (USA). This may be due to their legal system and fear of litigation. The following section of this chapter reviews a study comparing differences between ICUs in the USA and in NZ and highlights some important points that impact on end-of-life care in ICUs within the two countries. Much of the data gathered, with reference to the withdrawal or withholding of life-support, has been by investigating doctors. The subject comes under close scrutiny by doctors because any decision that may lead to a patient’s death, calls for this. Generally the studies are retrospective or prospective to provide data to determine concepts like the sequence, incidence and recommendations for the withdrawal of life support. There are many studies investigating conflict with decision-making and much research has also gone into perspectives regarding communication, negotiation and mediation between families and the medical team. The literature the author would like to focus on are the studies that impact on nursing care and these are what will be reviewed in depth. Very little literature was found regarding the NZ experience.

*The New Zealand experience*
An article in a national paper referred to the NZ experience of withdrawing treatment in our ICUs (Cameron, 2005). The on-call consultant in a busy ICU in Auckland explains that doctors in NZ try to lift the burden as much as possible from families facing impossible choices. … When death is inevitable, despite the best medical efforts, doctors will spell out the facts [with families] and raise the possibility that withdrawing treatment is sometimes the kindest option (Cameron, 2005, p. 25).

Cassell, Buchman, Streat and Stewart (2003) studied three ICUs, focusing on end-of-life issues using ethnographic research: a medical-surgical ICU in Auckland where patient decisions were made by intensivists (this is an example of a ‘closed’ administrative model ICU, where decision-making for patient care is provided by the intensivist); in Texas where a surgical unit was run by trauma surgeons (an ‘open’ ICU); and in the Midwest, a ‘semi-closed’ surgical unit (a unit where surgeons and intensivists shared responsibility for patient care) were all studied by a fieldworker who spent a varying amount of time in the ICUs (ten, three and seventy-five weeks respectively). Cassell et al. (2003) comment that in general the care in the closed unit (Auckland, NZ) is dictated by scarcity of resources evident by a strict admission criteria and treatment limitations (based on quality of life concerns and prognosis). In the open ICU (Texas), care is dictated by the covenant of trust between the patient and the surgeon, and care was not hastily withdrawn from gravely ill patients. In the semi-closed unit (Midwest), conflict occurred between the intensivist and the surgeon. The intensivist’s care ethic was based on scarcity of resources in which attempts are made to deliver the greatest good to the greatest number, whereas the surgeon’s moral stance was not to deprive a patient of their chance to battle death.

The above article alludes to scarcity as an individual factor with end-of-life care in NZ. In the USA there are 30.4 intensive care beds per 100,000 populations, while in NZ for the equivalent population there are 5.3 intensive care beds (Cassell et al., 2003). This is relevant because in NZ intensivists legally have the authority to determine who to admit to the ICU and who to deny, allowing intensivists to manage their scarce resource. Cassell et al. make the comment that the technological imperative (the use of highly technical equipment) was not as dominant in the NZ ICU as it was in the American, although NZ did have access to sophisticated technology if it was deemed necessary. The Auckland unit curtailed the amount of technology utilised if it meant delaying an inevitable death. The article alludes to administrative models of ICUs, mentioned previously (open, closed and semi-closed) and how this affects end-of-life decision making. Cassell et al. summarise the NZ experience, saying it is the intensivists who deal with scarcity by limiting treatments based on the probability of the patient to return to a reasonable quality of life and progress with treatment. This study has direct implications for nursing practice, as it reveals how end-of-life decision making is fraught with moral and ethical
complexities and is influenced by many factors including cultural and social issues. Nurses not only practice within these complex forces which influence end-of-life decision making, but also work with families, surgeons, intensivists and surgeons to provide the best outcome for the patient (Cassell et al.).

**The concept of a ‘good’ death**

Chapple (1999, p. 26) states studies have shown what a ‘good’ death is not;

a) “prolonged aggressive treatment”;

b) “no choices”;

c) “no communication”; and

d) “too much pain”.

Bookbinder, Rutledge, Donaldson and Pravikoff (2002) suggest the following concepts as important for a ‘good’ death:

a) pain and symptom management;

b) open and honest communication between patient, family and medical staff;

c) family support; and

d) environmental manipulation.

Nelson-Marten et al. (2001) comment a concrete definition of a ‘good death’ is tricky. What makes a ‘good’ or ‘bad death’ varies between individuals and is influenced by culture, religion, personal experience and the context of the situation (Nelson-Marten et al.). ‘Good’ end-of-life care is synonymous with a ‘good’ death and is defined by the Institute of Medicine (cited in Kirchoff, 2002, p. 201) as “one that is free from avoidable distress and suffering for patient, families and caregivers: in general accordance with patients’ and families’ wishes; and reasonable consistent with clinical cultural and ethical standards.”

Beckstrand, Callister and Kirchoff (2006) make the following suggestions for providing a ‘good’ death in the ICU (which they define as facilitating dying with dignity).

a) Patients should not die alone.

b) Managing patients’ pain and discomfort.

c) Knowing, and then following, patients’ wishes for end-of-life care.

d) Promoting earlier cessation of treatment or not initiating aggressive treatment at all.

e) Communicating effectively as a health care team.

f) Educational initiatives for health care professionals and for the public.

g) Facilitating environmental changes.
h) Nurses facilitating the appropriate place to die.
i) Developing a consistent plan of care.
j) Spiritual support.
k) Involvement of a palliative care team.

End-of-life care studies

Many authors who have published articles over the last ten years regarding death and dying and the withdrawal or withholding of life-supportive therapies refer to the following landmark study conducted in the USA as a trigger to examine their own practices. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT), was a four year multi-centre study of 9000 randomised hospitalised terminally ill patients and their families (The SUPPORT Principal Investigators, 1995). Many authors refer to this research as the gold standard responsible for changing attitudes towards end-of-life care (Baggs & Schmitt, 2000; Gabany, 2000; Hall et al., 2004; Kirchoff & Beckstrand, 2000; Kyba, 2002; Miller et al., 2001; Nelson-Marten et al., 2001; Puntillo, Benner, Drought & Drew, 2001; Rocker, Shemie & Lacrois, 2000). The findings of this study are described by Kyba (2002) as distressing. It showed that in the USA end-of-life care was sub-optimal. The study found that frequently aggressive treatment prolongs dying and does not contribute to a ‘good’ death (Kyba, 2002).

Some of the findings of the study include:

a) shortcomings in communication,
b) frequency of aggressive treatment and
c) questionable admission into ICUs, regarding
   i. unknown preferences about patients who wished to avoid cardiopulmonary resuscitation,
   ii. lateness of documented ‘do not resuscitate’ orders and
   iii. relatives reporting that over 50% of the time, those patients who were conscious were dying in moderate to severe pain (The SUPPORT Principal Investigators, 1995).

The implications for practice from the SUPPORT revolve around the quality of life and dying a ‘good’ death with regard to cultural issues, ethical decision making, medical futility, advance directives, pain and symptom management, family support and open communication between the patient, family and staff (Bookbinder et al., 2002). The study typifies how nurses juggle the cultural, social, and moral / ethical forces present when working with families and doctors for the good of the patient with end-of-life care. Nurses can influence any of these issues and therefore play a major role in improving end-of-life care (Bookbinder et al.). The study appears to have triggered a wealth of responses generally from overseas.
A brief summary of the SUPPORT has been given. The researcher acknowledges the study is not confined to the intensive care patient but encompasses the terminally ill collectively. The following text will address some of the shortcomings identified by the SUPPORT individually and present what experts have published from researching these issues under the following headings confining them to the ICU experience.

a) Advance directives.
b) Ethical issues.
   i. Do not resuscitate (DNR) orders
   ii. Medical futility and aggressiveness of treatment
c) Spiritual and cultural values.
d) Communication.
e) Pain.
f) Environmental manipulation.

**Advance directives**

Scherer, Jezewski, Graves, Bill Wu and Bu (2006) state advance directives can take the form of living wills, durable powers of attorney, healthcare proxies and do not resuscitate orders. Kirmse (1998) states a durable power of attorney and a living will are legal documents. Wareham, McCallin and Diesfeld (2005) comment how an advance directive can take the form of a written or verbal instruction. An advance directive informs people of a choice in the event of the patient losing decision-making capabilities. The purpose of an advance directive is to inform family, friends and health care workers of an individual’s choice in treatment options agreeable to his or her personal preferences and values (Kirmse, 1998).

Historically patients were not informed of their rights and medical treatment was decided by their doctor. With the growing interest in end-of-life decision making due to escalating health costs, increasing patient awareness, new life-prolonging technology and aging populations, the general public are becoming outspoken about their own medical treatment choices. Advance directives challenge the biomedical model to emphasise patient autonomy and right of individuals to participate in their own decisions concerning medical treatment (Kirmse, 1998).

An advance directive attends to a broad range of health issues, including life-saving treatments (Wareham et al., 2005). Some of the most important decisions are often made when a patient is no longer mentally able to participate in their own care (Faber-Langendoen & Lanken, 2000). Preston (2001) comments how 70 % of Americans die in medical institutions and about 40 % spend at least ten days in an ICU at the end of their life. Only 5 – 20 % of Americans have

In NZ society advance directives have a specific part to play with relevance to the cultural context of health care delivery (Wareham et al., 2005). The government has developed a policy recognising Maori rights and “is committed to improving Maori health and well-being” (Wareham et al., 2005, p. 350). The Maori health perspective of well-being integrates the spiritual, mental, physical and extended family as four dimensions important when considering the successful delivery of health care (Wareham et al., 2005). With reference to advance directives, it is important nurses’ consider alternate views, valuing cultural perspectives and recognising consumers’ rights. The New Zealand Bill of Rights Act (1990), notably, section 11 recognises that “everyone has the right to refuse to undergo any medical treatment” (Johnson, 2004, p. 81). Another relevant legal document is The New Zealand Code of Health and Disability Services Consumers’ Rights 1996 (the Code) (Wareham et al., 2005). Right 7(7) makes provision for every consumer having the right to refuse or withdraw consent to services (Wareham et al.). This will be discussed further in Chapter Four.

Campbell and Guzman (2003) proclaim some may argue the best way to improve end-of-life care in the ICU is to define the goals of care before admission. However, this strategy is uncommon in the seriously ill patient and even if the goals and preferences are known clinicians may not abide by these prediscussed ideals. Prendergast and Puntillo (2002) discuss how studies have shown advance directives do not cause patients wishes to be followed more closely.

There is very little research from nurses in this area; this could be attributed to the paternalistic approach associated with health care. Critical care nurses play an important role for patients, if an advance directive is known, with ensuring patients wishes are respected in regard to medical treatment choices. Gilligan and Raffin (1996) mention how although patients do not have the right to demand treatments clearly futile, physicians do not have the right to impose interventions contrary to the patient’s wishes. One of the most positive outcomes associated with advance directives is that it encourages discussion between family members, doctors and patients concerning patient preferences (Kirmse, 1998). One of the most essential things an individual can do is to plan in advance if you want control over how you die (Preston, 2001).

**Ethical issues**

Nurses who work in the ICU frequently encounter ethical dilemmas when caring for the patient through the long arduous journey of pain and suffering when onerous treatments dictate care. The nurse’s role of patient advocate can be challenging. Nurses who work in intensive care on
an eight or twelve hour shift work closely with the patient through one-to-one care and can’t help but have extensive contact with the patients family. Meltzer and Huckabay (2004) point out nurses who work in critical care units face complex ethical dilemmas more often than those who work in other acute care areas. Many of these ethical dilemmas centre on end-of-life care, for example, appropriateness of treatment, medical futility and decisions regarding forgoing treatment. All intensive care nurses will encounter these types of issues at some stage in their career.

Do not resuscitate orders

The SUPPORT showed only 47 % of physicians were aware of when their patients preferred a DNR order and 46 % of DNR orders were written within two days of death (Miller et al., 2001).

The DNR order was designed to allow patients a mechanism to forgo any or all unwanted treatments but they remain ambiguous and open to various interpretations whether it is the attending medical team, patient or family (Jezuit, 2000). To clarify this statement; it is not always clear what treatment a DNR order excludes. Does it mean the patient is not for external cardiac compressions, defibrillation or intubation in the event of a cardiac arrest? The previous statement is supported by a number of authors. Sherman and Branum (1995, p. 321) state although the word ‘resuscitation’ is used in other contexts, the definition of the word means “revival after apparent death”, therefore DNR should really be limited to measures to restart breathing and the heart. As discussed by Kyba (2002) a DNR order excludes cardio-pulmonary resuscitation in the event of a cardiac arrest but may allow for other treatments for example, resuscitation fluids, ionotropes, intubation and mechanical ventilation. Kyba remarks clear orders regarding a patients DNR status is essential; DNR or ‘comfort care’ orders are misleading. The DNR order has become ambiguous and no longer communicates the intent to withhold cardio-pulmonary resuscitation (Thibault-Prevost, Jensen & Hodgins, 2000). DNR policies need clarity to address legal and ethical issues and be documented and well communicated between all members of the health care team (Kyba, 2002).

Conflict often occurs for nurses when a patient with a DNR status is cared for in the unit. Intensive care nurses often question the appropriateness of the ICU environment for patients with a DNR status (Thibault-Prevost et al., 2000). Kyba (2002) states studies have shown that monitoring and physical care decrease for patients’ who have DNR orders. Other studies have shown it has made no significant difference to the level of care received by the patient (Sherman & Branum, 1995).

Medical futility and aggressiveness of treatment
Cogliano (1999, p. 81) states “futile care refers to medical care that either prolongs suffering, does not improve the quality of life, or fails to achieve a good outcome for the patient”. The context of futility can only be made within the context of individual situations. The SUPPORT showed despite evidence of poor prognosis being available to doctors, many patients received invasive, inappropriate medical treatment in the days and hours before death (Seymour, 2000). Decisions regarding initiation, continuation and termination regarding patient treatment are made everyday in the ICU.

As Frick, Uehlinger and Zuercher Zenklusen (2003) discuss clinical decision making is based on medical evidence, including survival probability, type and severity of the underlying disease, severity of the acute insult and treatment intensity. Scoring systems provide morbidity and mortality scores. More recently quality of life factors are becoming increasingly important with decision-making, but these perceptions are personal and estimating quality of life for patients is unpredictable (Frick et al.). Differing appreciations of survival and quality of life factors between caregivers can lead to conflict, burn-out and impaired patient care (Frick et al.). Nurses often find themselves questioning the appropriateness of treatment when caring for the dying and find themselves in the middle of controversy and conflict when disagreements occur between caregivers (Cogliano, 1999). Many nurses report concerns about how overly aggressive treatment prolongs dying for patients and results in inhumane uncompassionate care. Medical futility can be quite a dilemma for the medical team because it means the intensivist or health care provider has to utilise their own expert judgement about beneficial, appropriate therapy for the patient against the individual’s autonomy (Kyba, 2002).

**Spiritual and cultural values**

As Faber-Langendoen and Lanken (2000) note spiritual and cultural factors are often significant for patients and families who are confronted with end-of-life issues. The need for a multi-disciplinary approach is crucial if the patient requires their spiritual needs to be met. Questioning whether a patient’s spiritual needs have been met should routinely be asked at end-of-life and the hospital resources should meet these needs. Chaplains, social workers or any trained personnel may be required to be accessed. O’Gorman and Div (2002, p. 172) state spiritual care at the end-of-life “provides an opportunity to reflect on success and failure, hopes and fears, grief and sorrow”.

Different cultures have varying values with reference to discussing the limitation of patient treatment. Some cultures may be less willing to discuss resuscitation status and may be less likely to have an advance directive. Cultural and religious knowledge, sensitivity and respect are
required when discussions to forgo life-sustaining therapies are required (Faber-Langendoen & Lanken, 2000).

**Communication**

Communication has been identified as the most important and least accomplished factor associated with end-of-life care in the ICU for patients and their families (Boyle, Miller & Forbes-Thompson, 2005; Levy, 2001). Nelson and Danis (2001) note research shows this component in palliative care is one of the main areas which needs to be improved upon in the ICU between patients and family and the health care workers. The SUPPORT showed a substantial proportion of patients who spent 14 days or more in an ICU had not discussed their prognosis or preferences with a physician, almost 50% of patients who expressed a preference for palliative care received care to the contrary and 25% of patients did not know what approach to care was taken. Other studies by Asch, Hansen-Flaschen and Lanken; and Faber-Langendoen (cited in Nelson & Danis, 2001) show life-support was continued even when the patient’s preference was known to prefer to have life-support withdrawn.

Gilligan and Raffin (1996) comment on how effective communication is particularly important in the ICU. The ICU is an alien environment for patients and their families. Having an intensivist who takes time to make human contact with the patient and their family can go a long way to easing the burden and stress for the patient’s family. One of the obstacles preventing effective communication skills by medical staff may be their own discomfort associated with confronting death. Doctors may be uncomfortable with their own mortality and hence avoid spending time with dying patients, and they also may feel like failures when they allow a patient to die (Gilligan & Raffin). Levy (2001) points out doctors are not trained to feel comfortable with death. Combine the discomfort with lack of training in communication skills and this may result in a difficult time for patients and their families (Levy).

Published surveys have identified not only communication but continuity of communication as an essential ingredient in ‘good’ end-of-life care (Levy, 2001). As Levy notes even though doctors are overburdened with time restraints and the spiralling pace of medical care, good doctors must be willing to take time to talk to the patient and family about their care in a genuine manner in the proper environment. Boyle et al. (2005) comments how it is not only doctors who lack communication skills, nurses also lack the essential element to achieve better outcomes at the end-of-life. Evidence suggests improving communication regarding end-of-life issues in ICUs can improve the quality of care by resulting in earlier initiation of palliative care for patients who ultimately do not survive and increasing family members’ satisfaction with care (Boyle et al.).
Pain

The SUPPORT showed 50% of patients who were conscious until death, died in moderate to severe pain (Miller et al., 2001). Of note, Nelson and Danis (2001) comment on how one fourth of the original population in the SUPPORT did not have data obtained because they were unable to communicate. Pain and dissatisfaction with pain management were found in all categories of disease studied including acute and chronic respiratory failure, sepsis, liver failure, some cancers and congestive heart failure. Kyba (2002) comments how pain management and symptom relief frequently causes a dilemma in end-of-life care. Pain that is not treated undermines the patient’s autonomy (Kyba). It is estimated by Kyba control of pain is possible in 95% of patients but many patients suffer from professional caregivers’ lack of knowledge and the stigma of narcotic use. As Nelson and Meier (1999) discuss inadequate information about how drugs work in the critically ill patient, unwarranted concerns about addiction and the confusion about drug administration and the hastening of death all lead to uncertainties with drug administration for pain and symptom control in the suffering critically ill patient.

Environmental manipulation

The ICU is an area of high technology; noisy with alarms and people and bright with lights and equipment, an environment not at all conducive to peace and harmony required at the end-of-life. Bed spaces are often open or separated by partial walls or curtains. Visiting may be restricted to specific times and numbers at the bedside of visiting relatives and friends may be limited. If a side room is available it may be preferable to move the patient into this, remove all excess equipment, allow the visitors unlimited access and turn off all the alarms. In other words create an environment where the patient is allowed dignity and the family are given the privacy to express their feelings.

All intensive care patients are monitored, monitoring means the constant display of; heart rate through electrodes attached to a patient’s chest, blood pressure display through an invasive intra-arterial line, central venous monitoring through an invasive line into one of the patient’s large veins and oxygen saturation monitoring via a finger probe. This is basic monitoring in the ICU and all of these lines are attached by cables to a display unit giving tracings and recordings of the patient’s vital signs. Alarms sound if any of the readings deviate from preset limits. Ramsay (2003) raises the question is constant monitoring appropriate for the dying patient who has had treatment withdrawn and is expected to die imminently? Ramsay notes there are very few studies referring to whether monitoring should be suspended from the dying patient in the ICU.
It may be preferable to transfer the patient to a palliative care bed either within the hospital, hospice or home. However if death is imminent it may be more dignified to keep the patient in the unit if the family are agreeable. Invasive monitoring allows the medicalisation of death (Ramsay, 2003). Nurses need to judge carefully what is appropriate for patients nearing the end-of-life.

**End-of-life care nursing studies**

In the nursing articles reviewed, research designs centred around qualitative methods with semi-structured interviews and nurses reflecting on their experience with end-of-life care in the ICU (Cronqvist, Theorell, Burns & Lutzen, 2004; Halcomb, Daly, Jackson & Davidson, 2004; Jezuit, 2000; Kirchhoff, Spuhler, Walker & Hutton, 2000). Some nursing studies did utilize quantitative methods, namely surveys and questionnaires to capture nurses’ feelings (Beckstrand et al., 2006; Kirchhoff & Beckstrand, 2000; Meltzer & Huckabay, 2004; Puntillo et al., 2001).

Sample sizes in the previous authors’ texts varied from 6 – 3000 participants. Subjects also had varying degrees of experience in the ICU but the minimum amount was one year. Not all of the research articles stipulated whether participants worked full-time or part-time or worked a combination of both. The small sample sizes were researched generally from one hospital whereas the larger groups were taken from more than one hospital. Not all of the researched articles stipulated what type of ICU the nurses worked in. For example, neurosurgical, medical, trauma, cardio-thoracic. The literature reviewed was from a wide range of countries, Sweden, Australia, the United Kingdom and the USA.

Two themes have emerged from these articles: One; moral and two, ethical concerns for nurses with regard to decision making for the patient. Pellegrino and Sulmasy (2003) refer to the heart of clinical ethics as acting for the good of the patient. Whether it’s due to morals or ethics, conflict amongst medical and nursing staff regarding end-of-life issues occurs. As Robinson (2003) suggests nurses feel medical staff often treat death as a disease to be conquered and treated. Nursing staff may become frustrated with the persistence of high tech medical treatments, regarding death to be the outcome for the patient inevitably. If the patient is well sedated, generally this is well tolerated by nursing staff. However when the patient is perceived by nursing staff to be suffering, conflict may occur between medical and nursing staff. Meltzer and Huckabay (2004) suggest nurses should improve communication with colleagues, develop skills in moral reasoning and clinical situations should be approached with ethical principles. Ethical principles refer to “respect for others (autonomy), helping others in their best interest (beneficence), avoiding harm (nonmaleficence), and fairness (justice) are major components of
decision making in critical care nursing…” (Meltzer & Huckabay, p.7) as well as objectivity skills when assessing medical futility.

Generally, all investigators were in agreement about one thing. The delivery of ‘good’ end-of-life care is paramount to nurses. The confirmation of themes and ‘fittingness’ of findings ensures validity of the data in multiple settings. The commonest themes surrounding patient care centred on ensuring patients were as pain free as possible and comfort and dignity were preserved (Beckstrand et al., 2006; Cronqvist et al., 2004; Halcomb et al., 2004; Kirchhoff et al., 2000; Puntillo et al., 2001). Other common themes that emerged to improve standards of care was that communication and collaboration between health professionals and with family is essential (Beckstrand et al., 2006; Halcomb et al., 2004; Kirchhoff et al., 2000; Puntillo et al., 2001). The need for nursing education with ethical situations was also agreed. Jezuit (2000) states this is necessary to improve and identify principles to justify difficult decisions rather than form conclusions simply because it is right or wrong. Another common theme was a lack of clearly defined policies regarding end-of-life issues, meaning patient management was dependant on specific individuals at the time. Halcomb et al. (2004) discuss while policy and guidelines should remain flexible, the scope of practice should be defined for nurses; this would likely reduce workplace stressors and provide quality care. Kirchhoff et al. (2000) describe a lack of certainty of prognosis as an obstacle in the transition of cure to comfort in ICU patients. This has been referred to previously and confirms not all patients die when treatment is withdrawn.

Meltzer and Huckabay (2004) report a direct link between situations where nurses were involved in futile care and work-related moral stress. There was in all studies a lack of professional debriefing for nursing staff in the workplace. Religion was mentioned as an obstacle for providing ‘good’ end-of-life care by intensive care nurses. Meltzer and Huckabay comment if religion was important in a nurse’s life, end-of-life issues were viewed differently, perhaps seeing hope in death.

Limitations of the studies
Of the studies mentioned above, the smaller studies raise some concerns about validity. In the largest study, Puntillo et al. (2001) studied 3000 members of a professional critical care nursing organisation. Response rates were low; this may be attributed to two factors, length of the survey and the sensitivity of the questions. The responses may represent the nurses who were most interested with end-of-life care; or it may be those nurses belonging to a nursing organisation may differ in their commitment and professionalism to those who do not belong to a professional organisation. In the surveys, nurses may interpret the same question or scenario
differently, complicating results. Using surveys as methods of data collection may be too limiting to adequately study such a personal arena of nursing. Halcomb et al. (2004) note there may be an inability of the nurses to articulate their perceptions. For example, those with extreme difficulty with the subject may be less likely to contribute; consequently those who are comfortable with the situation may over participate.

**Nurses and dying in intensive care**

Stroud (2002, p. 182) states: “The contradiction between compassionate care … and the reality in practice, has prompted nursing researchers to explore what constitutes expert behaviour when caring for the dying patient ...” Nurses in intensive care are ideally placed as advocates for ‘good’ end-of-life care by having the advantage of one to one contact. Health care teams need to manage the approach of death with the same skill used to keep the patient alive. Because death is not the mission of ICUs, do professionals working in the ICU know how to manage the dying? As Levy (2001) comments just because ICUs see death all the time, it does not mean to say doctors and nurses are comfortable with it. Nelson-Marten et al. (2001) suggest care of the dying patient receives little attention in the nurses’ educational curriculum or for nurses orientating to the ICU. Doctors are also ill-prepared, with medical programs lacking educational implementation on end-of-life care (Nelson-Marten et al.). Support for nurses who are caring for patients who are dying is also lacking. Rarely is there a forum for discussion organised, or time for personal reflection (Nelson-Marten et al., 2001). As Chapple (1999) discusses one of the reasons staff who work in intensive care find end-of-life care so difficult, is because the rules are undefined. ICUs have endless protocols for any clinical diagnosis where the rules are known, whereas generally, end-of-life care has no rules.

**Conclusion**

Halcomb et al. (2004) state end-of-life issues in critical care are likely to become increasingly familiar with an aging population and the burden of chronic disease. Nursing research should revolve around “issues such as advance directives, models of collaborative decision-making, communication about issues of death and dying, palliative care management options for chronic disease processes, and bereavement care initiatives” (Halcomb et al., p.221).

Once the decision has been made to withdraw or not to escalate treatment, the nurse’s role in managing the death is paramount; trust must be fostered, family support is critical, the manipulation of drugs and the ICU environment to achieve a peaceful death is now the focus (Simpson, 1997).
Baggs and Schmitt (2000) state the best care and what drives the decision-making process should be the care which is in the patient’s best interests. Nurses who provide one to one care have the advantage of being patient-focused and therefore are advocates for ‘good’ end-of-life care. Although nurses unlike doctors have no legal liability in the decision to withdrawal treatment, we do have a moral responsibility for patient and family advocacy. End-of life care, including pain management and comfort measures are no less important than when care revolves around the patient receiving life-saving treatment. Accompanying a patient and family on the journey towards a peaceful death, truly encompasses the art of nursing (Rushton, Williams & Sabatier, 2002).
Chapter Three

Methodology

Gillis and Jackson (2002, p. 94) state “… it is the nature of the research question asked that determines which design is most appropriate.”

Introduction

The literature review has shown there is an abundance of research generally originating from America about what constitutes ‘good’ end-of-life care for adult patients who die in intensive care after treatment has been withdrawn or withheld. In NZ there appears to be very little literature published on the subject. This chapter will begin by identifying the research design selected to identify what nurses perceive to be ‘good’ end-of-life care for the patient who is expected to die in intensive care following treatment withdrawal. The questionnaire devised by the researcher to gain information will be discussed. Sample setting and sample criteria will be identified followed by data analysis procedures and finally ethical considerations will be outlined.

Research design

With reference to the quote at the beginning of this chapter, the researcher appreciates this is to the experts the most basic concept one could apply, yet a struggle it has been. There is no doubt end-of-life care is a quality issue and for this reason alone may best be investigated utilising a qualitative design. For example, interviews may be the best research approach to hear stories of nurses’ experiences when caring for the dying patient. This piece of research utilises a mixed qualitative / quantitative design.

Initially this research project (and this has been one of many changes) was going to be restricted to the provincial ICU where the researcher works, utilising two focus groups. However, when a visiting academic stated this subject is the focus of much discussion for a research project by intensive care nurses and suggested broadening the project to include nurses practising outside of the region, the researcher chose to re-evaluate. On this basis it was decided to use a quantitative approach (although three qualitative short answer questions are included) for ease of distribution of the questionnaires and analysis. It was decided against utilising wholly qualitative questions in the survey design as this would be too ‘open’ to interpretation by the participants and the researcher may interpret responses differently to how the participant intended.
As previously noted there is no doubt the investigation of end-of-life care in ICUs is a quality issue. LoBiondo-Wood and Haber (2002, p. 215) state studies of quality assurance or evaluation “are concerned with the determination of the quality of nursing and health care and with assurance that the public is receiving high-quality care.” Quality assurance and quality improvement in nursing are terms frequently referred to by managers of District Health Boards when evaluating costs and the benefits of nursing care. LoBiondo-Wood and Haber (p. 215) state “the goal of quality improvement studies is to evaluate the effectiveness of nursing interventions and to provide direction for further improvement in the achievement of quality clinical outcomes and cost effectiveness”. This research could be broadly classified under the umbrella of evaluation research. Evaluation research utilises experimental, quasi-experimental and non-experimental designs (LoBiondo-Wood & Haber). The latter design has been utilised for this project. LoBiondo-Wood and Haber (p. 222) state:

Non-experimental designs are used in studies in which the researcher wishes to construct a picture of a phenomenon; explore events, people, or situations as they naturally occur; or test relationships and differences among variables. Non-experimental designs may construct a picture of a phenomenon at one point or over a period of time.

In non-experimental research, variables occur naturally and can not be manipulated by the researcher. This type of study explores the relationships or differences between variables (LoBiondo-Wood & Haber, 2002). To further classify non-experimental research designs is to broadly label them as survey studies or relationship / difference studies (LoBiondo-Wood & Haber). This thesis is a survey. A survey has been conducted to explore, utilising a questionnaire, what intensive care nurses perceive to be important when providing ‘good’ end-of-life care for patients who are expected to die when treatment has been withdrawn or withheld. Survey studies can further be classified into descriptive, exploratory, or comparative studies (LoBiondo-Wood & Haber). Gillis and Jackson (2002, p. 136) state: “A survey design is one in which a researcher collects information from respondents on some topic at one point of time.” Surveys are used to collect data from large representative samples by questionnaires or interviews.

In summary the research design for this thesis is;

mixed quantitative / qualitative
i. non-experimental design
ii. descriptive survey study (questionnaire).

Research question
What do intensive care nurses perceive as important for ‘good’ end-of-life care when caring for the adult patient who has had treatment withdrawn or withheld?

**Research aims**

a) To identify what the intensive care nurse perceives to be important for the patient, family and themselves when providing ‘good’ end-of-life care for the adult patient who has had treatment withdrawn or withheld.

b) To identify participating units’ (collective) strengths and weaknesses when providing end-of-life care.

c) To provide a NZ perspective on a subject widely researched overseas.

**Setting**

To minimise the breadth of a potentially large research project for a two paper one-year thesis (60 credits), after consultation with the Clinical Director of the Hawkes Bay District Health Boards ICU, (R. Freebairn, personal communication, October 17, 2005) it was decided to limit this project to the nine non-metropolitan North Island ICUs.

A letter from the researcher was sent to the Director of Nursing (Appendix IX) representing each District Health Board (DHB) invited to participate. At the same time a covering letter was also sent to each ICUs Nurse Manager with the Locality Assessment Form (required by The Central Regional Ethics Committee), with a pre-paid, pre-addressed envelope, ready to return to the researcher if they consented to the nurses within their jurisdiction being studied.

After satisfying all of the Central Regional Ethics Committee’s requirements (more detail to follow) and the return of the Locality Assessment Forms, the questionnaires were couriered to the nursing staff in each participating ICU.

Participants were clinical nurses who worked at the bedside. The researcher, having a strong clinical focus herself, believes nurses who work at the bedside are in the best position to comment on the care patients receive (excluding the patients themselves) while they are in hospital.

**Sample**

*Sample size*

The target population was bedside nurses who work in ICUs located in nine non-metropolitan North Island hospitals. The researcher did not know how many nurses were on the roster in each ICU (this changes frequently with staff resignations / recruitment and maternity leave). Many
nurses work part-time, however full–time equivalent staffing numbers were requested when investigating each unit’s demographics.

Many regional hospitals have a combined ICU / Coronary Care Unit (CCU). The researcher works in an eleven bedded regional ICU (CCU is located in a different area and staffed separately), based on this unit’s staffing numbers (one of the biggest of the units participating in the study) and also on a presentation at the Australia and New Zealand Intensive Care Society (ANZICS) annual scientific meeting by Hicks (2006), the questionnaires were allocated. To clarify further, approximately 56 nurses were listed on the roster of the ICU where the researcher works at the time of questionnaire allocation; therefore approximately 20 questionnaires were required to fulfil the requirement of sending a questionnaire to every third nurse on the roster. The ANZICS presentation (Hicks, 2006) classified Level 1 and 11 units according to ventilated patient numbers. Of the eight participating units, six units had annually between 50 – 250 ventilated patients and two units had less than 25 ventilated patients annually. The researcher has used this presentation as a guide to the size of the units (the number of ventilated patients should equate with staffing resources). Based on these two guidelines 20 questionnaires were sent to the six larger units (50 – 250 ventilated patients annually) and 15 were sent to the two smaller units (less than 25 ventilated patients annually). One unit did not participate. This equated to a total of 150 questionnaires sent out.

Inclusion criteria
The only inclusion criterion was that nurses must be on the ICU roster and work at the bedside. Participants were asked to exclude the coronary care patients.

Subject recruitment and informed consent
In each ICU participants were recruited by a member of nursing staff who works in the ICU and was the Link Nurse for their unit (liaison nurses for the organ transplant co-ordinators). All of these nurses were known to the researcher through this association and became the ‘contact nurse’ at each ICU in this project. All these nurses were e-mailed by the researcher prior to the study. Where the nurse did not answer, either due to an invalid e-mail address or moving on from that department, the nurse manager, clinical charge nurse or team leaders (DHBs have conflicting titles for the same job description) were contacted. This person was requested to allocate the individual questionnaires to every third nurse from a random starting point on the nursing roster. The participants were given one month to fill out the questionnaire. At three weeks the researcher e-mailed each ‘contact nurse’ to remind them one week was left before return of the questionnaires was requested.
**Systematic sampling**

It was intended this form of sample selection technique would represent the views of the larger population (all nurses) and avoid bias on the researcher’s behalf. When the sample is representative of the population from whom it is drawn, the researcher can have confidence the results are representative of the entire population and setting studied (Gillis & Jackson, 2002). The type of sample technique utilised by the researcher is sub-grouped under the broad classification of probability sampling techniques and is called a systematic sampling procedure where the population has an equal chance of being selected for participation in the study by choosing every \( n \)th person, starting randomly (Gillis & Jackson). The purpose of a random commencement point is to ensure all members on the list have a chance to be included in the sample (Downs, 1999). As Gillis and Jackson discuss when probability sampling techniques are utilised, each individual has a known chance of being selected and this type of sampling technique yields samples representative of the population from which it is drawn and avoids bias. If the researcher is to make generalisations about the study results of the larger population not measured, the representativeness of the sample is necessary (Gillis & Jackson). Downs notes one of the major advantages for using this type of sampling is its simplicity. The researcher can only presume that the sample selection in each unit was implemented as planned.

**Informed consent**

Informed consent from the participants was presumed by the researcher by the return of the questionnaires.

**Data collection**

Data collection was by a questionnaire designed by the researcher. On each questionnaire was a request from the researcher to write no identifiable information on the form. The questionnaire consisted of four sections and a covering letter (Appendix I).

a) **Section 1** – Demographic data of the participant (Appendix II)

b) **Section 2** – A table of important end-of-life issues listed for numerical ranking (Appendix III)

c) **Section 3** – Three qualitative questions and one yes / no question (Appendix IV)

d) **Section 4** – Demographic data of the participating units (Appendix V).

**Covering letter**

The covering letter was located at the start of the questionnaire and invited the participant to be part of the research project. It included the following information.

- Project title
Researchers name and contact details and study institution
Affiliations
Research description
Time to fill in the questionnaire / assurance of anonymity / instructions for postage / a note that there was no obligation to fill in questionnaire / an assurance of participant confidentiality
Benefits and risks to the participant
How the information would be collated / analysed / stored
Assured circulation of results to participating units on completion of thesis publication
How completion and return of the questionnaire presumes participant consent
A note that Ethics committee approval had been gained

Section 1 – Requested the following demographic data from the participant:
- Age
- Gender
- Ethnicity
- Years experience in ICU
- Highest qualification
- If unit had a bereavement program are they a member of the committee?
- Any educational sessions attended regarding bereavement / palliative care?
- Clarification of whether they had ever nursed a patient who had had treatment withdrawn or withheld?

Section 2 – There are two parts to this section. Part A lists a series of end-of-life issues to be numerically ranked according to how the nurse perceives the priorities of care for the patient, family and her / himself (1 = most important and 10 = least important). Part B requests the nurse to numerically rank those same priorities of care according to how effectively they perceive their units to do them (1 = most effective and 10 = least effective). Both of these parts were formatted as a table.

There were ten end-of-life issues nurses were requested to rank for the patient, family, themselves and the unit. The ten issues were chosen from the literature and from the researcher’s own experience of working in a provincial ICU for more than fifteen years.

The ten issues were:
- Respect of cultural beliefs
- Privacy
- Unlimited family access
- Respect of religious beliefs
- Documentation of an alternative care plan based on maximisation of comfort
- Open communication channels (between family / medical / nursing staff)
- Administration of medication for pain and symptom relief
- Dignity
- Environmental issues (noise, lighting, technology)
- Advance directives respected

**Section 3** – This section consisted of three open-ended short answer questions and one yes / no question. The questions revolved around the following issues:

1. Requesting nurses to comment on the barriers to providing ‘good’ end-of-life care to patients in the unit in which they worked.
2. Requesting nurses to comment on the statement: Nurses frequently try to bridge the gap between aggressive ‘medical’ interventions and holistic compassionate care for patients at the end of life (Scanlon, cited in Chapple, 1999).
3. Requesting nurses to comment on the statement: Caring for patients during the dying process consumes health care resources. In an environment of resource limitation the supporting of the dying process in intensive care is justified.
4. The yes / no question investigated whether nurses have accompanied a patient home (treatment is withdrawn in the patients home) because the family has requested their loved one die at home.

Five or six lines were left after each of these statements allowing for nurses comments.

**Section 4** – This section collected demographic data on the unit. A phone call was made by the researcher to each unit (usually the unit manager) participating in the study to document the following information:

1. What level ICU it was / annual ventilated patient numbers?
2. Was it a combined ICU / CCU?
3. How many full-time equivalent nurses did the unit employ?
4. Administrative model of unit?
5. How many total patient beds / ventilated / high dependency / coronary care beds?
6. Did the unit have a resident intensivist?
7. Annual patient deaths?
8. Utilisation of a prognostic model?
9. Generic end-of-life care policy for the unit?
10. Bereavement follow-up program?
11. Admission criteria for unit?
12. Written DNR policy for unit / hospital?
13. Does the unit you work in accept patients who are not for CPR / ionotropes / invasive ventilation / renal replacement therapy?
14. Hospital palliative care team?
15. ICU consult with palliative care team or hospice?
16. Formal debriefing sessions for nurses?

The researcher has mentioned how a visiting academic had previously advised how this research topic causes much discussion with nurses practicing in ICUs, suggesting a questionnaire may have already been developed. The researcher was unable to locate any existing questionnaires. Therefore an original has been devised. The questionnaire was piloted four times by colleagues and changes were made in response to their comments. Generally piloting feedback involved concerns surrounding the length of time taken to complete the questionnaire and confusion surfaced about the instructions given to complete the table of end-of-life issues. The final format was settled on. However, one colleague had still one area of concern; as all the issues in Section 2 could be of paramount importance for the patient, nurses would rank all of these priorities of care as number one, instead of one through to ten.

The questionnaire took no more than 15 minutes to complete and questions were kept as short as possible so respondents were influenced favourably to participate in the research. The questionnaires were distributed to each unit by courier within a sealed NZ Post EasyTrak envelope addressed to either or both of the unit manager or the link nurse. Inside the envelope were instructions addressed to the link nurse for distribution of the questionnaires. A central, anonymous collection point in each ICU was organised for return of the questionnaires, and at the end of the month all completed questionnaires were couriered to the researcher. Each of the individual questionnaires had an envelope attached to it, so the completed questionnaire could be placed in the envelope, sealed and then placed in the larger pre-supplied EasyTrak envelope. On return to the researcher the questionnaires were collated into a single file and will be shredded on completion of the research project. All the data collected was recorded on the researcher’s password protected personal computer.

Data analysis
All the data were collated in a central location and then the quantitative data was entered on to computer using a software programme database (EXCEL) for statistical analysis. Thematic analysis was utilised for the qualitative data.
**Ethical considerations**

Approval for the thesis topic was given by the Eastern Institute of Technology Research Committee (Appendix VI). Ethical approval was sought from the Central Regional Ethics Committee and consent (Appendix VII) for a multi-centre research project was given when all the Locality Assessment Forms had been signed and returned by the unit managers. As already stated the Director of Nursing for each District Health Board was contacted requesting approval for the project at the same time. Before approval was given from one DHB, the Director of Nursing requested further information about the research project. A submission was sent for The Clinical Board to review and following this, approval was given for the survey to be initiated to the two hospitals within the DHB’s jurisdiction. The appropriate documentation was also sent as requested to another DHB’s Research and Ethics Committee before approval was given. Feedback will be provided to all units participating in the research and the Central Regional Ethics Committee on completion of this thesis.

**Conflict of interest**

There was no conflict of interest by the researcher. The researcher is a senior staff nurse working clinically in one of the provincial ICUs participating in the study. In the researcher’s own unit the questionnaires were distributed by a colleague to prevent researcher coercion.

**Potential risks to the participant**

The participants knew who the researcher was, as this was written on the covering letter. This may alter the nature of the responses given (more so a risk for the researcher rather than the participant). A potential risk factor for the participants from the unit where the researcher works was identification of their handwriting by the investigator when correlating the data. Another potential risk to participants in all units revolves around the sensitivity of the subject and, on the Central Ethics Committee’s request, a number of options were listed for participants should they require counselling or emotional support after completing the survey.

The researcher did know when each hospital returned the questionnaires, as each EasyTrak envelope had the hospital name in the space identifying the sender. This was done so the researcher could identify any hospital who had not returned the questionnaires.

**Anonymity and confidentiality**

Individual participant anonymity was assured by the researcher and participants were specifically requested to not include any identifiable information on the questionnaire. Identification of the hospital or individuals is not possible in any conclusions to this research.
All information will be kept confidential and participating hospitals and individuals were assigned a number for entry into the computer analysis programme.

**Cultural considerations**
Consultation with the Hawke’s Bay (HB) DHB’s Maori Health Service took place prior to the commencement of this project. A letter from the Service Manager is included (Appendix VIII) supporting the project. The Service Manager acknowledged there are very few Maori nurses working in the DHB’s ICU and suggested Care Associates may be able to contribute to the questionnaire. This was not taken further by the researcher; Care Associates (to the researcher’s knowledge) are exclusive to the HBDHB and within the DHB’s ICU are not responsible for patient care. Feedback will be provided to the HBDHB Maori Health Service on completion of the project.
Chapter Four

Findings and Discussion

“… death in the ICU is neither simple or natural” (Chapple, 1999, p. 25).

Introduction

Chapter Three outlined the methods of data collection and analysis. Data have been generated from two sources, written (participants questionnaire) and by phone (section 4 - unit demographic data). The questionnaire has been further categorised into three sections;

a) Section 1 - the demographic data of the participants.

b) Section 2 - table of end-of-life issues, numerically ranked.

c) Section 3 - open-ended questions.

All the quantitative data (sections 1, 2, 4) were able to be analysed by an Excel software programme. Thematic analysis was utilised for the qualitative data (section 3). Errors have been minimised by double checking the data entries. The findings of the four categories will be discussed in this chapter commencing with each unit’s demographics (section 4), acquired by ringing the nurse manager of each unit participating in the study and entering the data on Excel.

Out of the original nine hospitals invited to participate, one hospital was eliminated as despite two reminders, the Locality Assessment Form was never returned, so this disqualified this hospital’s ICU and left eight hospitals in the study.

A. Verbal information from Unit Managers.

Section 4. Unit demographic data. This information was gained by a phone call to the unit manager or clinical charge nurse or team leader of each ICU. The information to follow is correlated according to the format of the questions asked (Appendix V).

1. All units who participated in the study were either Level I or II units. The only other classification of ICUs according to ANZICS guidelines are Level III units which are tertiary units catering for 400 – 1000 ventilated patients annually. Eight units participated in the study out of the original nine who were approached. Four units catered for 100 – 250 ventilated patients annually, two units catered for 50 – 100 ventilated patients annually and the remaining two units catered for less than 25 ventilated patients annually.

2. Six units were a combined ICU / CCU, leaving two units solely ICU / HDUs.

3. Full time equivalent nursing staff numbers ranged from 14.95 to 34.8. The researcher appreciates this is probably not important. To work out accurately the response rate of the
questionnaires, it would have been necessary to ask how many permanent staff members were on the nursing roster at the time each unit distributed the questionnaires. As it is the researcher does not have an accurate calculation of the response rate. One hundred and fifty questionnaires were posted and 80 were returned completed, accounting for a response rate of 53% (providing all the questionnaires were distributed). The researcher did request any questionnaires not required to be sent back in the EasyTrak envelope with the completed ones (so the response rate could be calculated) but this was not done by every unit.

4. Administrative models of ICUs have been briefly discussed in Chapter Two with reference to a study by Cassell et al. (2003). To recap, a ‘closed’ administrative model ICU is where intensivists (trained critical care specialists) have sole input into the care of the patients while in ICU. An ‘open’ unit is where decisions regarding patient care are made by the physician or surgeon caring for the patient and a ‘semi-closed’ unit is where the intensivist and the physician or surgeon share responsibility for patient care. Five of the ICUs described themselves as having an ‘open’ administrative model, two ‘closed’ and 1 ‘semi-closed’. Having so many ‘open’ administrative model ICUs is not surprising in the non-metropolitan regions where not all units are fortunate enough to have an intensivist employed. These areas rely on anaesthetists who are rostered to care for the ICU and rotate frequently and/or on the medical or surgical team the patient is admitted or referred to. Cassell’s et al. research concluded the way the ICU is run impacts significantly on end-of-life issues. When intensivists controlled the ICU, attention was given to quality of life concerns, but when the responsibility is shared between two specialties conflict regarding end-of-life decisions was observed.

5. Excluding coronary care beds, intensive care beds / high dependency beds numbered between 2 for the smaller units and 12 for the larger units.

6. Three units had an intensivist caring for the unit. Five units did not have an intensivist.

7. The ICU death study conducted in 1999 / 2000 reported a death rate of 9.3% (Hicks, 2006). Out of the eight contributing units from the death study, three of the units are also participants in this study.

8. Three units did not use any form of prognostic model. Prognostic models are a way of classifying the severity of disease. Knaus, Draper, Wagner and Zimmerman (1985) state the high cost service ICUs provide have prompted demands for better evidence of the indications and benefits of intensive care. Utilising a prognostic model is one of the best ways to estimate patient outcomes. Prognostic models stratify acutely ill patients’ prognosis using basic physiologic principles (Knaus et al.).

9. None of the ICUs participating in the study had a generic end-of-life care policy to guide patient care.

10. Half of the units had a bereavement follow-up programme established.
11. Six units stated they had a written admission criteria for patients although this was not always adhered to, and the major contributing factor to this was dependant on “who was on” (doctor) for the ICU on the day.

12. No individual units had a written DNR policy although seven hospitals had a generic hospital DNR policy which was not always relevant to patients in the ICU. The one remaining hospital was working on a hospital DNR policy.

13. All units except one stated they accepted patients who had a ‘not for cardiopulmonary resuscitation’ (CPR) instruction. All units accepted patients who were not for invasive mechanical ventilation. Not all units provided continuous renal replacement therapy for acute or chronic renal failure so this part of the questionnaire is not relevant.

14. Four hospitals had a hospital palliative care team.

15. Four ICUs had at some stage consulted or referred (regarding end-of-life care) with the local hospice, but this was not routinely done.

16. Four ICUs provided formal debriefing sessions for nursing staff.

B. Questionnaire

Section 1. Demographic data of participants. These data are written information from the 80 participants and follow the format of the questions asked (Appendix II).

1. The majority of the staff identified themselves as being in the 31 – 40 and 41 – 50 year old age groups (55 participants or 65.7 %). 11 staff (13.8 %) were in the 20 – 30 year old age group and 14 staff (17.5 %) identified themselves as more than 51 years of age.

2. Seventy staff (87.5 %) identified themselves as female, ten (12.5 %) as male.

3. Participants were asked to identify their ethnicity in written form (no tick boxes were supplied). Forty five participants (56.25 %) identified themselves as NZ European and an additional twenty staff (25 %) simply wrote European. Other (16.25 %) ethnic affiliations included; 5 English, 2 African, 2 European of Maori descent, 1 Maori, 1 Chinese, 1 Indian, 1 Irish. Two staff did not complete this question.

4. Twenty four staff (30 %) identified themselves as having 6 – 10 years intensive care experience. The second largest group (28.75 %) had more than 15 years experience. Less than three years experience was 16.25 %, 13.75 % had 3 – 5 years experience and 8.75 % had 11 – 15 years experience. 2 staff did not complete this section.

5. There was a broad range of qualifications identified. Two of the staff who completed the questionnaire had a Master of Nursing degree. Importantly, over half the staff (56.25 %) identified themselves as having some sort of ICU qualification, which ranged from having a hospital certificate in intensive care and / or post-graduate certificate in intensive care and / or post-graduate diploma in intensive care.
6. The first part of this question asked the staff to identify whether the unit they worked in had a follow-up bereavement program or not. Some discrepancies occurred in the individual survey, so instead this question was asked as part of the unit demographic data and will be discussed in Section 4. Five staff (6\%) who completed the questionnaires identified themselves as members of the unit’s bereavement team appropriate only for the units who had a bereavement team.

7. Over half (51\%) of respondents answered yes to attending some sort of education session / conference or course relevant to end-of-life care.

8. Forty percent of staff who had completed an educational qualification, as identified previously in 5, stated the course content included information about palliative care, withdrawal of life-support or DNR orders. About a third (34\%) of staff said the course they completed did not.

9. Only 1 nurse stated he / she had not nursed a patient who had had treatment withdrawn or withheld. This person chose to continue with the survey.

Section 2. Table of end-of-life issues. This was a table of 10 end-of-life issues to be numerically ranked in accordance with what the nurse perceives to be important for the patient, family and themselves (part A) (1 = most important and 10 = least important). On the same page, formatted separately (part B) the nurse was asked to rank those same issues on how they perceive their unit does most effectively to least effectively. (1 = most effective and 10 = least effective) (Appendix 111). The results of all of Section 2 will be reported next and then discussed.

Part A1. Patient
Nurses perceived the three most important issues to providing a ‘good’ death for the patient who is nearing end-of-life was the;

a) administration of medication for analgesia, sedation and symptom relief,
b) preservation of the patient’s dignity and
c) the importance of unlimited visiting for the patient’s family.

These three issues averaged 7.9, 7.6 and 7.3 respectively out of a possible 10. Standard deviations (SD) ranged from 1.9 – 2.4.

The next four most important issues (average score) were;

d) the respect of religious beliefs (6.96),
e) the respect of cultural beliefs (6.92),
f) advance directive respected (6.5),
g) open communication channels (6.5) and
h) privacy (6.3).
All SDs were less than 3.5.
The final two issues to be ranked and which scored the lowest averages in importance were;
i) environmental issues (5.2),
j) and the documentation of an alternative care plan with the emphasis on comfort (4.6).

These results can be seen illustrated graphically in Figure 1.

**Part A2. Family**
Nurses perceived the most important issue to the family was that they were given unlimited access and were offered the opportunity to participate in basic nursing cares for patient comfort if they wished. Averaging a score of 8.1 with a SD of less than 1.3 was
a) family access.
Following close behind in the following order was;
b) open communication channels (7.5),
c) dignity (7.4)
d) and the administration of medication (7.2),

![Figure 1: Nurse’s rankings of end-of-life issues perceived to be important for the patient.](image)

All of these issues had a SD less than 2.
The next most important issues, with SDs less than 2.4, are as follows;

e) privacy (6.72),

f) cultural beliefs respected (6.69) and
g) religious beliefs respected (6.5).

The lowest ranked items were;

h) advance directives respected (5.7),
i) environmental issues (5.1),
j) and the documentation of an alternative care plan (4.2).

These results can be seen illustrated graphically in Figure 2.

![Figure 2: Nurse’s rankings of end-of-life issues perceived to be important for the family.](image)

**Part A3. Nurse.**

Clearly the three outstanding issues nurses perceived as important for themselves when caring for the patient nearing end-of-life (SDs less than 2.5) were;

a) administration of medication for analgesia and symptom relief (8.0),
b) patients dignity (7.5) and
c) the maintenance of open communication channels (7.2).

The next most important issues, averaging between 6.3 and 5.2 were;

d) family access,
e) privacy,

f) respect of advance directives,

g) respect of religious beliefs,

h) the documentation of an alternative care plan

i) and the respect of cultural beliefs.

The least important with an average score of less than 5 was;

j) environmental issues.

These results can be seen illustrated graphically in Figure 3.

![Figure 3: Nurses’ rankings of end-of-life issues perceived to be important for themselves when caring for the patient.](image)

**Part B. Unit**

Part B refers to how effectively nurses believe the unit they work in ranks with the same end-of-life issues. Nurses believed unlimited family access to dying patients who had had treatment with drawn or withheld is what the unit they work in does best, with an average score of 7.3.

a) Unlimited family access.
Close behind are the following four issues, averaging scores of 7.1, 6.8, 6.6 and 6.3. The SDs were all less than 2.6.

b) The administration of medication for analgesia and symptom relief,
c) maintenance of dignity,
d) open communication channels between medical staff / family and nurses and
e) respect of the patients cultural beliefs.

The lowest scoring issues were respectively;
f) respect of patients religious beliefs,
g) privacy,
h) respect of advance directives,
i) environmental issues,
j) and the documentation of an alternative care plan based on comfort.

These results can be seen illustrated graphically in Figure 4.

Scores were then averaged and ranked for patients, families, nurses and units, and these results are shown in Table 1.
One of the main objectives from this exercise was to compare what nurses perceive as important for the patient, family and themselves and to compare this to how the unit they work in performs with the those same issues. This can be seen in Figures 5a and 5b.

Table 1: Average ranking for end-of-life issues across patients, families, nurses and units.
Discussion

A pattern seems to have emerged with the results from Section 2.

a) the administration of medication for analgesia, sedation and symptom control,
b) the preservation of the patients dignity and
c) unlimited family access,

feature consistently in the top four of what the nurse perceives to be most important for the patient, family and themselves in end-of-life care for the adult patient who has had treatment withdrawn or withheld and is expected to die. Interestingly enough according to what nurses believe their unit does well, these same issues featured in the top 3.

The administration of medication for analgesia, sedation and symptom relief ranked first for what nurses believe is important for the patient and what nurses believed is most important for themselves when caring for the dying patient. It is pleasing to read nurses consider there is no reason a patient should suffer once the decision to forgo treatment has been made. Rocker and Randall Curtis (2003, p. 821) state when life-sustaining treatments have been withdrawn the use of narcotics and sedatives “to achieve patient comfort constitutes good-quality care”. To withhold palliative treatment, allowing patients to die in distress is poor-quality care. Rubenfeld (2000) states critically ill, haemodynamically unstable patients do not always receive optimal sedation for fear of drug induced hypotension or respiratory depression preventing weaning or liberating from mechanical ventilation. However, when the goals have changed, assuring patient comfort with any dose of medication is justified (Rubenfeld).
Overall it is pleasing to read this is something that nurses believe the unit they work in does well, ranking second overall. Occasionally in practice the researcher has observed nurses to be reluctant to increase sedation or narcotics for the dying patient who may show, in the researcher’s opinion, signs of distress. Rocker and Randall Curtis (2003) speak about the double-effect of administering medications for control of pain and other symptoms (anxiety, dyspnoea); a potential adverse effect may be to unintentionally hasten death. It may be some nurse’s struggle with this concept when caring for the dying patient and feel they may be hastening their death. To take this one step further, nurses may feel they are administering medications generally initiated without the patients consent; this may also restrict the administration of medications in the dying patient. As Prendergast (2000) comments the administration of large opioid doses to control pain and respiratory distress does not constitute euthanasia. The size of the dose is much less important than the goals of administration and it is entirely appropriate to administer large amounts of medication if carefully titrated for symptom relief (Prendergast).

Maintaining a patient’s comfort is the goal of treatment at end of life. Truog et al. (2001) discuss how palliative care prioritises symptom management before diagnosis and treatment. Assessment of pain should not be through pain score scales (if the patient is cognitively impaired), but through the patient’s non-verbal cues, for example, consciousness and awareness, agitation, moaning and respiratory distress. Management of pain and distress should receive the highest priority. Therapies and interventions that cause discomfort should therefore be withdrawn. Certainly in the Level I and II units researched in this study many of the advanced technological therapies are not available and so this minimises the number of therapies that could be withdrawn. Not all units perform continuous renal replacement therapies (CRRT) for example. Certainly CRRT or haemodialysis is one of the earliest treatments that could be discontinued, as this is unlikely to cause an immediate death.

The sequence of events for withdrawing therapies is initiated by the medical staff with the help of an expert ICU nurse if required. The goal of care may be short term survival, while family members gather around the bedside. Withdrawing haemodynamic support may induce cardiovascular collapse and the patient may die quite quickly. Withdrawing mechanical ventilation is one of the commonest therapies to be discontinued. It is imperative, during this process the patient does not show any signs of respiratory distress. Prior to withdrawing the ventilator, sedation needs to be commenced or increased (anticipatory dosing) to overcome the patients predicted distress once this has been communicated to the family. Rubenfeld (2000) suggests the following steps to ventilator withdrawal. Once the appropriate sedation has been
achieved the fraction of inspired oxygen can be reduced to 0.21 along with removing positive end expiratory pressure, while allowing adequate pressure support or mandatory ventilated breaths to meet the patient’s ventilatory requirements. This allows time to reassess the patient’s sedation requirements before removing the ventilator. Once the appropriate sedation level has been accomplished, the remaining ventilatory support can be weaned fairly rapidly, until the patient is spontaneous breathing through an endotracheal tube with humidified air. Extubation may or may not be performed or required. This is not always a clear cut decision. Certainly every patient is different and no two deaths are the same. When a patient is extubated who can not protect their airway, obstruction and the inability to clear secretions can create noisy, distressed breathing. Again, it is imperative the patient’s sedation is titrated to prevent this happening. Loud, distressed breathing can be very upsetting to family members. Family may request the endotracheal tube be removed and this should be considered. Family members may wish to stay during these steps but must be warned in advance of what may occur and reassured the patient will be attended to if any signs of distress are observed.

Attention must be paid to symptoms such as pain, dyspnoea, anxiety, discomfort, fatigue, grimacing, restlessness, fear and agitation. Morphine is often the drug of choice for ‘terminal sedation’ if necessary to eliminate suffering (Preston, 2001). In many cases the required drug doses may be sufficient to induce a coma. Rubenfeld (2000) comments how there is no role for paralytic agents in the withdrawal of treatments. These agents should be reversed or the effects allowed to wear off before ventilator weaning occurs (Brody et al., 1997; Prendergast, 2000; Truog et al., 2001). The drug regime differs for every patient dependant on the variability of individual responses and drug tolerance. There is no one rule of thumb. Rubenfeld (2000) discusses how a combination of morphine or similar narcotic with a benzodiazepine will provide adequate analgesia and sedation in almost all cases and should be titrated to effect. The benzodiazepine also helps to prevent seizures in the premorbid patient. Dyspnoea may be due to potentially treatable causes (for example, pneumothorax) and this must be assessed before focusing on other ways of dealing with the symptom. Anti-emetics should be charted for nausea and vomiting. Previously discussed in Chapter Two were the concepts around feeding and intravenous fluids. Truog et al. (2001) clarify that loss of hunger and thirst are normal physiological responses to the dying process and that forced nutrition and hydration does not contribute to the patient’s comfort.

**Dying with dignity** ranked 2nd or 3rd as important for the patient, family and nursing staff. Benner (2001, p. 355) states a dignified death is closely related to the persons identity, meaning the person “who is dying be met as a person with a particular life - a particular human face”.
This is a hard thing for nurses to do – we care for a patient in the last days or weeks of their life. Sometimes this life has spanned decades. Regardless of age, we as nurses have not been privileged to be a part of their life, until now. Now, in death, when family and loved ones put their trust in our care, allowing us (strangers) to become intimate with a small but significant part of their life. The nurse, with reference to Benner’s (1984) (cited in Pearson, Vaughan & Fitzgerald, 1996) novice to expert passage of practice, must be adaptable and intuitive to how the family feels and how we treat this person who is dying, of who essentially we know so little about.

**Unlimited family access.** This was described by nurses as being the most important issue for the family and has also ranked first for how well the unit performs. It appears to nurses that units cater for the family well, allowing the ‘rules’ to waver and allowing the families of patients who are dying unlimited access. Encourage family members to stay with the patient and participate in care if they request this. Unrestricted visiting is important for family members. A family-centred approach is important. Families may want to participate in patient cares such as washing and repositioning. In a study by Berns and Colvin (cited in Beckstrand et al., 2006) it was found family members either present or absent at the death of their loved one held a significant memory for them as survivors. This leads on to one of the issues that scored poorly as important for the patient, family, and nurse (ranking 9, 9, 10 respectively) and equally as poorly scoring a 9 for how well the unit performs: attention to environmental issues, noise lighting etc.

**Attention to environmental issues, noise lighting etc.** This will also be discussed further in the next section when referring to barriers to dying a ‘good’ death in the ICU. Environmental issues relates to noise levels, lighting, space, equipment, seating, the availability of facilities for relatives etc. Attention to the environment during the dying process is not always catered to well and some of these issues are easily tended to. Others, like the luxury of space, are not and are well out of our control. However, it appears out of the list of ten factors of the most important for end-of-life care in the ICU this features 2nd to last or last in importance for all groups.

**The documentation of an alternative care plan based on maximising comfort.** This also consistently features as 9th or 10th and this figure corresponds with how the unit the participants work in performs. It is an issue that can be easily catered to and although, as has been documented in a previous chapter, we have protocols and policies for almost every aspect of patient care in the ICU, we do not have one catering for end-of-life care, for the patient who has had treatment withdrawn or withheld, which accounts for a large percentage of overall intensive care deaths.
Truog et al. (2001) admit some patients receive a combination of curative and palliative therapies inconsistent with the palliative care plan. One way to address this is to completely rewrite the patient’s care plan. This should reduce the amount of unnecessary tests and interventions. Laboratory and radiological tests should be stopped. It is important nurses prompt the medical team to review the patient’s medications. Ionotropes, antibiotics, blood products, intravenous fluid regimes, naso-gastric feeding, and total parenteral nutrition all need to be reviewed. The patient’s progress notes should document family meetings. The sequence of events for treatment withdrawal should be documented as well as the specific plan for ‘comfort cares only’. Comfort cares can be a confusing term. Adequate medication for symptom control must be charted. This means the use of intravenous drugs such as narcotics, sedatives and anti-emetics must be prescribed to ensure the patients comfort. The doctor must reassess the goals of treatment from the patient’s perspective.

The researcher would like to speak briefly about those issues that were ranked in the middle as important in end-of-life care. The importance of open communication channels between family, medical and nursing staff has been well documented in America as the single most important factor least accomplished in quality of care (Boyle et al., 2005; Levy, 2001). Norton, Tilden, Tolle, Nelson and Talamantes Eggman (2003) report communication problems regarding end-of-life revolve around poor access to medical staff, inconsistency and lack of information and absence of medical staff initiating discussions. From this piece of research it appears in NZ we cater to it fairly well. It scored as 2nd most important for the family, after family access, 3rd most important for the nurse and in the units the participants worked in, it scored 4th overall as most well done. Scoring so highly as important for the family and nurse is not surprising. Poor communication can lead to conflict, anger and dissatisfaction with end-of-life care between already stressed, tired family members and members of the health care team (doctors and nurses). But perhaps most importantly the patient’s wishes may be neglected (communicated through their family) and this is almost certainly unacceptable. For the patient it came in as 6th. One reason for this may be, generally patients in the ICU who have treatment withdrawn are in a state of ‘unawareness’ and unable to communicate. Furthermore, the administration of medication to prevent distress generally prevents the patient regaining consciousness. Scoring low by the nurses as important for the patient is almost certainly a reflection of the patient’s mental state and the inability to participate in decision making.

There is an enormous amount of literature concentrating solely on improving communication skills between health care workers and the family and /or patient at the end-of-life. Ciccarello (2003) comments how the health care professional must first be comfortable with death in order to communicate openly and honestly about death and dying to family members. Other good
communication skills are being attentive, listening, exercising compassion, minimising interruptions, sitting at eye level, addressing concerns and maintaining eye contact.

If the patient is unable to participate in decision making, end-of-life care can be fraught with difficulties. Interpreting the patient’s wishes often falls on the family members who are often stressed and in an alien environment. Developing trust is one of the first steps nurses must do when spending time with families of critically ill patients. Honesty and clear explanations are vital. Nurses must act as mediators and interpreters during family meetings with the medical staff. Communication must also be effective between the health care team. There should be consensus amongst the health care team about end-of-life decisions (Rubenfeld, 2000). Doctors and nurses can achieve a ‘good’ death when ultimately working towards the same goal.

Family end-of-life conferences are the basis for developing open communication channels between medical staff and families. It may be preferable to identify a spokesperson for the medical staff when communicating with family (this may be the doctor who has had the most contact with the family and has developed a rapport). Azoulay (2005, p. 804) states: “Intensivists need to listen carefully, respond adequately, acknowledge emotions, and alleviate family guilt …”

It is important the family is not made to feel responsible for withdrawing treatment for their loved one and consequently causing his or her death. Civetta (1996, p. 348) describes a practical approach.

Physicians must never ask for permission to stop treatment. Asking the family for permission is wrong ethically and medically. The role of the family is to provide information concerning the patient’s wishes. The role of the physician is to describe what can be achieved by medical care. The death of the patient depends entirely upon an untreatable disease, not upon the physician’s or the family’s wishes. The question should never be “What do you want us to do?” Nor should you ever accept the answer, “I don’t want him or her to suffer.” The proper question is “If your loved one could speak to us, what would he or she say in this situation?”

‘Story listening’ is an invaluable skill nurses may or may not have when family members need to find meaning and healing in a death of a person where there may be unresolved conflict (Kirchhoff, Walker, Hutton & Spuhler, 2002). During the dying process it is important nurses provide opportunities for family members to say good-bye. It is also important nurses explain to families what to expect during the dying process, what they may see and feel. After the dying process it is important to give the family time with their loved one. Attention to detail can make a big difference to families. Dressing the patient in their own nightwear, or freshly shaving a mans face is greatly appreciated.
Nurses ranked Cultural beliefs as 5th important for the patient nearing end-of-life and this is also how it ranks with how well the units performs. For the nurse it has ranked as less important for themselves at number 9. Cultural safety must be surely one of the aspects of nursing care most frequently referred to by educational nursing institutions and I suspect also during job interviews, yet it scores low in importance for nurses with regards to end-of-life care. Why is this? With reference to Maori, one reason may be there appears to be a lack of Maori nurses working in intensive care. In this study, 1 nurse out of 80 identified her ethnicity as Maori. There appears to be a variety of ethnic groups working in the ICU who have immigrated here, or perhaps are in NZ on short term contracts on working holidays and it may be this is a trend we are seeing. It is important to note that ethnic groups may have different attitudes towards withdrawal of therapy or rather towards maintaining life-supportive treatments. No one culture is more important than any other and respecting every patient’s culture is important with reference to equality. In NZ, Maori and Polynesian people are large consumers of intensive care services (Freebairn, Hicks & McHugh, 2002). Consideration of race, religion, socio-economic status and nationality should not dictate medical therapy or decision making.

Societies are becoming increasingly diverse and this is apparent in our health care system. More than ever in clinical practise we are confronting cultural backgrounds different to our own. Some of these diversities (as with religion) can be seen with decision-making. Jewish clinicians, for example view the withdrawal of therapy as ‘killing’ and so it is prohibited (Truog et al., 2001). Hyun Kim (2005) states culture ultimately shapes the way people derive meaning from illness, suffering and death and how they make health care decisions. For effective health care, providers need to develop sensitivity to varying cultures through communication about the patient’s and their family’s personal beliefs and values (Hyun Kim, 2005).

The Maori way

Clair (2006) suggests the experience of the tangi may have contributed to Maori feeling relatively at ease around death. The three or four day tangi means people can laugh, cry, celebrate and work through a range of emotions people feel in grief, to ultimately promote the healing process. The sharing of song and prayer during the tangi help Maori feel a sense of calm.

H. Flavell (personal communication, October 27, 2006) denies there is a ‘Maori way’, and states nurses caring for dying Maori patients need to be guided by the whanau. The whanau do not like to leave the dying alone and prefer to help with physical cares like sponging, brushing hair, mouth cares and massaging. Karakia (prayers) are important, often in the presence of a large
number of whanau, by the hospital chaplain, priest or a minister of their choice. Hymns and songs may accompany the karakia. After treatment is withdrawn, whanau may request to take the patient home to die. After death the whanau require space to grieve. The dead person is tapu (sacred) and the room needs to be cleansed once the body is removed to make it noa (ordinary) again. Maori people almost never cremate their dead (Drewery & Bird, 2004). Consultation with a hospital Maori liaison officer may be invaluable for the patient, family and staff when caring for the Maori dying patient.

**Respect of patients advance directives** feature near the bottom of the scale in all 4 groups. The highest ranking achieved gave equal importance to the patient and the nurse (6th). One reason for the low ranking may be due to how infrequently advance directives are encountered in clinical practice. Furthermore, if there is a written reference, family members may be unaware of it, or, may choose to ignore or override it and so the patient’s wishes may remain unknown. Generally in the researcher’s experience, when medical staff sit down with family members and discuss the patient’s prognosis, there is often one member of the family who speaks of what the patient would have or would not have wanted and this is considered for the patient whose outcome is poor.

In NZ, The Code of Health and Disability Services Consumers’ Rights (the Code) made law in 1996 confers ten rights on consumers of health and disability services (Johnson, 2004). Right 7(5) allows a person to “make an advance choice about receiving or refusing services” within the legal boundaries of the common law (Johnson, 2004, p. 102). Right 7(7) provides that “every consumer has the right to refuse services and to withdraw consent to services” (Johnson, 2004, p. 509). Johnson suggests if the patient’s doctor or lawyer becomes involved with the development of an advance directive, it adds validity and is more likely to be adhered to by health care providers. As previously mentioned, medical approaches with decision making in health care have recently altered; this has been brought on by the advent of a consumer movement and the influence of kaupapa Maori (Wareham et al., 2005). Nurses are advocates for patients; the researcher expects to see in the future an extended role for nurses in understanding the complexities of an advance directive.

As McNutt (2005) comments, ideally advance directives would accompany each patient who enters the health care system, before an acute illness occurs. The reality is only a small percentage of patients have an advance directive which communicates their wishes for the extent and type of treatment wished for at the end-of-life (Lang & Quill, cited in McNutt). A study of critical care nurses in America by Beckstrand et al. (2006) revealed nurses believed living will documents should be legally binding but instead, as stated by one nurse, they
appeared to be worthless and used only as a guideline that the family may or may not follow. Advance directives can be problematic in the ICU. As Scherer et al. (2006) note, in the ICU care is not simply agreeing or not agreeing to have CPR. In the ICU there are many invasive interventions available like CRRT, therapies prolonging life, which most people do not even know are available or possible, and therefore are unable to account for them. One such patient may be the leaking abdominal aortic aneurysm patient who is admitted to the emergency department with severe pain requiring narcotics, is transferred to theatre where the aneurysm is repaired, and then to the ICU ventilated and sedated and develops renal failure requiring CRRT. It is difficult for people to account for the course of events that may potentially occur.

As already discussed, the patient is often unable to physically or mentally participate in end-of-life decision making when arriving in the ICU. Recently in clinical practice the researcher heard of a situation where, a patient did not wish to be mechanically ventilated. This was overruled by the medical staff and the patient, after weeks of intensive care, was extubated, rehabilitated and returned home to live alone (as previously) with a good quality of life. The patient returned a few weeks later and could not thank the staff enough for all that was done for him. Is this an example of the patient medical staff perceive to be too ill to participate in decision making? Many of the staff at the time thought not.

It may be a written advance directive is more instrumental for allaying anxiety for medical staff when faced with ethical decisions, in comparison to a verbal preference of care. The findings of a study by Tilden, Tolle, Nelson and Fields (2001) showed advance directives help families think about decisions patients make and play a crucial role in relieving stress and focusing on quality of life for patients, rather than prolonging life at any cost. The patient’s own values and preferences should be what families and clinicians endorse as the most important factor in making decisions (Tilden et al.). Kirmse (1998) suggests there is a strong role for nurses in the implementation of advanced directives to improve patient care, but before nurses can teach the patients they need to be educated themselves. Pertinent educational directives should include issues such as patient autonomy, cultural safety, family support, legal considerations, ethical implications, health and psychological effects and this should be with the appropriate people like attorneys, ethicists and specialist practice nurses who are experts in this field (Kirmse).

There are two remaining issues, privacy and the respect of the patient’s religious beliefs. Privacy again ranks poorly by nurses as important for the patient. One somewhat crude explanation may be again, how the patient is unaware of their surroundings and therefore will never know. Privacy scored 8th for what the nurses perceive to be most important for the patient. The researcher is surprised how low this has scored. Privacy is closely linked to dignity
which scored so highly. It is also poorly done according to how well the unit attends to this issue (scoring a 7) and this may be due to the environmental barriers units may have. This will be discussed further in Section 3. Religious beliefs are ranked relatively high (fourth) by nurses as important for the patient but this ranked low on all other lists.

Spiritual support incorporates religious beliefs and is part of the holistic nursing approach required at the end-of-life. It is now well recognised that accommodating to the patient’s and family’s spiritual needs is an important intervention with end-of-life care. Religious beliefs along with many other factors are incorporated into a patient’s and family’s decision about how death should be approached (Stock, 2006). The nurse should attempt to find out whether there are any religious requirements that will support the patient and family through the dying process (Contino, 2006). The nurse, by meeting their religious beliefs, is catering to the patient’s values by providing comfort, alleviating suffering and reducing anxiety (Contino). Recognising a patient’s faith includes allowing uninterrupted time and space for a prayer, reading, or church group song or blessing (Rex Smith, 2006). The hospital chaplain is a valuable resource to provide or access the appropriate care.

Spiritual care is care that extends beyond the realms of religious beliefs. It incorporates finding out what is important or meaningful in life for the patient, by talking to family, if the patient is unable to communicate and providing a caring environment where the patient is the focus. Touch, eye contact, voice and body language are all important elements in creating a caring environment (Page, 2005).

It appears from the findings from Section 2 there is a link between the top 4 most important issues in all 4 groups and the bottom 2. The scoring is quite similar for what nurses perceive to be important for the patients and how well the unit scores with regards to how effective the unit performs. So what does this mean? Well, it probably means nurses believe we perform relatively well with end-of-life care for what we perceive to be most important for the patients in provincial North Island ICUs and there does not appear to be any major problems. Problems may surface in the following section when nurses are able to comment on specific points asked by the researcher.

**B. Section 3. Close-ended questions**

In this section there were two statements nurses were asked to comment on; one open-ended question and one closed question (see Appendix IV). The researcher would like to discuss the closed question first (question 3).
Five nurses out of the eighty replied they had accompanied a patient home from the ICU to die (6.25 %). Three nurses stated they had not accompanied a patient home but had helped to organise this. 72 nurses (90 %) said they had never done this. Out of the eight units participating, 2 unit’s nurses gave no indication they had ever heard of this happening in the unit they worked in.

A second and third part to this question asked the nursing staff how many times, if they answered yes to escorting a patient home to die, had they done this in the last five years and is this end-of-life care service offered to the families in the unit they work in? Of the five nurses who had accompanied a patient home to die, 4 of the nurses commented they had done this once in the last five years. The remaining nurse did not answer the question.

Eleven nurses did not answer the question concerning is this end-of-life care service offered to patients and families. Thirty one nurses (39 %) said no, 19 nurses (24 %) said yes taking a patient home to die is offered to the families in the unit they worked in, while the remaining nurses (19) wrote comments like; “occasionally”, “once in last 3 – 5 years”, “case-to-case basis if hospice willing”, “at families request”, “dependant on which physician is caring for the patient”, “this has increased”, “this year we have had three patients / families who have chosen to go home”, “we tried but couldn’t get enough medical support after hours”, “not routinely but yes when appropriate”, “no, but it is something I applaud and would willingly help with, plus I have been proactive in discussing it”.

On this evidence the researcher can confidently say taking a patient home to die is not a service routinely offered to families in the units that have been studied (although in one unit the majority of the staff said this service was offered). Occasionally, it is offered and this is dependant on the families request and resources available at the time.

B. Section 3. Open-ended question

Question 1 requested nurses to comment on the perceived barriers in the unit they worked in to providing ‘good’ end-of-life care. In order to analyse this question recurrent themes were highlighted and then classified according to how often nurses from different units referred to them.

Two main issues were referred to by nursing staff and received an equal amount of comments;

a) failure of medical staff to stop futile treatment

b) environmental issues

Thirty four nurses (43 %) commented on either or both of these two issues. With reference to a) the researcher has included a few quotes to illustrate how the nursing staff feel:
“Prolonging the inevitable”
“Doctors not wanting to cut short what they believe could be beneficial therapy in the face of a clearly futile endpoint”
“Biggest barrier is aggressive ‘medical’ intervention”
“I think there is too much emphasis on keeping someone ‘alive’ at ‘all cost’ without looking at the ‘big picture’ to me some people suffer unnecessarily when the outcome is death anyway or patient very old”.
“Delayed decision making to withdraw aggressive treatment”
“Inability to accept death. Death being seen as failure”

The researcher confesses to illustrating with two patient scenarios at the beginning of this thesis how much this has been the motivation behind this project. It appears many nurses who work in the ICU feel the same way.

The researcher is aware this thesis is not about decision making when considering the withdrawal or withholding of patient treatment, but it is hard to ignore this concept when it has been alluded to so frequently by intensive care nurses as one of the barriers to providing ‘good’ end-of-life care in the unit they work in. A study by Elpern, Covert and Kleinpell (2005) of a medical ICU (an ICU for medical complaints, as opposed to neurological, trauma, surgical or cardio-thoracic ICU) in America identified the provision of aggressive care to patients not expected to benefit from that care, as the cause of the highest levels of distress for nurses. This has been supported by other research efforts (Badger, 2005; Beckstrand & Kirchhoff, 2005; Dracup & Bryan Brown, 2005; Redman & Fry, cited in McBride, Robichaux & Clark, 2006; Meltzer & Huckabay, 2004; Puntollo et al., 2001). The researcher has recent experience in clinical practice of a colleague who refused a patient allocation because she believed the patient to be suffering while attached to aggressive therapy with an extremely poor prognosis and it would be preferable to keep him / her comfortable. In other words she did not agree with the patient’s treatment. Moral distress results from nurses feeling they are contributing to a patients suffering without providing any benefit to the patient. (Thelen, 2005). Moral distress adversely affects job satisfaction and retention and has important consequences, including burnout and stress.

Before end-of-life care in the ICU can begin, the recognition of an intensive care patient whose outcome is extremely poor needs to be recognised. This is an issue of much controversy and often, as Baggs and Schmitt (2000) refer to, has been shown to lead to disagreement between doctors and nurses about the appropriate level of treatment to provide. Nurses who work in intensive care have shown from this study how this causes a great deal of concern and anguish
in their practice. Baggs and Schmitt discuss how decisions regarding treatment are not solely clinical; but are a combination of clinical information including diagnosis and prognosis, along with values and beliefs of multiple participants when making a decision that may lead to a patients’ death. Ethical principles such as autonomy, disclosure, truthfulness and fidelity all support the inclusion of patients, families and nurses. The researcher believes the principal ethic of nursing is ‘caring’. To many this may appear an old fashioned term when discussing nursing but to the researcher it is still more than applicable. Nurses should be included when decisions regarding end-of-life are discussed.

Data have supported the inclusion of patients when discussing the limitation of treatment options. As Baggs and Schmitt (2000) comment, in one medical ICU in the United States, 60 % of patients were found to have normal intellectual functioning when admitted to the ICU, but few were asked about their end-of-life preferences. Often the decisions regarding end-of-life are discussed when the patient reaches irreversible unconsciousness, preventing patient inclusion. Baggs and Schmitt state studies have shown there has been a lack of essential information provided to the patient by doctors and there has been a failure to consider the patients’ personal values and goals of treatment when limiting treatment.

Family focused studies have identified providers’ helpful and unhelpful behaviours when the patient has lost the capacity to participate with decision making. Baggs and Schmitt (2000, p. 160) summarise these as the following:

Helpful behaviours included encouraging advanced planning, timely communications, clarifications of families’ roles in decision making, facilitating family consensus, emotionally supporting family decisions, providing access to the patient before and after death, and accommodating family grief. Behaviours that were not helpful included postponing discussions about treatment withdrawal, delaying withdrawal once it was scheduled, placing the full burden of decision making on one person, withdrawing from the family, and defining death as failure.

Baggs and Schmitt (2000) discuss how the patient, family, doctors and nurses all have important information relevant to the limitation of treatment decision making. It is important all needs are met when considering the next intervention. It is essential the bedside nurse attends family conferences with medical staff. Thiers (2006) confirms regular meetings are important to provide information to families about prognosis and to discuss families concerns. The nurse is present to support the family and medical staff, to have an accurate account of what has been said to the family and to clarify terminology with family if required at a later date. Thiers comments on the importance that all members during the family conferences are seated as this ‘levels the playing field’. 
Nurses acknowledge the heavy burden the medical staff are responsible for when making end-of-life decisions and the difficulty of the task when documenting these decisions. Dilemmas with end-of-life decision making has not only been identified by nursing staff but also by medical staff as the most frequent ethical problem in clinical practice (Thelen, 2005).

**Environmental barriers**

Environmental issues received an equal amount of comments as a barrier to providing ‘good’ end-of-life care. It appears this is in many units a real problem. The unit where the researcher works is a reasonably new building, with a purpose built ICU / HDU. A nice environment with new (at the time) equipment, space, windows, two side rooms, a toilet for family members, a kitchen they are welcome to use and a compact room with two small sofas (initially called the ‘grieving’ room, but have since reviewed the title and now call it the ‘quiet’ room). It is ‘space’, and in many cases is not large enough, but nevertheless ‘space’ for medical staff to discuss with families the injuries, treatment and prognosis of their beloved family member.

Environmental limitations received an equal amount of highlighted comments as medical futility when discussing barriers to ‘good’ end-of-life care.

> “if the unit is very busy, … , family visiting can be affected adversely”
> “poorly conducive to allow family unlimited and unrestrictive access”
> “relatives restricted to 2 at bedside when other beds occupied”

The nurses did not just refer to the failure to allow unlimited visiting with reference to environmental issues. Nurses spoke of environmental pollution as being intrusive as quoted below.

> “Compulsion to use monitoring equipment because of the environment the patient is in, rather than focusing on the patient … - other patients TVs, visitors, staff talking loudly.”
> “Generally, high tech, noisy, busy atmosphere of ICU incongruous with quiet reflective process of dying”
> “… large population of Maori, so size a problem may need to transport patient to whanau room which is not always appropriate …”
> “… unavoidable high turnover of patients … patients can be moved to the ward, when close to the end. This can be regrettable.”
> “lack of space”
> “lack of facilities for family”

These same themes were repeated again and again. It is ironic when analysing the statistical data, how unlimited family access was perceived by nurses as being done most efficiently in their ICU when reading these comments.
Transforming the ICU into a suitable place for terminal care is not simple. Comfort, quiet, dignity and family access are not always given the highest priority (Rubenfeld, 2000). If available, side rooms should be utilised for the dying patient away from the commotion of a busy ICU. It may be appropriate to encourage the family to bring in a favourite piece of music or photo or even a blanket to place nearby to the patient. Quiet places should be made available for family gathering with tea and coffee facilities, a phone, tissues and chairs. Quiet places for prayer may be able to be negotiated with the hospital chaplains. Attention should be made to noise and lighting; and excess equipment should be removed. Complimentary therapies may be encouraged, for example, massage. Bedrails may be lowered.

Monitoring the dying ICU patient. Ramsay (2003) suggests the oxygen saturation probe should be removed. It often leaves marks on the patient, the reading is often incorrect when the patient’s blood pressure is low and it also disrupts the family’s ability to hold the patient’s hand. But what about other vital signs, for example the patient’s heart rate or blood pressure? Some families focus intensely on the patients dwindling vital signs on the monitor. If the patient was in the ward they would not be monitored, but the patient is still in the unit and nurses may keep patients monitored just because they can. This researcher advocates discontinuing electronic monitoring; the family can then focus on the patient and their own grief. This should be done with the complete understanding of the family. Rubenfeld (2000) comments that removing monitoring confirms to the family the goals of care have changed.

However, if the patient continues to be monitored, there is no doubt alerting the nurse to the patient’s death is easier. Vital signs can be visualised from a central station if available and this allows the family more privacy when the nurse is not required to be at the bedside. Monitors may be angled to avoid the gaze of the families. Many people would argue monitoring the dying intensive care patient ‘medicalises’ death. If the patient is monitored there is no doubt alarms should be silenced. Ramsay (2003) suggests the continuation of monitoring witnessed by the family up till death may help bring ‘closure’ to the situation. Monitoring the trend of blood pressure can also be an indicator of how long the patient has to live and therefore families are better able to prepare themselves and ensure the patient does not die alone.

The researcher could find no reference to how frequently vital signs of dying patients should be documented and admits to finding it very frustrating when a dying patient is found to have a non-invasive blood pressure cuff on automatic hourly cycles and these signs are recorded just as frequently on the patients chart. In the researcher’s experience, these cuffs hurt, smell, are noisy and leave pressure marks on the oedematous patient with poor circulation and are unnecessary.
Hourly documentation of vital signs on the patient who is not mechanically ventilated is unnecessary. If the patient has been extubated, generally when the nurse attends to comfort cares (oral hygiene, turning etc.), vital signs can be discreetly noted.

Facilitating the appropriate place to die. As Truog et al. (2001) comments there are pros and cons for keeping the dying patient in the ICU. The benefits of leaving the ICU is that they may transfer to a more familiar or private environment as well as having less technology attached to them. As Heyland, Rocker, O’Callaghan, Dodek and Cook (2003) discuss, there is growing international evidence that at the end-of-life people prefer to be cared for and die at home. This current piece of research showed nurses did not always consider the ICU the appropriate place to die if death was not going to occur imminently and many nurses advocated the facilitation of patients’ home to die with hospice support. This takes meticulous attention to detail and a substantial amount of organisation of resources, but if this is what the family prefers, nurses should advocate for this. Nurses have an obligation to customise a plan that honours the patient’s (if known) and families wishes (Counsell & Guin, 2002). Mann, Galler, Williams and Frost (2004) suggest there are some instances where it is appropriate to take a patient home to die. There are many issues to consider if this option is offered to the family and these are presented fully in the paper by Mann et al. There is also a list of conditions the patient must meet with full explanation to the family before this can take place.

There are other options, other than dying in the ICU, available to the patient and family that may be appropriate in some circumstances when considering where a patient may die. Certainly if death is imminent the preferable choice may be to stay in the unit. Taking the patient home to die has been mentioned. A side room may be available in a ward and if there is a palliative care team in the hospital they may be transferred to their care. The hospice presents another alternative. Chapple (1999) comments how hospice care developed because hospitals were not good at terminal care. Hospice care utilises a home setting while providing expert care for symptom relief so the family and patient can define what works best for them. The role of the hospice for intensive care patients who have had treatment withdrawn or withheld and are expected to die is one that has caused much debate. Hospice care is well known for relieving symptoms palliatively within the holistic model, attending to the mental and social well-being of the patient (Chapple). The researcher suggests this is also the goal for end-of-life care in the intensive care setting. Kyba (2002) believes the highest level of care at the end-of-life is provided by hospice care and palliative care but the hospice is underused, largely because it is seen as abandoning hope. Many consultants are reluctant to refer patients to the hospice.

Palliative care service
To the best of the researcher’s knowledge a palliative care service differs to a hospice service in that the palliative care service is in-hospital. Hospices are generally located in the community, not attached to the hospital. As McNutt (2005) comments, if a palliative care team does not exist in an organisation, the development of a multidisciplinary palliative care team committee may be one of the first steps towards assuming a proactive position to improving end-of-life care for patients and their families. Nelson and Meier (1999) advocate the use of a palliative care team, stating it has improved the efficiency of the ICUs resources, by focusing on the appropriate level of medical intervention, and by providing an alternative setting for end-of-life care if needed, either in the ward with follow-up by the palliative care team or in a specialist palliative unit. In the smaller units in the North Island of NZ this research has shown not all hospitals have a palliative care team. It also is apparent from this research even if a palliative care team is available dying patients in the ICU are not always referred to them and if death is imminent this may be appropriate. Although death is not the focus of the ICU, to bring the two paradigms together, curative and palliative care when appropriate may be in the best interests of the patient. Recognising the two specialties for their worth may result in a timelier death (Nelson & Meier).

The third most frequent issue commented on was privacy, or lack of it and this was mentioned by approximately 30 nurses (38%) as a barrier in the units they worked in to providing ‘good’ end-of-life care. This is closely linked to environmental issues, with lack of space and side rooms being the main issues for the patient and the visiting family. Some units had no side rooms.

“…no side rooms in ICU. If no side rooms available in another ward only curtains can be used to try and privatise bed space – curtains very thin …”

Communication issues were next most frequently referred to. Communication problems were generally referred to as a problem between medical staff (conflicting opinions about ‘where to draw the line’), between medical staff and the family (mixed messages) and lack of clear documentation for nursing staff by medical staff when the treatment regime changes.

“…lack of liaison between the various medical teams”

“communication to patient’s family especially from doctors is not always clear and mixed messages and confusion result.”

“lack of clear documentation by doctors of a palliative care plan.”

Lack of continuity of doctors. This has been discussed previously. The researcher sympathises with the nursing staff who work in units lacking an intensivist or a medical member of staff who is responsible for the ICU on a consistent level.
“… we see different physicians on call each day … so different opinions each day”
However this is not just confined to those units who do not have an intensivist. One nurse illustrates this point;

“ICU doctors working independently in treatment decisions resulting in inconsistent and contradictory treatment”.

Presuming the ICU doctors refers to intensivists, it appears problems for patients, nurses and families may appear when there are several intensivists in the one unit, with contradictory approaches to care.

**Lack of knowledge or experience** by nursing colleagues and also by medical staff was mentioned next most frequently as a barrier to providing ‘good’ end-of-life care in the provincial ICUs. The researcher has broadly classified comments like the following into this category

“Nurses – lack of understanding of end-of-life care as opposed to euthanasia”

“At times very junior inexperienced doctors ….”

**Educational initiatives**

Beckstrand et al. (2006) showed nurses believed all members of the health care team should receive education about quality end-of-life care. Nurses felt ill-prepared when caring for these patients and largely developed skills through trial and error. Nurses’ education should include, “communication strategies, symptom assessment, management and bereavement support,” … (Campbell, 2002, p. 199). The researcher is uncertain how much education is done in nursing schools about caring for the dying. When browsing through intensive care books there appears to be little written information, and most of the text on end-of-life issues focuses on legal and ethical guidelines. Intensive care courses provided for nurses may include aspects of resuscitation, monitoring and technology usage but may not include information on withdrawing and withholding of therapies, DNR orders or palliative care (Campbell, 2002). Campbell suggests practical clinical aspects about palliative care need to be incorporated into critical care courses for the novice nurse and the experienced intensive care nurse should be accountable for their own practice by continuing his / her education.

Truog et al. (2001) also discuss how clinicians should be educated about intensive palliative care, notably how to support and counsel families, respect differing cultural and religious beliefs and improve teamwork and communication skills. Danis et al. (1999) believe the most valuable principle to teach in the ICU setting is that goals of treatment should dictate technology usage and not vice versa.
Following these five main categories mentioned above, the researcher has classified other comments into the following four groups:

**Lack of nursing staff resources** with high workloads impeding the time able to be spent with the patient and family. Administrative support is vital to protect nursing staff. A common misconception is the dying patient requires less care. Truog et al. (2001, p. 2335) have labelled patient requirements as “time-intensive palliative care”. The family also need support, which may take a substantial amount of the nurse’s time.

**Patient and families unrealistic expectations about treatment outcomes**, although this could be linked into communication barriers. It is our responsibility to ensure time, by all members of the health care team, is given to family members when discussing a patient’s poor prognosis. Despite the best of intentions and the amount of time given to a family, there may still exist some members of patients families who may be termed ‘difficult’ for example, unwilling to accept a poor prognosis or obstructing verbally the use of medication for comfort at the end-of-life.

**Personal beliefs** generally referred to by nurses when discussing different doctors’ varying approaches to patient care, however some comments, like the following were generic;

“Values and beliefs of some health professionals, perhaps don’t consider where the family is coming from”.

And finally, **lack of compassion from medical and nursing staff**, comments by nursing colleagues like, “they are dying why aren’t they in the ward not here in ICU”.

**B. Section 3. Statement 2** Nurses were asked to comment on the following statement.

*Nurses frequently try to bridge the gap between aggressive ‘medical’ interventions and holistic compassionate care for patients at the end of life*” (Scanlon, cited in Chapple, 1999).

Six nurses chose not to comment and no reason was given, but 2 nurses (2.5 %) strongly disagreed with this statement.

“I think the “aggressive doctor vs. compassionate nurse” statement is insulting to our medical teams and we as a nursing profession should not be perpetuating this myth”.

The second nurse also disagreed with this statement when comparing her nursing experience in NZ to the United Kingdom stating

“Don’t agree … I feel nurses here … are very much in awe of the “Medical Model” and tend to follow it without questioning”
Some nurses’ comments tended towards neither agreeing or disagreeing with this statement but simply spoke of nurses being concerned with “caring” and preserving a “patient’s dignity”. Words were utilised such as “humanistic”, “holistic”, “advocacy”, “quality of life”, “respecting patient and family”, “questioning”, and spoke of how nurses do not see “death as a failure” and are quicker to recognise “futility” in medical treatments than medical staff.

Many nurses ‘agreed strongly’ and used such words as “true” when commenting on this statement.

“Agree totally. Some doctors are great with this – others seem to struggle”

“Yes, I think in general that nurses want the very best medical care for their patient while seeing the whole picture of the person’s health, future and quality of life as equally important”

Many nurses spoke of the emotional challenges when faced with these situations:

“True, the nurse at the bedside bears a large emotional burden for the welfare of the patient”

“I strongly agree. This however is intensely stressful for the nurse”

“… emotionally like a roller coaster …”

“It can be a hard job being the “go-between” the two differing parties”

“… it can be difficult though to please both parties and at times may seem that we as nurses are being difficult”

“… meat in the sandwich …”

Many nurses spoke of how the time they spend with the patient and family building a rapport allows them insight into the patients and families wishes. Many nurses spoke of how they see their role in these circumstances as the liaison between the family and medical staff, becoming a “key advocate” and “mediator” between patient, family and doctors “re directives of care and patient wishes”.

This statement is closely linked to medical futility and the idea behind this comment has been prompted by articles of interest from the researchers literature review. Medical futility has been discussed as an influential factor for this research project. It appears from this piece of research nurses generally agreed with this statement. Many provided invaluable comments supporting their initial response. Nurses must continue to utilise their communications skills when articulating concerns to medical staff when they feel it is appropriate to advocate for the patient and their family in order to influence how end-of-life care is approached in the ICU.
The researcher can empathise with the nurse whose comment has been selected to conclude this discussion. I have seen many compassionate, caring nurses put their feet in the shoes of this nurse when she states:

At times this happens but I often think nurses don’t respect that doctors have to carry these decisions not only clinically but emotionally and ethically also. I try to view this from an empathetic standpoint if I think decisions are too slow in coming – try to think about how I would feel or my decisiveness if I were making these calls

B. Section 3. Statement 4
Nurses were asked to comment on the following statement.
*Caring for patients during the dying process consumes health care resources. In an environment of resource limitation the supporting of the dying process in intensive care is justified.*

Eight nurses chose not to comment and no reason was given, while only 4 nurses (5%) believed supporting the dying process in the ICU where they worked was not justifiable.

“No not in this unit. Can be very inappropriate especially due to lack of bed spaces.”

There was an overwhelming response of support for justification of the dying process in the ICU although most participants followed this up by stating providing there were available resources. For example, beds, staff and providing death was imminent (say within the next twenty-four hours). Many nurses believed when a rapport has been developed with the family, particularly when the patient has been in the ICU for a long time, it was preferable for the family to remain in an environment where they felt they were supported and it also helped to promote closure for the health care team and the opportunity to do death well.

“Absolutely – I have a huge problem with transferring patients out of the ICU to die soon after … Makes the process so much more stressful on patient and families. And difficult for nurse on ward too.”

Many of the nurses in this group believed the ICU was not always the appropriate place to die with excessive noise, light and equipment alongside the lack of space and risk of a quick transfer out, if the bed was needed for an incoming patient. Many nurses in this group suggested the appropriate place to die may be at home, in the ward where a side room could be assured, or in a hospice with the support of a palliative care team.
Certainly the scarcity of the health care dollar was not thought of as a justifiable cause for transferring a dying patient out of the unit. No nurse thought patients should be transferred out of the unit as a cost saving measure. Rather the prolonging of patients lives when futility was apparent was the far greater consumer of health care funding and a far better example of the ineffective, inappropriate use of resources.

“We often use huge resources in attempting to save lives of those who are hopelessly ill … I support caring for dying patients in ICU if the death is imminent …”

It would be fair to conclude from these data that nurses do not believe patients should be transferred out of the ICU to die, purely on the grounds to save money. Despite nurses supporting the dying process in the ICU, many believed it was not always appropriate to die in this environment. Factors such as time till death, availability of beds and staff and the patients and families wishes should be taken into account when considering options.

Before concluding this chapter, the researcher would like to briefly refer to three more aspects relevant to end-of-life care that may ease the transition from cure to comfort for staff, patients and their families in the ICU.

1. **Clinical bereavement and debriefing**
   Rarely do we as nurses look after ourselves. Truog et al. (2001, p. 2341) state one option here is to have time allocated to “regularly scheduled meetings where staff can share their thoughts and experiences as well as critique the quality of care they provided”. This is where the opportunity arises for assessing whether the patient received a ‘good’ death; what went well and what can we improve on? Nurses often debrief informally to colleagues during quiet times or breaks but a formal recognised opportunity to talk, share experiences and reflect on their practise can only benefit members of the health care team.

2. **Bereavement follow-up programs**
   These nursing initiated programs are becoming increasing recognised as a part of ensuring quality care. Rubenfeld (2000) comments how quality improvement procedures are important for evaluating the dying process just as they are for evaluating other hospital procedures. Families should be involved with evaluating the care of the dying. The ultimate goal of providing a bereavement follow-up service is to improve the care of the dying patient. Some ICUs in NZ have an established bereavement program, other units are developing them (refer to p. 43). A bereavement follow-up service gives the staff in the unit the opportunity to send a sympathy card with a personalised message and to follow this up with a phone call to a previously identified member of the family at a later date, giving them the opportunity to clarify
issues, provide feedback and meet with medical staff if not already arranged and if required. It is important during the follow-up phone call, for nurses to realise their job is not to counsel, referral to the appropriate service may be required.

3. End-of-life care pathways
Ellershaw (2001) comments how clinical care pathways (CCP) or integrated care pathways originated in the United States and in recent years they have become popular in the United Kingdom and Europe. They are developed by a multidisciplinary team using evidence-based practice and appropriate guidelines, which then act as a template to describe the care to be delivered in a given clinical situation (Ellershaw). Variances (deviation from expected care delivery) may occur when the expected outcome is not achieved and the explanation of why it didn’t happen is documented (Ellershaw).

The CCP and palliative care
Many people would disagree with the use of a CCP in palliative care, arguing it is too rigid for delivering care. Ellershaw (2001) discusses how CCPs have been utilised in this setting, advocating they give the clinical freedom to work within a framework. Various authors name different pathways; Inpatient Comfort Care Program (ICCP) (Bailey et al., 2005); Palliative Care for Advanced Disease pathway (PCAD) (Ellershaw); Liverpool Care Pathway (LCP) (Jack, Gambles, Murphy & Ellershaw, 2003). Introducing a CCP is essentially implementing best practice hospice care into the hospital inpatient system where most deaths occur. Mirando, Davies and Lipp (2005) claim the CCP aim is to change practice and implementing one can be challenging. Firstly the diagnosis of dying may be difficult to make in an acute care setting where the emphasis is on cure (Bailey et al; Ellershaw; Ellershaw & Ward, 2003). Not only is a substantial amount of education required for staff but also a change in attitude in the hospital setting (Ellershaw). Many nursing and medical staff would argue against introducing something new when excellence in care of the dying is already being delivered. Mirando et al. (2005) suggest for successful implementation of a program to occur, the recipe is time, resources and skilled manpower. The overall goal of the CCP for the dying is to provide excellence in care, they also have the potential to set standards and provide a framework for quality assurance measures.

The Liverpool Care Pathway (LCP)
One example of such a pathway is the LCP. During the course of the past year this has been brought to the researcher’s attention by a hospice nurse manager and also by a palliative clinical nurse specialist as the gold standard of care for the dying patient in the community and in the hospital. The LCP was developed by the Royal Liverpool University Hospitals Trust and the
Marie Curie Centre Liverpool (Ellershaw & Ward, 2003). It is split into three sections; initial assessment and care, ongoing care and care after death and benefits all patients not just the cancer patients for whom it was initially developed. An evaluation program has identified the pathway as having a positive impact on the care of the dying patients, their relatives and medical and nursing staff (Jack et al., 2003).

**Conclusion**

This chapter has analysed and discussed the findings of the research project. In summary, the researcher believes from the data collected it would be fair to say end-of-life care for the dying adult patient after treatment has been withdrawn or withheld is done reasonably well in North Island non-metropolitan ICUs. The biggest concern appears to be the environmental problems identified by nurses for the dying patient and their family in ICU. The allowing of patients to die in a technologically advanced environment where the emphasis is on saving lives is difficult to achieve.

Chapter Five will summarise conclusions and discuss recommendations for end-of-life care in the ICU. Limitations of this research project and further research opportunities will also be referred to before the researcher concludes with some final comments.
Chapter Five

Conclusions and Recommendations


Introduction
The aim of this research was:

a) To identify what the intensive care nurse perceives to be important for the patient, family and themselves when providing ‘good’ end-of-life care for the adult patient who has had treatment withdrawn or withheld.

b) To identify participating units’ (collective) strengths and weaknesses when providing end-of-life care.

c) To provide a NZ perspective on a subject widely researched overseas.

A literature review showed there was an abundance of material available on the subject, generally originating from the USA where there was considerable evidence to suggest end-of-life care was sub-optimal. The researcher has since read extensively and appreciates the wide variances between ICUs in America and ICUs in NZ. There was, however, a lack of literature found on the NZ experience with end-of-life care in our ICUs. International trends are seeing chronically ill people living longer with the availability of life-prolonging therapies and end-of-life decisions in ICUs are becoming increasingly familiar (Nelson-Martens et al., 2001).

To investigate the above aims a survey study was utilised. The researcher developed a questionnaire with a mixed quantitative / qualitative design and this was mailed to a total of eight non-metropolitan ICUs in the North Island and completed voluntarily by clinical nurses. The response rate was 53 %. The questionnaire was divided into three sections.

a) Section 1 – participant demographic data.

b) Section 2 – table of end-of-life issues requesting nurses to numerically rank what they perceived to be most important for the patient, family and themselves and then to compare those same issues with how well the unit they worked in performed.

c) Section 3 – Open-ended questions.

Section 4 – the unit demographic data was accessed by the researcher requesting the information by phone.
Qualitative data was analysed into themes and the quantitative data was analysed by Excel. All data was entered on to a personal computer and password protected.

This chapter will list conclusions from the study. Limitations of the study will be addressed. Recommendations will be presented for the smaller units in NZ regarding end-of-life care. Finally areas for future research will be identified.

**Conclusions**

Section 2. Table of end-of-life issues (numerically ranked 1-10).

Of the nurses who completed the questionnaire, featuring consistently in the top four as most important for the patient, family and themselves were the following issues;

- administration of medication for analgesia and symptom relief,
- preservation of the patient’s dignity,
- unlimited family access and
- open communication channels.

These same four issues were also featured in the top four for how well the units perform with end-of-life care for the patient who has had treatment withdrawn or withheld and is expected to die.

Featuring consistently in the bottom 3 issues most important for the patient, family and nurse were the following two;

- environmental issues and
- the documentation of an alternative care plan based on comfort.

The most common themes from Section 3 are summarised next.

Question 1. The two most common themes referred to by nurses as the biggest barrier to providing ‘good’ end-of-life care in the unit they worked in were;

- failure to stop treatment when the outcome was believed by nurses to be futile and
- environmental issues restricting visiting and privacy.

Statement 2. Most nurses agreed with the comment of how nurses often bridge the gap between aggressive treatment and compassionate care.

Question 3. On the evidence submitted from the nursing staff, occasionally a family is offered the opportunity to take their loved one home to die, generally though this service is not routinely offered to families of loved ones who are expected to die in the ICU.

Statement 4. There was wholehearted agreement for supporting the dying process in the ICU if the patient was expected to die imminently and if the resources were available for allowing full care. However, those same nurses did not always favour the intensive care unit as the
appropriate place to die and generally this was due to other constraints, such as lack of staff and the lack of a private bed space. Certainly, transferring patients out of the unit who were dying should not be considered as a cost saving measure.

It appears generally that end-of-life care in our provincial ICUs is done reasonably well. Nurses prioritised care according to the needs of the patient and family and generally this complied with how well the unit performed. Environmental issues were well documented; noise, lights, alarms and lack of privacy etc., as poorly conducive to the quiet reflective dying process and for this reason nurses advocated the ICU was not always the appropriate place to die. Many nurses believed it may be more appropriate for the patient to die at home or within a palliative care service.

**Research limitations**

Although a satisfactory response rate was achieved in the questionnaire, a number of factors which might have influenced the results should be mentioned.

1. The researcher does not have an accurate measurement of the participant response rate. Instead of asking full time equivalent staffing numbers the researcher should have asked how many staff were on the roster at the time of questionnaire distribution so the participant response rate could have been calculated accurately. The response rate was calculated at 53%.

2. The richness of the data has been from the participants comments. Researching end-of-life care is a quality issue and this may have been more effectively assessed by utilising a qualitative approach for the whole project. Although the quantitative results were interesting; the information collated, the researcher suspects, probably does not add any new information to what we already know clinically and suggests that nurses believe end-of-life care is done reasonably well in non-metropolitan ICUs. Any improvements that are required appear relatively simple to address. It is however worthwhile having this documented and sharing a NZ perspective.

3. One of the limitations of ranking the table of end-of-life issues numerically was when nurses wrote 1 – 1 – 1 etc. in every box. Approximately 49 out of the 80 questionnaires returned were not filled in as per the instructions. Out of the questionnaires returned 61% of participants did not fill in the boxes using numbers 1 – 10. Instead participants wrote all 1s in the boxes or used a combination of 1, 2, 3, 4, or 5. Thirty-one participants (39%) entered 1-10 as requested (questionnaires filled out as per the researchers instructions). Two reasons may account for this phenomenon. A number of participants commented on how all issues were equally important and therefore ranked all accordingly or it may have been the researcher’s instructions were unclear.
4. Much of the expert literature referred to in this thesis originated from the USA where, when reading patient scenarios, critical care patients are treated very aggressively and for long periods. After extensive reading the researcher acknowledges end-of-life care appears to be approached from a different perspective in New Zealand ICUs. However, this could also be seen as valuable with a small NZ nursing study adding to the pool of literature.

5. In Section 3 of the questionnaire statement 2 and 4 may have been leading comments. This may alter the response of the participants to agree with the comment rather than oppose it or more importantly writing how they feel.

6. The researcher did not have any statistical evidence to show how many deaths in NZ ICUs occur after treatment has been withdrawn or withheld. This would have justified the importance of this research.

7. There were discrepancies from nurses within units with the answering of questions. For example, some nurses documented a bereavement program had been established in their unit, some nurses in the same unit said they did not have a bereavement program. Some nurses said families were routinely offered the opportunity to take their relative home to die, other nurses said this was not routine. Discrepancies between nurses in the same unit when answering the same question means the researcher’s conclusions may not be accurate.

**Recommendations for practice**

The researcher’s recommendations for practice revolve around the development of an end-of-life care plan for patients who are expected to die in the ICU after treatment has been withdrawn or withheld. The documentation of an alternative care plan maximising patient comfort was ranked poorly as important for the patient, family and nurse and it was also documented as poorly attended to in the ICUs, and it was mentioned in the nursing comments as a barrier to providing ‘good’ end-of-life care. Results from the unit demographic data suggested no units had a generic end-of-life care policy.

The researcher suggests nurses develop the documentation of a generic end-of-life care plan specific for their unit, for patients who are expected to die when treatment has been withdrawn or withheld. The development of a protocol may also aid those units who do not have a consistent approach to care, when there is a lack of uniformity in medical staff. In this survey, half of the hospitals where the ICUs were located had a palliative care team available and half of the units surveyed had a bereavement follow-up service established. For those units and hospitals where this service is available the input from these committees would be valuable. For those units lacking a palliative care team, the resources may be available for forming one. The team would have to be recognised by the management team as an invaluable commodity and given the time and resources to fulfil this role. A motivated team with an interest in end-of-life
care would require education and support to adequately prepare for this role. The team could also be responsible for the development of a bereavement program for the unit they work in, debriefing sessions for the staff, and if all goes well maybe even developing a plan or protocol for the transportation of patients home to die. All this would have to be with the support from the medical team. Chapter Four has discussed at length many ideas for developing an alternative care plan or it may be preferable to adapt an existing CCP already discussed. Either way the opportunity exists for individual units to develop their own protocol / plan or pathway unique to their requirements.

Recommendations for further research
An opportunity exists for this research to be replicated. Now the survey has been tested once, the option to change the research tool is available. Clearer instructions are required to eliminate the opportunity for nurses to write 1 – 1 – 1 in all the boxes in Section 2. Some of the unit demographic data asked was not required for the purposes of this research, for example, does your unit utilise a prognostic model? The unit demographic data could have been collected by the researcher by e-mail for ease of convenience for the team leader or clinical charge nurse to complete in their own time. Furthermore, as noted previously, the richness of the data has developed from the nurses written comments, rather than the statistical data. Utilising focus groups or one to one interviews may be a favourable way for collecting data for a qualitative survey. If a survey is replicated as a questionnaire and dispensed by postage, it is necessary to have an accurate response rate; this requires knowing how many participants in total were approached to complete the questionnaire. There is also the opportunity to narrow this research further by concentrating on one of the questions in Section 3. For example, interesting comments evolved from the first question regarding barriers to achieving a ‘good’ death in the unit the nurse worked in. To explore in depth the experiences behind the comments would be invaluable.

Further suggestions
1. There is opportunity to broaden this study to include all ICUs in NZ and then compare end-of-life care in the tertiary units (level III), to the level I and II provincial units. Including tertiary hospitals in this study may significantly alter results. The tertiary hospitals in NZ may have a palliative care service established to care for these patients after the ICU.
3. Research the quality of end-of-life care by evaluating the family members’ perspective of what a ‘good’ death means to them as a relative of a patient who dies in intensive care after treatment has been withdrawn or withheld.
4. Concentrate solely on nurse’s perceptions of obstacles to providing ‘good’ end-of-life care for patients dying in NZ ICUs.

5. Investigate the doctor / nurse relationship with decision making regarding end-of-life care in NZ ICUs.

6. Are nurses better at predicting patient outcomes?

7. Is the ICU a good place for the transition to palliation or should patients be transferred elsewhere for ongoing care? (Baggs, 2002).

8. What influences decision making at the end-of-life for intensive care patients in NZ?


10. How can end-of-life care and decision making be improved?

**Final comments**

We are seeing a general trend both in the public eye and in our profession “of the need to preserve the dignity of the dying – to infuse their last days with peace and compassion” (Rinpoche, cited in Drewery & Bird, 2004, p. 355). Intrusive medical intervention can sometimes undermine this concept (Drewery & Bird, 2004).

Fortunately many patients in NZ survive the ICU, but according to statistics approximately 10% do not. The majority of patients who die in the ICU do so when treatment is withdrawn or withheld. For those patients who are expected to survive only a short time after treatment is withdrawn, transferring to another department or new environment is awkward for family and new caregivers, and patient care may be disrupted. For these reasons the health care team who work in the ICU need to be as proficient at looking after the dying as they are at working towards survival. At the heart of palliative care lies the concept of a ‘good’ death. The provision of care for the patient in intensive care who has had treatment withdrawn and is expected to die revolves around comfort, dignity, patient and family-centred choices and communication (Chapple, 1999).
References


Wiles, V., & Daffurn, K. (2002). *There's a bird in my hand and a bear by the bed - I must be in ICU. The pivotal years of Australian critical care nursing*. NSW: Southwood Press Pty Ltd.
Information for Research Participants

Appendix 1

<table>
<thead>
<tr>
<th>Project Title:</th>
<th>Intensive care nurse’s perceptions of “good” end-of-life care for adult patients who have had treatment withdrawn or withheld.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Researcher(s):</td>
<td>Catherine Hine</td>
</tr>
<tr>
<td>Affiliations:</td>
<td>Senior Nurse, Hawke’s Bay DHB ICU. Eastern Institute of Technology Master of Nursing candidate.</td>
</tr>
</tbody>
</table>

Date: 2/03/06

Description of the research:
You are invited to take part in a survey which revolves around adult end-of-life care for patients who have had treatment withdrawn or withheld and are expected to die. In particular I am interested in what you, as a bedside nurse, think is important when caring for these patients with regard to dying a “good” death. As a rostered staff nurse you have been selected on behalf of the researcher by the link nurse in the unit you work in. She/he has selected you at random from the roster to voluntarily complete this survey.

What will participating in the research involve?:
The attached survey or questionnaire should take no longer than 15 minutes of your time to complete. The questionnaire is anonymous and has been sent to clinical staff nurses, such as yourself, working at the bedside in selected provincial hospital intensive care units. There are three sections to the questionnaire:
Section 1. Demographic data of each participant.
Section 2. Part A. Your opinion on a series of issues regarding a “good” death, to be ranked in numerical order of importance, and Part B. How you would rank the unit you work in relative to the same issues.
Section 3. Four open-ended questions.

Once the questionnaire is completed please place the questionnaire in the attached envelope, seal it and then place this envelope in the larger pre-paid, pre-addressed envelope held by the link nurse, which will be returned to me in four weeks time.

There is a question regarding whether you have been involved with a patient who has had treatment withdrawn or withheld. If you answer no, but you wish to continue with the questionnaire, please feel free to do so.

What are the benefits and possible risks to you in participating in this research?
The researcher appreciates this is a sensitive subject. Should you require counselling or emotional support please consult the available resources contactable through the hospital you work in, such as the hospital chaplain, staff counsellor, or social worker. Alternatively consult your General Practitioner for referral to an appropriate service, the yellow pages of your local telephone directory, or The National Association of Loss and Grief via www.nalag.org.nz

We currently know little about what nurses consider important in caring for patients who have had life support withdrawn or withheld and are expected to die. This research will provide some information for nurses to consider when working in this area. It may also be useful for administrators and managers in ICU and hospital planning.

Your rights:
- You do not have to participate in this research if you do not wish to.
- You do not have to answer all the questions
- If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact your professional organisation.
Appendix I cont.

Confidentiality:
No material which could personally identify you will be used in any reports on this study. Please do not write your name or any identifiable information on the questionnaire. All responses will remain confidential. Information will be collated with all other surveyed hospitals and analysed collectively. The anonymous questionnaires will be stored until the end of the project, when they will be shredded. The computer data files will be password protected on a computer in a locked office and stored for seven years.

By completing and returning this questionnaire you are giving consent to participating in this research.

If you wish to know more about this research, please contact:

<table>
<thead>
<tr>
<th>Contact Person:</th>
<th>Catherine Hine</th>
</tr>
</thead>
<tbody>
<tr>
<td>Work phone #</td>
<td>06 878 8109 Ext. 2745 (ICU)</td>
</tr>
<tr>
<td>Email address</td>
<td><a href="mailto:catherineh@xtra.co.nz">catherineh@xtra.co.nz</a></td>
</tr>
</tbody>
</table>

Thank you.

Catherine Hine
Senior Nurse
Intensive Care Unit
Hawke’s Bay DHB

This research has been approved by the Central Regional Ethics Committee
Appendix I cont.

February 2008

To: Provincial Intensive Care Nurses

Dear Participant,

Re: Intensive Care Nurse’s perceptions of “good” end-of-life care for adult patients who have had treatment withdrawn or withheld.

I am a registered staff nurse working in the intensive care unit at Hawkes Bay DHB, nearing the completion of my Master of Nursing at the Eastern Institute of Technology and undertaking this research project. I would appreciate you taking the time to complete this questionnaire and when this has been done placing it in the attached individualized envelope, sealing it and then placing the envelope with the questionnaire enclosed in the pre-addressed, larger postage paid envelope provided for your nurse representative (link nurse), who will return it to me within the month.

As an intensive care nurse you have been selected from the roster by the link nurse for your area. They have kindly selected every third person on the roster, at a random starting point, to voluntarily complete this survey. The questionnaire should take no longer than 15 minutes of your time to complete. It is an anonymous questionnaire, sent to selected intensive care units in provincial hospitals. All responses will remain anonymous and confidential. Information collected will be collated with all other hospitals surveyed and analyzed collectively. The survey has gained multi-centre approval from the Central Regional Ethics Committee. Before approving this project, the committee also required a locality assessment form to be completed by the hospitals surveyed. This has been done.

The survey revolves around adult end-of-life care for patients who have had treatment withdrawn or withheld in your unit. In particular I am interested in issues which you, as a bedside nurse, regard as contributing to a “good death”.

For those units who have coronary care and intensive care combined, please exclude the coronary care patients.

The survey is divided into three sections:
Section 1: Demographic data
Section 2: A series of issues to be ranked in numerical order
Section 3: Four open-ended questions.

There is a question regarding whether you have been involved with a patient who has had treatment withdrawn or withheld. If your answer is no, but you wish to continue with the questionnaire, please feel free to do so.

Results will be published and distributed to participating ICUs in 2007.

Thank you.

Catherine Hine - contactable via Hastings Hospital ph: 06 878 8109 Ext. 2745 (ICU).
ICU QUESTIONNAIRE

Please do not write your name or any identifiable information on this questionnaire.

SECTION 1
Please tick the appropriate answer for each question.

1. Your age?
   - 20 – 30 years
   - 31 – 40 years
   - 41 – 50 years
   - 51 + years

2. Your gender?
   - Male
   - Female

3. Please state your ethnicity.

4. How many years experience have you had in ICU?
   - < 3 years
   - 3 – 5 years
   - 6 – 10 years
   - 11 – 15 years
   - 15 + years

5. What is your highest qualification?
   - BN
   - Hospital certificate in ICU
   - Post-graduate certificate in ICU
   - Post-graduate diploma in ICU
   - Master of nursing
   - Other (please write)

6. Does your unit have a bereavement team?
   - Yes
   - No

   If so, are you a member of the bereavement team?
   - Yes
   - No

7. Have you ever attended any bereavement courses, conferences, and/or education sessions regarding end-of-life care?
   - Yes
   - No

8. If you have done an intensive care course, did it include any content about palliative care, withdrawal of life support or ‘do not resuscitate’ orders?
   - Yes
   - No

9. Have you ever nursed a patient who has had treatment withdrawn or withheld in an intensive care setting?
   - Yes
   - No

If you have answered ‘No’ to this question you do not need to complete Sections 2 & 3. You are, however, welcome to continue with the survey.
SECTION 2 – There are **TWO** parts in this section: A & B. Complete Part A first, then Part B.

**Part A** From an intensive care nurses’ perspective when referring to the list below, what do you perceive are the priorities of care (for the patient, the family and you as the nurse) when considering what we can do to ensure a “good” death for the patient who has had treatment withdrawn or withheld? *(1 = most important and 10 = least important)*.

**Part B** State how the unit you work in ranks with the same issues from **most effective** (1) to **least effective** (10).

<table>
<thead>
<tr>
<th>Cultural beliefs respected</th>
<th>Patient</th>
<th>Family</th>
<th>Nurse (yourself)</th>
<th>Part B</th>
<th>Rank in order 1 – 10 (as above) what you believe the unit you work in does most effectively to least effectively</th>
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<tbody>
<tr>
<td>Privacy</td>
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<tr>
<td>e.g. side room for patient</td>
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<tr>
<td>Family access</td>
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<td>e.g. unlimited visiting, involvement with cares, etc.</td>
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<tr>
<td>Religious beliefs respected</td>
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<tr>
<td>Documentation of an alternative care plan based on maximizing comfort</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Open communication channels (family, medical and nursing staff) maintained throughout process</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Administration of medications for analgesia, sedation and symptom relief</td>
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<td></td>
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<td></td>
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<tr>
<td>Dignity</td>
<td></td>
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<tr>
<td>e.g. pt without distress, attention to hygiene and grooming, etc.</td>
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<tr>
<td>Environmental issues</td>
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<tr>
<td>e.g. attention to noise, lighting, etc.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Advance directives respected</td>
<td></td>
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</tbody>
</table>
Appendix 1

SECTION 3
1. What do you perceive are the barriers in your unit to providing "good" end-of-life care to patients?

2. Please comment on the following statement.
   *Nurses frequently try to bridge the gap between aggressive 'medical' interventions and holistic compassionate care for patients at the end of life.*

3. Have you ever accompanied a patient home to die (life-support is withdrawn at home) because family have requested their loved one die at home?

   Yes  No

   If YES, how many times in the last five years.

   Is this end-of-life-care service offered to the families in the unit you work in?

   Yes  No

4. Please comment on the following statement.
   *Caring for patients during the dying process consumes health care resources. In an environment of resource limitation the supporting of the dying process in intensive care is justified.*

Thank you for your time and effort for completing this survey.
Appendix V

Section 4 (researcher will ring and gain the following information by phone)

Questionnaire
Nursing Research 2006
Catherine Hine

Non-metropolitan North Island nursing research questionnaire.

Demographics of units by phone

1. What level ICU are you?  
   Level 1  100 – 250 ventilated pts  
   Level 11  50 – 100 ventilated pts  
   < 25 ventilated pts

2. Are you a combined ICU/CCU?

3. Number of FTE’s (full time equivalents) nursing staff?

4. What is the administrative model of your ICU?  
   Open  
   Closed  
   Semi-closed

5. How many beds (total) do you have?  
   Total ventilated ICU beds  
   High dependency beds  
   Coronary care beds

6. Do you have an intensivist working in your unit?  
   Yes/No

7. Approximately annually what is your percentage of deaths?  
   _____

8. Does the unit you work in utilize a prognostic model when predicting patient outcomes?  
   Yes/No

9. Do you have a generic end-of-life care unit policy available to guide patient care?
10. Is there a bereavement follow-up program in your unit?  Yes/No

11. Does your unit have a written admission criteria for patients?  Yes/No

12. Is there a written do not resuscitate policy  
   a) for the unit?  Yes/No  
   b) for the hospital?  Yes/No

13. Does the unit you work in accept patients who are?  
   a) not for cardiopulmonary resuscitation?  Yes/No  
   b) not for ionotropes and vasopressor therapy?  Yes/No  
   c) not for invasive ventilation?  Yes/No  
   d) not for continuous renal replacement therapy?  Yes/No

14. Is there a palliative care team in your hospital  Yes/No

15. Does your unit consult with the hospice or other palliative care service for patients who have had treatment withdrawn or withheld and are expected to die?  Yes/No

16. Do you have formal debriefing sessions in the unit you work in?  Yes/No
13 October 2005

Catherine Hine
16 Trevelyan Street
Onekawa
Napier

Dear Catherine,

I am pleased to inform you that your Master of Nursing thesis topic “Withdrawal of therapy in ICU – nurse’s perspectives” has been approved in principle by the MN Research Committee. Congratulations on developing your research interests to this stage.

In discussion, the Committee was concerned that your proposal to survey every regional ICU would create a project which was too large for a 60 credit thesis. The Committee also believe that your listed aims were too broad, and that in conjunction with your supervisors, you should re-examine them with the intention of reducing the number and breadth. Finally, it was suggested that you will need to work very hard on your questionnaire in order to get good data on your topic, and that this is, again, something to work on with your supervisors.

From this point you will need to determine an Associate Supervisor, and then organise a meeting between yourself, your Associate Supervisor and me. At that meeting we will look to set a tentative schedule for the next year, for both major events in the thesis as well as regular meeting dates for the three of us.

Please be aware that it is possible your supervisors, in discussion with yourself, may require some (usually minor) changes to the methodology or objectives that you have developed.

Again, congratulations, and I look forward to hearing from you.

Yours sincerely,

[Signature]

R.N. Marshall, PhD
Research Professor
ph.: 974 8000 ext 5422
e-mail: bmarshall@eit.ac.nz
31 March 2006

Ms Catherine Hine
Intensive Care Unit
Hastings Hospital
16 Trevelyan Street
Napier

Dear Catherine

CEN/06/02/003 - INTENSIVE CARE NURSES' PERCEPTIONS OF “GOOD” END-OF-LIFE CARE FOR PATIENTS WHO HAVE HAD TREATMENT WITHDRAWN OR WITHHELD
Ms Catherine Hine
Eastern Institute of Technology

Thank you for your letter of 2 March 2006 responding to the points raised in my letter to you of 22 February 2006. As all outstanding issues have now been satisfactorily addressed, the above study has been given ethical approval by the Central Regional Ethics Committee.

Accreditation
The Committee involved in the approval of this study is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, March 2002.

Final Report
The study is approved until December 2006. A final report is required at the end of the study and a form to assist with this is available from the Administrator. If the study will not be completed as advised, please forward a progress report and an application for extension of ethical approval one month before the above date. Report forms are available from the administrator.

Amendments
It is also a condition of approval that the Committee is advised of any adverse events, if the study does not commence, or the study is altered in any way, including all documentation eg advertisements, letters to prospective participants.

Please quote the above ethics committee reference number in all correspondence.

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

Yours sincerely

Claire Yendell
Central Ethics Committee Administrator
Email: claire_yendell@moh.govt.nz

Administered by the Ministry of Health
Approved by the Health Research Council
http://www.newhealth.govt.nz/ethicscommittees
3 March 2006

Catherine Hine
Senior Nurse: Intensive Care Unit
Hawkes Bay Regional Hospital
Hastings

Tena Koe Ms Catherine Hine

Re: Study on Intensive Care Nurses’ Perceptions of “Good” end-of-life
Care for Adult Patients who have had treatment withdrawn or withheld

Thank you for consulting with the Maori Health Service with regard to the above study.

As with all studies/research concerning Maori it is important that the Researcher is aware of “equal explanatory power” i.e. producing information that may impact on Maori to at least the same depth and breadth as that obtained for non-Maori. Where health questionnaires/surveys are concerned a central requirement is to obtain enough Maori participants to explore potential explanations for disparities and develop effective strategies to address them. The simplest method is to seek equal numbers of Maori and non-Maori respondents.

I am aware that there are very few (if any) registered Maori Nurses working in the Hawkes Bay Intensive Care Unit however with some broad lateral thinking and in association with a Registered Nurse, Care Associates may be able to contribute to the questionnaire.

The biggest issues of studies/research for Maori such as this is informed consent and individuals being informed to make a decision about their participation and the findings that result from the trial. Another issue that relate to Maori are cultural considerations such as having a support person present and karakia should they wish it.

Naku ano na,

Rapai Pohe
Service Manager, Maori Health.

---

Te Wahanga Hauora Maori
Corporate Services, Hawke’s Bay District Health Board
Private Bag 9014, Hastings, New Zealand - Telephone (06) 878 1654 Fax (06) 878 1655
Email: maoribeach2@hawkesbaydhb.govt.nz
Appendix IX

February 2006

Intensive Care Unit,
Hawkes Bay DHB,
Omahu Road,
Hastings.

Re: Research 2006. M.N. completion

Copy to: Charge Nurse or Nurse Manager of the Intensive Care Unit.

To the Director of Nursing;

To whom it may concern,

I am a staff nurse working at the Hawkes Bay Regional Intensive Care Unit, nearing completion of my Master’s qualification with the Eastern Institute of Technology. As part of my Master’s qualification, research is required. I have decided my thesis will explore end-of-life care in the ICU for dying patients who have had treatment withdrawn or withheld and in particular the concept of dying a “good” death.

I wish to study nursing staff working clinically in non-metropolitan North Island ICUs. Currently I am applying to the Multi-region Ethics Committee, however in conjunction with my application I require a Locality Assessment Form to be signed by the unit manager allowing me to study nurses’ working in the ICU. (Please find enclosed with letter to unit manager only).

The survey allows participant confidentiality by individual anonymity. The questionnaire is voluntarily filled out by the nursing staff. Results will be collated collectively and published. The results will be available (from early 2007) to the hospitals selected to survey.

Thank you.

Yours faithfully,

Catherine Hine. (SN ICU, Hawkes Bay Hospital).