

# **FOOD FOR THOUGHT: ETHICS AND ARTIFICIAL NUTRITIONAL SUPPORT**

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**THESIS SUBMITTED IN FULFILMENT OF THE REQUIREMENTS OF  
THE DEGREE OF DOCTOR OF PHILOSOPHY**

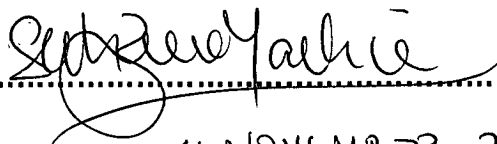
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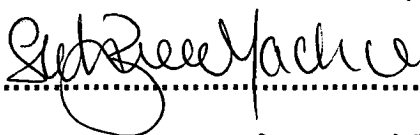
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## **ABSTRACT**

### **'Food for Thought: Ethics and Artificial Nutritional Support'**

A narrative ethics analysis is utilised to explore the nature and practice of the provision of artificial nutritional support. This technology is utilised in a variety of settings, with increasing acceptance of its efficacy and utility in health care. The administration of artificial nutritional support was originally intended as a transitory measure to allow for the restoration of a patient's normal digestive functioning. It is now, however, often provided to those who have irretrievably lost all higher brain functioning, people with terminal illness, and those with critical illness. Accordingly, the ethical analysis which is pursued embraces the multidisciplinary nature of the socio-political space which is artificial nutritional support.

This modality of treatment has emerged as a site of contested ethics. Some commentators argue that providing nutrition regardless of route is a basic human function, symbolic of care, and constituting 'ordinary means' that should never be forgone. They also suggest that forgoing these techniques directly causes death, and are concerned about the social implications of depriving vulnerable people of basic human attention. Other authors suggest that the burdens of life with pain, discomfort, immobility, impaired consciousness, and loss of communication so overwhelm the benefits of life that there is no obligation to assist in sustaining life. Thus, a dichotomy of views exists. Different perspectives regarding the ethics of artificial nutritional support often depend on the model of health service delivery within which the author operates. Accordingly, research is undertaken which includes data from two distinct health service delivery systems. This research draws upon experience and literature within Australia, the United Kingdom and The United States of America, markedly different health care delivery systems that have been described as either 'socialised' or 'privatised'.

This thesis is informed by interviews with 32 participants from diverse health care disciplines, ranging from Intensivist to Chaplain. Drawing upon the richness of narrative, these interviews utilise the informants as experts from Australia, the United Kingdom and the United States of America. The findings from this research move well beyond the sphere of artificial nutritional support to encompass the practice of medicine and end-of-life



care in general. Specifically the case is made for a cycle of care and communication practices, which assist us to debunk death myths regarding the inevitable painful tragedy of death, myths that inform the discursive shaping of contemporary health care.

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Finally, I would like to acknowledge the work and teachings of the late Reverend Chuck Meyer, former Vice President of Operations, St. David's Hospital, Austin, Texas who was tragically killed in a motor vehicle accident during the completion of this research. Chuck's writings, passion, wit and company truly inspired me to embrace this project wholeheartedly. I therefore dedicate this thesis to his memory.

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## INTRODUCTION

Ethical issues continue to loom large in the international health care arena, as the paradigm of physician-driven health care shifts to the multidisciplinary health care team, and patient-driven care. Since its birth in the early 1970's, contemporary bioethics has developed to become a major academic and service oriented discipline with its own research centres, journals, conferences and degree programs. A major reason for this marked expansion has been the unremitting pace of technological development and the challenge of an increasingly secular society seeking moral direction and certainty. As researchers and clinicians discover new and improved methods of medical treatment, we discover that each development has its own attendant ethical issues, which are discovered and defined as we interrogate and utilise the technology. The nature and practice of the provision of artificial nutritional support is an excellent example of a technology which is being utilised in a variety of settings, and with increasing acceptance of its efficacy and utility in modern medicine. The administration of artificial nutrition was originally intended as a transitory measure to allow for the restoration of a patient's normal digestive functioning. It is now, however, often provided to many patients who have irretrievably lost all higher brain functioning, those patients diagnosed with a terminal illness, and those who are critically ill. Dunlop *et al* (1995) raise an issue that deserves delineation when discussing artificial nutritional support in this context:

*Nutritional support should be considered as a separate issue from hydration. The administration of conventional dextrose solutions via peripheral veins does not constitute nutritional support. This can only be achieved by enteral feeding (nasogastric tube or gastrostomy) or by parenteral administration into a central vein (Dunlop et al 1995:141).*

Accordingly, hydration is not the focus of this thesis. It is a strange paradox that, as Macfie (1997:850) states, 'society and many members of the medical profession have no hesitation in recommending long-term nutritional support in these vegetative patients, but at the same time fail to recognise or treat malnutrition in hospitalised patients'. There is, of course, more to the issue of providing nourishment than biological integrity. An

analysis therefore, of the ethical issues surrounding the provision of artificial nutritional support, serves to emphasise not only the changing face of bioethics but also demonstrates how naming and exploring of ethical issues have influenced the clinical application of nutritional support therapies.

Health care professionals have an ethical obligation to respect human life and to provide relief from suffering. The so-called Georgetown mantra<sup>1</sup> of beneficence, nonmaleficence, autonomy, and justice are accepted moral principles governing the behaviour of health care professionals within society. Technological developments have seen particular tensions in applying such principles in particular areas of medical treatment. For example, in clearly delineating disproportionately burdensome treatment in end-of-life care where limits need to be applied.

Health care ethics include the study of obligations, rights and values in patient care. Nutrition is a fundamental part of life and, even when withheld for short periods, can have profound detrimental effects on the body (Taylor and Goodinson 1992). The provision of various types of artificial nutritional support carries an assortment of ethical implications. Many theories defend the use of artificial nutritional support on ethical rather than scientific grounds (Phillips 1992). One of these regards artificial nutrition as a symbolic message to a helpless person. Such a theory contends that withholding such a support hastens the person's death, resulting in loss of integrity for the health care services and the destruction of a symbol of human interdependence and caring.

There has been considerable conflict on this subject matter. As discussed in Chapter One, some commentators argue that providing nutrition regardless of route is so basic a human function and so symbolic of care that it constitutes 'ordinary means' and should never be forgone. They also suggest that forgoing these techniques is a direct cause of death, and wonder about the social implications of a policy that would deprive the most helpless of basic human attention. Other authors on the subject consider that the

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<sup>1</sup> As Ronald Bailey notes, this is the colloquial expression for the principlist account which has emerged from this American University. See Reason Magazine: 'Uncommon Morality: Can Bioethics Bring Us All Together?' ([www.reason.com](http://www.reason.com))



burdens of a continual life of pain, discomfort, immobility, blurred consciousness, and loss of communication would not be desired by any human, and those burdens so overwhelm benefits of life that there is no obligation to assist in sustaining life.

Thus, a dichotomy of views exists. Interestingly, variance often depends on the model of health service delivery within which the author operates. Accordingly, it was decided to undertake research that included data from two distinct health service delivery systems in three different countries. Consequently, this research draws upon experience and literature within socialised and privatised health delivery systems as experienced by various practising health professionals in Australia, The United Kingdom and The United States of America.

Accordingly, this thesis commences in Chapter One with an in-depth exploration of the relevant literature. This literature and the interviews discussed in Chapters Three to Ten establish a need for alternative ways for problem solving and meaning-making in the area of ethics and nutritional support research. Our contemporary Western lifestyles offer few avenues for the exploration of meaning-making, the pursuit of ethics and values as ends in themselves, or even for the quest for personal understanding (Kegan 1994; Lifton 1993; Taylor 1989). Given this reality, in this research project opportunities were created for meaningful, ethical dialogue regarding the provision of artificial nutritional support. This involved the use of narrative and a dialectic between research participants, health care colleagues and the researcher as mediator. Hence, narrative research as a method underpinned by what has come to be known as narrative ethics research, was chosen as the most appropriate methodology for this project. An in-depth discussion in defence of this method is provided in Chapter Two. In the chapters which follow the methodology chapter we encounter a series of interpretation chapters (Three to Ten) that explore, examine and theorise on the ethical issues associated with the provision of artificial nutritional support. These eight chapters form the empirical foundation of the research. Then in chapters Eleven and Twelve we discuss the implications for practice and the relevance of the research for the health care professions. In the final chapter we arrive at some conclusions which move well beyond the sphere of artificial nutritional support to encompass the practice of medicine and end-of-life care in general. Specifically the case

is made for a cycle of care and communication which assists us to debunk the death myths discussed by Meyer (1997) regarding the inevitable painful tragedy of death that plague both the practice and construction of ethical health care.

This thesis constitutes more than a mere contribution to the literature. It may also be considered as a political challenge to the dominant medical and principlist approach to clinical practice and medical education across various health systems and regions. Within such a context, it is now worth exploring the 'received wisdom' of the ethics and artificial nutritional support literature, which is the subject of Chapter One.

## **CHAPTER ONE**

### **REVIEWING THE LITERATURE**

#### **Introduction**

This chapter reviews literature concerning the ethical issues in artificial nutritional support. Artificial nutritional support is abbreviated throughout this thesis as either enteral nutrition (EN), parenteral nutrition (PN) and/or total parenteral nutrition (TPN). These abbreviations are commonly used throughout the literature and are embraced by all the informants participating in this research. An introduction to the dominant issues drawn from this literature as well as the popular arguments is also offered. This includes a synopsis of those areas including medico-legal decisions whereby a case-by-case explanation is provided on those cases that are considered as landmark cases. The question of medical intervention or basic care is explored within the context of artificial nutritional support, as are those popular and dominant views held regarding withholding and/or withdrawing such treatment. Ordinary versus extraordinary care is examined in detail including the issues of medical killing, self-determination and suicide, benefits versus burdens of treatment, medical futility, quality-of-life, and the issue of justice as it pertains to resources, access and economic considerations. Finally, the gaps identified within the literature are discussed. Consequently, an explanation into the relevance of the ensuing research is provided. More specifically, the lack of multidisciplinary qualitative research is discussed therefore providing some indication of the identified gaps in the related literature. This is also discussed as an introduction to the research methodology underpinning this thesis.

#### **The Dominant Issues and Popular Dichotomies**

The ethical issues involved in the provision of artificial nutritional support in patients with chronic, serious, and/or terminal illness are difficult. Yet within the literature, this patient group is invested with the overwhelming majority of related discussion. This discussion is predominantly authored by ethicists and clinicians specialised in the fields of palliative care and gerontology. The other patient population considered in this research rates

very little mention, if any, that is, the critically ill and/or perioperative patient. In fact, only one author, a consultant surgeon in a combined gastroenterology unit in the UK, Dr. John Macfie, offers any specific exploration of ethical provision of artificial nutritional support in these areas. The shortfall of any specific exploration in these areas not only shows the importance the ensuing research, but also identifies the 'placement' of artificial nutritional support into the convenient category of all those therapies that are considered complex medical treatments in the acute care setting, despite the overwhelming 'non-complex' emphasis that artificial nutrition has attracted over the past 20 years. The symbolism of food, its nurturing provision and its life-sustaining necessity is a context afforded much discussion and exploration in the chronically or terminally ill. However, this symbolism is completely overlooked and not even mentioned in the critical care literature. It is this concentration that renders these aspects of the literature devoid of any discussion on ethical appropriateness. This literature review discusses the common themes arising out of the associated literature, as well as justifying an ongoing exploration into the area of ethics and artificial nutritional support. This exploration is of a discursive nature which is truly multidisciplinary and multinational.

When it comes to decisions about feeding and withholding or withdrawing artificial nutritional support, dilemmas abound. According to Burk (1996) some ethicists have sought to resolve these dilemmas by formulating dichotomies, such as, withholding versus withdrawing treatment, ordinary versus extraordinary care, killing versus letting the patient die, and heroic versus basic care. These dichotomies have become traditional in health care ethics, and are therefore worthy of interpretation via an expansive review of the literature for the purpose of this research.

### **Interpretations**

The interpretation of ethical issues in artificial nutritional support can be accomplished through several means. This review is a synthesis of the current literature on the ethics of the provision of the technology of artificial nutritional support. When patients lose the ability to ingest adequate amounts of food and fluids necessary to sustain life, the health care team may be faced with two questions. The most difficult question of the two is,

should artificial nutritional support be provided or discontinued? If it is to be provided, what form of artificial nutritional support, and by what route, is in the patient's best interest? The decision of whether or not to institute aggressive nutritional support, especially in those patients who are judged incompetent to understand the risks and/or benefits of therapy, in whom such support is of questionable value, and in those with irreversible or severely debilitating illness who are judged to be competent yet refuse nutritional intervention, is particularly troublesome. How one comes to formulating rational decisions for the provision of artificial nutritional support for these patients and their families crosses the intersection of individual and societal morals, ethics and precedents in law.

### **Medico-Legal Decisions**

The assumption that specialised nutritional support should be used to sustain life for all patients unable to ingest adequate amounts of nutrition has been the subject of much medico-legal and ethical debate. More specifically, the potential withholding or withdrawal of the same from patients has become one of the most controversial and intensely debated issues in modern biomedical ethics and law (Ahronheim and Gasner 1990; Boisaubin 1993; Dresser and Boisaubin 1985; Lynn and Childress 1983; Nelson 1987; Siegler and Weisbard 1985). The outset of this, and other medical and legal issues that have surfaced in the past two decades are primarily in the scientific and technological advances that permit essential life processes to be maintained during critical and even in chronic illnesses (Boisaubin 1993). The provision of adequate nutrition is, unequivocally, a critical priority for a majority of patients, especially for those who are considered to be critically ill. According to Knox (1993) it is generally agreed that no patient with a disease process benefits from total or partial starvation. The medico-legal literature provides numerous examples of cases where patients may not be best served by artificial nutritional support (Luce 1990; Oley Foundation in McCamish and Crocker 1993; Smedira *et al* 1990). Nevertheless, one of the most controversial legal and ethical debates concerns the provision of nutrition through artificial means. A major public policy issue of the past decades has revolved around the question, under what conditions, if any, is it acceptable to withhold or withdraw nutritional support.

Meisel (1991) claims that there are a number of myths about what law permits the termination of life support, some of which spring from a fundamental misconception of what law is. He is concerned that serious misunderstanding of the law can lead to tragic results for physicians, health care institutions, and families. These misunderstandings are: (1) anything that is not specifically permitted by law is prohibited; (2) termination of life support is murder or suicide; (3) a patient must be terminally ill for life support to be stopped; (4) it is permissible to terminate extraordinary treatments, but not ordinary ones; (5) it is permissible to withhold treatment, but once started, it must be continued; (6) tube feeding is legally different from other treatments; (7) termination of life support requires going to court; and (8) living wills/advance directives are not legal (Meisel 1991:1497). The following examples summarise the prominent legal cases concerning artificial nutritional support that clearly expose the myths described above.

#### Karen Quinlan

The history of legal cases involving withdrawal of medical care is a short one, spanning only 25 years. The first important case to achieve both widespread public awareness and legal precedent, that of Karen Ann Quinlan, was decided in 1976 (*In re Quinlan* 1976 cited in Boisubin 1993). Miss Quinlan lapsed into a persistent vegetative state<sup>2</sup> (PVS) after a drug overdose and subsequently her family requested, and permission was granted, to discontinue ventilatory support. Interestingly, withdrawal of tube feeding was not an issue in the decision since the family did not request it. With artificial nutritional support, Ms Quinlan lived for more than ten additional years until her death in 1981. Her somewhat tragic life provided not only a legal landmark, but also evidence of how long life can be continued when excellent medical care, including artificial nutritional support, is maintained.

#### Paul Brophy

The case of Paul E. Brophy was also a significant legal decision in the use of artificial nutritional support. Mr. Brophy, a former fire fighter and emergency technician had

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<sup>2</sup> The potential derogatory interpretations of the term 'PVS' are acknowledged, as explained by Chris Borthwick (1995) in 'The Proof of the Vegetable: A Comment on Medical Futility', *Journal of Medical Ethics*; 21: 205-8.

unsuccessfully undergone surgery in 1983 for a ruptured basilar artery aneurysm and never regained consciousness (Steinbrook and Lo 1988). He remained in PVS for three years. During this time his wife sought consultation with clergy, an ethicist, and a lawyer, requesting that artificial nutritional support be stopped. The couple's children and other family members were supportive of the decision, yet Mr. Brophy's personal physician and the hospital administration were opposed. Mrs. Brophy asked a probate court to allow her husband's tube feeding to be discontinued yet the judge ruled against her. Following an appeal to the Massachusetts Supreme Judicial Court, Mr. Brophy's enteral feeding was discontinued. On October 23, 1986, eight days after the withdrawal of artificial nutritional support, Paul Brophy died of pneumonia with his wife and children at his bedside (Boisaubin 1993).

The Brophy case was a significant decision in a number of ways. The state court majority upheld the common law rights of individuals and assumed the constitutional rights of refusal of medical treatments including artificial feeding. The right of refusal was given precedence over other competing claims, including the state's interest in preserving life and the disapproval of some of the health care providers involved in the case. The case was also remarkable in the reliance of the justices upon the authority of a number of medical professional groups, such as the American Medical Association, the American Academy of Neurology, and the Massachusetts Medical Society, all of which deemed removal of artificial nutritional support from such patients as ethical (Ahronheim and Gasner 1990).

### Nancy Beth Cruzan

The case of Nancy Beth Cruzan has become the single most important decision (in American law at least) addressing the general issue of withdrawal of medical care, and specifically the issue of termination of artificial nutritional support. This case has been exhaustively discussed in the medico-legal literature. In summary, Nancy Cruzan was 33 when she was severely injured in a car accident in Missouri in 1983. Despite being resuscitated, she never regained consciousness and remained in PVS being nutritionally supported via a gastrostomy. Five years later, her parents requested that their

daughter's feeding tube be removed on the basis of her statement that she would not want to continue to live if she could not be 'at least half normal' (Boisaubin 1993:140). A trial judge agreed with her parents' requests, but the Missouri Supreme Court overturned the decision by stating that the patient's right to refuse treatment was hers' alone and no one could exercise it for her. Ms Cruzan's parents appealed the decision to the United States Supreme Court in 1990. The court stated that incompetent patients did not have the same right as autonomous patients because they cannot directly exercise it. The majority opinion declared that the individual's right to refuse treatment must be balanced against relevant state interests, including the protection and preservation of human life. After the Supreme Court ruling, the Cruzan's petitioned the trial court of Missouri to rehear their request to discontinue feeding, arguing that new witnesses had come forward who had had specific discussions with Nancy before her accident about her statements about not wanting to be kept alive as a 'vegetable'. In December 1990, a state judge authorised Cruzan's parents to 'cause the removal' of artificial nutritional support, arguing that Cruzan's intent, if medically able, would be to terminate her nutrition and hydration. The tube feedings were stopped and Nancy Beth Cruzan died 12 days later.

### Tony Bland

Tony Bland was a 21-year-old English football fan who was crushed in the Hillsborough football stadium disaster in the United Kingdom on April 15, 1985. Mr. Bland suffered massive anoxic brain damage and was subsequently confirmed as being in PVS. Artificial nutritional support was maintained by nasogastric tube feeding. After some months in this condition his attending physicians approached the local coroner to examine as to the legality of withdrawing artificial nutritional support. They were advised that this would constitute judicial murder. The case was ultimately heard by the House of Lords, the highest court in the United Kingdom, and on February 4<sup>th</sup>, 1993, they authorised the removal of the feeding tube. Tony Bland died 11 days later (Dyer 1993).

The prevailing clinical (American Academy of Neurology 1989; American Dietetic Association 1992; American Medical Association Council on Ethical and Judicial Affairs



1989; American Nurses Association 1992), ethical (Hastings Center 1987; President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research 1983), and judicial (Cruzan versus Director, Missouri Department of Health in Knox 1993; Paris and Reardon 1985) positions are that the provision of nutrition through artificial means is an invasive medical intervention. As such, medical procedures for supplying nutrition impose burdens as well as provide benefits, and may under certain circumstances, be forgone.

Within the North American literature, in general, the courts have held that a competent person maintains the right to refuse any medical treatment, including artificial feeding. The courts and other medical bodies have supported the notion that artificial nutritional support as a mode of therapy that supports basic physiological processes is to be considered no different from the provision of ventilatory support (President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research 1983; American Medical Association 1986). Both forms of treatment are to be considered extraordinary if the medical risks of providing such treatment outweigh the benefits, that is, reduce the patient's overall quality-of-life by causing undue pain and suffering, directly from the therapy or by the prolongation of terminal illness. However, the legal discussions within the literature have left considerable doubt regarding the specific guidelines that are to be applied for either withholding or withdrawing artificial nutritional support.

While these generalisations have been upheld in most cases for competent persons, they have varied considerably in situations in which the patient's judgement was in question, or in cases in which the patient's wishes prior to irreversible illness were not clear. These variations are exemplified in the case of Paul Brophy (Brophy versus New England Sinai Hospital 1986), in which the judge ruled that the feeding tube had to remain, choosing to note that without it the patient would suffer; in the case of Conroy (In re: Conroy, New Jersey 1985 cited in Groher 1990), who had to be tube fed before dying because her self-removal of the tube was judged not to constitute refusal; in the case of Browning (In re: Guardianship of Estelle M. Browning, Florida 1989 cited in Groher

1990), and Hazleton (In re: Hazleton, Virginia 1987 cited in Groher 1990), the tube was not withdrawn because it could not be shown that death was imminent; and in the case of O'Connor (Annas 1988), who in spite of her well-known oral protestations regarding her desire not to be tube fed, was denied removal because her wishes were not in writing. Hence, the inception of advance care planning that is variably known as advance directives, living wills, and/or durable power of attorney for health care.

By 1990 in the USA, forty-one states and the District of Columbia had enacted natural death acts authorising the use of living wills (Orentlicher 1990). These legal documents allow competent adults to give legally binding instructions that, in case they are diagnosed as terminally ill and are unable to give directions concerning their care, no extraordinary treatments shall be employed that will simply prolong the act of dying (Mishkin 1986). Twenty-five USA living will statutes make some mention of artificial feeding, and some testify that artificial feeding can be withdrawn under certain circumstances (Schiller *et al* 1999). Others consider artificial feeding as comfort care and stipulate that it may not be rejected under the law (Society for the Right to Die cited in Schiller *et al* 1999). Despite clear directives from patients, some hospitals and physicians refuse to honour living wills and advanced directives for fear of litigation from opposing family members (McLeod 1990). Similarly, it must be acknowledged that one reason physicians might use for employing artificial nutritional support for the dying is to avoid a lawsuit. Thomasma *et al* (1986) argue that the fear of a lawsuit or even murder charges is understandable considering the events surrounding the Kaiser Permanente case in California where two physicians (Barber and Nejd) were indicted for murder when they withdrew intravenous feeding from a comatose patient. In the UK, the House of Lords Select Committee on Medical Ethics (1994) supported the development of advance directives on the basis that they enable expression of individual preferences and stimulate discussion between doctor and patient. In Australia, no formal implementation of such advance care planning strategies were legislated at the time of data collection, however in a subsequent review of the literature<sup>3</sup>, Bielger and colleagues

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<sup>3</sup> This subsequent review of the literature has been termed a 'last minute review' and is discussed in Chapter 12 'Reflections', p. 293 of this thesis.

(2000) explain that three Australian states and two territories now have legislation which provides for advance directives.

### **Medical Intervention or Basic Care?**

The associated medico-legal literature by and large grapples with the issue of whether artificial nutritional support should be considered medical treatment or obligatory care, that is, the routine and mandatory care as part of any hospitalisation. This distinction is important, because if one accepts the fact that artificial feeding is a medical treatment, the decision to implement such a treatment should be subjected to a risk/benefit analysis that generally is a fundamental part of any medical decision. While most decisions have held that artificial nutritional support is considered a medical treatment (Cohen and Cohen 1988), few courts have focused their attention on the risk/benefit analysis as it related to the decision of whether or not to initiate or withdraw artificial nutritional support. One reason may be that there are very few data that detail the risks or benefits in well described populations over specified periods of time. This concept of risk/benefit analysis is examined in more detail under the separate subheading 'burdens and benefits' later in this chapter.

Ethicists generally agree that, when a patient is under the care of a physician, nurse, or other health care provider, basic care such as food and shelter must be provided to the patient (Goldstein and Fuller 1994). The ethical question of artificial nutritional support may be framed as the problem of deciding whether the use of feeding tubes and vascular access devices is basic care (and therefore ethically obligatory) or medical care (and therefore required only in certain situations, depending on the medical indications). Although the majority of opinion among ethicists at present, according to the above authors, is that artificial nutritional support is a medical intervention, a substantial minority holds otherwise. A brief discussion of each viewpoint follows.

### **Artificial Nutritional Support as Basic Care**

Dolan (1991) presents several arguments for considering any form of feeding as basic care. He considers the withdrawal of artificial feeding as murder. Dolan (1991)

considers a case in which a man in PVS is fed via enteral feeding tube and his concerns focus on the disabled, but nonterminal, state of the patient. Dolan is concerned that a society that authorises the withdrawal of tube feeding from a patient devalues the personhood of the patient. He contends that withholding treatment based on quality-of-life is the path that led hospitals under the Nazi regime from euthanasia of the severely disabled to murder of those society believed were undesirable. This concern is shared by other people, and it is one of a class of arguments sometimes called the 'slippery slope' (Goldstein and Fuller 1994:192). In this case, the argument is that, once we start to allow some patients to die by withholding nutrition, we will be unable to decide where to draw the line and will ultimately lose our respect for all patients and for the value of human life.

#### *Artificial Nutritional Support as Medical Care*

The emerging ethical consensus appears to be that artificial nutritional support via the enteral or parenteral route are medical interventions and are subject to the same considerations of risk versus benefit that govern other medical decisions (American College of Physicians 1992; American Thoracic Society 1991; Callahan 1988; Lynn and Childress 1983). In several USA states however, feeding tubes are specifically excluded from the list of interventions that a patient may refuse in an advance directive. The California Second District Court of Appeals permitted the removal of a nasogastric tube from a competent patient who requested this action on her own behalf (*Bouvia v. Superior Court* in Goldstein and Fuller 1994). The Massachusetts Supreme Judicial Court approved the removal of a feeding tube from a man in PVS (*Brophy versus New England Sinai Hospital* in Goldstein and Fuller 1994); and the Supreme Court of New Jersey, based on its conclusion that there is no distinction between artificial nutritional support and other forms of life-sustaining therapy, permitted the withdrawal of both a nasogastric tube (case of Peter) and a jejunostomy tube (case of Jobes) (Steinbrook and Lo 1988). Justice O'Connor, writing in a concurring opinion for the United States Supreme Court in the *Cruzan* case, stated unequivocally that artificial nutritional support should be considered as a form of medical intervention (*Cruzan versus Director* in Goldstein and Fuller 1994).

### **Withdrawing and Withholding Treatment**

As recently as seventeen years ago, the idea that artificial nutrition might be withdrawn from dying patients without moral or legal impunity, was a notion that would have been repudiated, if not condemned, by most health professionals (Siegler *et al* 1985):

*They would have regarded such an idea as morally and psychologically objectionable, legally problematic, and medically wrong. The notion would have gone 'against the stream' of medical standards of care (Siegler et al 1985:129).*

Bernat *et al* (1993) also explains that throughout the 1980's, many thinkers expressed serious reservations about allowing such withdrawal of artificial nutritional support to become accepted medical practice. Yet, as illustrated in numerous publications since within both the medical and bioethics literature, this practice has received increased support from both medical practitioners and bioethicists. Siegler *et al* (1985) argue that this opinion is typically couched in the discourse of caution and compassion, yet the underlying analysis suggests:

*...that for an increasing number of patients, the benefits of continued life are perceived as insufficient to justify the burden and cost of care; that death is the desired outcome, and - critically - that the role of the physician is to participate in bringing this about (Siegler et al 1985:129).*

Likewise, Bernat *et al* (1993) explain that the reservations regarding withdrawal and withholding were not based on any information about the discomfort or suffering experienced by patients under such circumstances. Rather, caregivers experienced psychological distress due in part to the failure to understand the distinction between killing and letting die, and the social implications of withdrawing or withholding food and fluids, particularly because of its symbolism as communicating lack of caring (Derr 1986; Callahan 1983). Hence, the morally vexing question has been repeatedly asked, as phrased by Holt (1991:5), 'is it ever in a patient's best interests to become malnourished and dehydrated through the removal of artificial supports'? Such a question resurrects

some old issues that are involved in the cessation of any life-maintaining treatment, while simultaneously raising some new issues.

The withholding or withdrawing of artificial nutrition is an emotionally charged issue and, as Callahan (1983) argues, the removal of food and fluid strikes a chord in us all. He suggests that denying these comfort measures challenges human decency and one's sense of community. The act of feeding has an emotional and symbolic significance derived from our culture (Miles 1985). Food has a significant role in ethnic traditions and has evolved as a symbol of caring, commitment and comfort (Knox 1993). Some consider the relationship involved in feeding as the most fundamental of all human relationships and see no distinction between oral feeding and feeding through artificial means (Callahan 1983; Derr 1986; Meilaender 1984). Indeed, feeding, unlike other medical treatment, has a moral and emotional significance derived from culture. Cox (1998) explains that from breast-feeding to wedding feasts to food brought to families in mourning, feeding is integral to the experience of passage. In the Judaic and Christian traditions, the shared meal is an important representation of the faith's 'corporate' life and its moral significance (*ibid.*). In North American society, Thanksgiving and potluck dinners acknowledge mutual interdependence. Bernat *et al* (1993) argue that because feeding is integral to relationships, decision-making authority concerning feeding is shared between patient and caregiver.

Wurzbach (1990) explains that food and fluid symbolise nurturing, warmth and a minimum commitment to the well being of another. Starvation and dehydration symbolise neglect and abuse. Priester (in Wurzbach 1990) however, believes that focusing on the symbolic value of providing food and fluids may mask important distinguishing characteristics of this treatment. He stresses that artificial nutritional support is provided to prevent or treat malnutrition and dehydration; they may or may not relieve hunger or thirst. Conversely, hunger and thirst may be treated without resorting to artificial nutrition and hydration, for example, moistening a patient's lips with mouth toilets or ice chips.

Many articles have outlined the competing ethical factors and the positions taken on this issue. Some authors come to certain conclusions whilst others discuss the issue as a dilemma fraught with uncertainty (Annas 1983, 1985, 1986; Green *et al* 1994; Meilaender 1984). Sometimes the literature sends mixed messages, that is, support for the self-determination of the patient but concern that we are stepping onto a 'slippery slope' (Hospital Ethics Editorial 1988:14). In contrast to termination of treatment decisions in general, there is no consensus on withholding or withdrawing artificial nutritional support.

Articles by Meyers (1985) and Dresser and Boisauvin (1985) review legal and clinical thinking on the issue of withdrawing artificial nutritional support from terminally ill or permanently unconscious patients. The conclusions by Meyers is one that finds support in a number of court decisions in the 1980's and in the majority of scholarly comments on this subject in the medical and bioethics literature:

*Certainly, we are talking about relatively few cases. Nourishment should be provided in the vast majority of cases as long as physically possible. If the patient can be fed manually, he or she of course should be. However, in those rare cases where nourishment can only be provided through invasive means and cannot improve the patient's hopeless prognosis, it seems the law should not mandate medically provided nourishment (Meyers 1985:125).*

Dresser and Boisauvin (1985) explicitly limit their argument to cases of permanently unconscious patients, suggesting their approval of the New Jersey appellate court's decision in the Conroy case, which refused to endorse withdrawal of artificial nutrition and hydration support from a severely demented but conscious patient. Meyers (1985) goes further, arguing that artificial nutrition and hydration support may be withdrawn from the terminally ill and the nonterminally, yet seriously ill, as in the Conroy case, as well as from the permanently unconscious. Others go further still. A group of distinguished clinicians published an article advocating the withholding of parenteral nutritional support from severely and irreversibly demented patients and perhaps, at times, from elderly patients with permanent mild impairment of competence (Wanzer *et al* 1984).

Many health care providers consider withholding or never initiating a treatment as morally permissible but regard withdrawing a treatment as wrong. Although it is psychologically more difficult to withdraw a treatment, there is no ethical requirement that, once employed, a treatment must be continued (Hasting's Center 1987). A major dilemma with making a moral distinction between withholding and withdrawing a treatment is that it may lead to misgivings on the part of the health care providers to begin a potentially beneficial treatment for fear of being forced to continue the treatment, even if it proves to be of no benefit (Knox 1993). For many treatments, not just artificial nutritional support, there is scepticism as to actual burdens and benefits.

Several sources do raise the question of whether it is justifiable to withdraw artificial means of nutritional life support when its removal hastens rather than causes death? Curtin (1994) suggests that in situations in which sentient life is a reasonable expectation, nutritional life support measures, once started, generally should be continued unless a rational adult patient refuses them. When permanent unconsciousness can reliably be predicted, artificial life support can be terminated. The President's Commission on Deciding to Forego Life Sustaining Treatment (1983) explains this argument as follows:

*Most patients with permanent unconsciousness cannot be sustained for long without an array of increasingly artificial feeding interventions - nasogastric tubes, gastrostomy tubes, or intravenous nutrition. Since permanently unconscious patients will never be aware of nutrition, the only benefit to the patient of providing such burdensome interventions is sustaining the body for a remote possibility of recovery. The sensitivities of the family and of care giving professionals ought to determine whether such interventions are made...When all remedial attempts have failed to bring the patient out of chronic coma, but where the patient is able to sustain respiration and circulation, it would seem to be a matter between physician and family as to whether or not other, more mundane care would continue...if the family feels the emotions or financial drain too great and the physicians in attendance indicate not reasonable possibility of any recovery, then it can be anticipated that the courts, when presented with petitions for appointment of a conservator with power to refuse consent to further treatment*



*of any kind, including I.V. drip...can be expected to grant such requests (Report of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research 1983:288).*

Fletcher *et al* (1993) argue that there is no ethical or legal difference between withholding and withdrawing treatment if the intent is to provide the greatest degree of comfort and optimal life for the dying patient. Although from an emotional standpoint it is often more difficult to withdraw technological interventions like artificial nutritional support, patients have a right to trials of therapeutic procedures without a commitment to indefinite use of such procedures (*ibid.*). Artificial nutritional support is considered a minimal standard of care for hospitalised patients (Jett 1995:59), yet it is difficult to dispel the notion that this therapy is 'the least that can be done' - when, in fact, the procedures are invasive and uncomfortable (that is attaining parenteral and/or enteral access), and may be harmful to the patient.

In the case of the dying patient, Jett (1995) explains that decreased nutritional intake and dehydration are the natural state of the dying organism. There is ample evidence that this decrease in intake may enhance the comfort of the dying patient by decreasing secretions, oedema, pain, incontinence, cardiac load, and pulmonary distress (Andrews *et al* 1993; Billings 1985; Musgrave 1990; Stone 1993). In a USA study of 32 terminally ill patients admitted to a palliative care unit, hunger and thirst were found to be either non-existent or minimal. Those patients who did experience hunger or thirst were satisfied with small amounts of food and liquids (McCann *et al* 1994). In a UK hospice, 13 of 31 amyotrophic lateral sclerosis patients with severe dysphagia were tube fed while the remaining 18 were managed conservatively with assisted oral intake. Retrospective analysis showed the patients with nasogastric tube feeding had significantly more problems with oropharyngeal secretions and required suctioning more often than patients without tubes. There was no difference in survival time after onset of swallowing difficulties in the two groups (Scott and Austin 1994).

Even when artificial provision of food and fluids is begun there is controversy over whether it can be done on a trial basis or whether once begun it can be stopped. In fact,

the President's Commission makes no moral distinction between withholding and withdrawing artificial nutrition. There may, however, be psychological differences. Withholding treatment, according to Wurzbach (1990) does not allow for the possibility of improvement in the patient's condition and may leave the family wondering if they made the correct choice:

*Withdrawing nutrition and hydration has a psychological impact on family and practitioner because it may be seen as abandoning hope or deliberately removing a requirement for the survival of the family member (Wurzbach 1990:227-228).*

Furthermore, the President's Commission suggested that greater moral justification may be required for withholding treatment because the positive effects of treatment are at that time unknown (Fry 1990). Thus, although withholding and withdrawing foods and fluids are morally equivalent, each has its own distinct consequences psychologically. This notion, however, is not explored in further detail in the literature reviewed for this research.

There is a marked division in the literature, in the way in which withholding/withdrawing debates are generated, and that difference depends on the mode of feeding. It appears that EN via feeding tubes generates ethical discussion around quality-of-life issues and the right-to-die controversy. On the other hand PN via central venous access generates discussion around clinical appropriateness and cost. It is here that a certain demarcation is observed between the two modes of feeding that seem to fall into either the ordinary or extraordinary classification. There is some crossover observed, but for the purpose of clarification, this ordinary/extraordinary classification is discussed in more detail.

### **Ordinary versus Extraordinary Care**

The distinction between ordinary and extraordinary care also creates controversy. Paris (1986) contends that the argument is that 'ordinary' and 'extraordinary' refer not exclusively to the technique or means employed to preserve life but to these means in relation to the condition not the patient. Historically, even the most simple, basic and

easily available remedy, if offering no hope or benefit to the patient, was considered 'extraordinary' (Wurzbach 1990):

*There was no obligation to accept a remedy unless it offered reasonable hope of checking or curing a disease. No one was obliged to use "useless" remedies (Wurzbach 1990:227).*

Underlying the social and cultural implications of feeding is the ethical concern implicated by the previously mentioned 'slippery slope' theory. Put simply, in situations where patients have not provided advanced directives, any decision to terminate their medical therapy including artificial feeding would tend to be subjective. In such cases, a surrogate decision maker cannot presume that treatment decisions made by a third party on a patient's behalf will further the patient's right to self determination, because, according to Cox (1998) effectuating another person's right to self-determination presupposes that the substitute decisions maker knows what the person would have wanted. Underpinning this ethical concern is the fundamental issue of whether artificial nutrition is regarded as 'ordinary' or 'extraordinary' measures. Katz and Kane (1995) offer this distinction:

*Ordinary means of preserving life are all medicines, treatments, and operations which offer reasonable hope of benefit for the patient and which can be obtained and used without excessive expense, pain, or other inconvenience. Extraordinary means of preserving life are all medicines, treatments, and operations, which cannot be obtained or used without excessive expense, pain or other inconvenience, or if used, would not offer a reasonable hope of benefit (Katz and Kane 1995: 28)*

The ordinary or extraordinary distinction has also been discussed in terms of the benefits and burdens of treatment for the patient. If the benefits of the treatment outweigh the burdens imposed on the patient, it is characterised as ordinary and therefore ethically required. If not, it is characterised as extraordinary and therefore optional (Matter of Conroy in Cox 1998). If the patient is not comatose and does not face imminent death, nourishment accomplishes the substantial benefit of sustaining life until the illness takes its natural course (Cox 1998). Under such circumstances, nutrition will always be an

essential element of ordinary care that health care providers are ethically obligated to offer (*ibid.*).

The distinction between ordinary and extraordinary care has historically been used to distinguish care that is morally required from that which is volitional (Paris 1986). Some regard ordinary care as that which is common, regardless of the complexity, and extraordinary care as that which is rare or unusual. Others define ordinary care as simple and extraordinary care as complex, elaborate or artificial. According to the Hasting's Center's guidelines (1987), no treatment is intrinsically ordinary or extraordinary. All treatments, regardless of complexity, have benefits and burdens. Any treatment that imposes an undue burden or that provides no benefit may ethically be withheld or withdrawn.

Cox (1998) argues that ordinary or extraordinary appellations are passé. She explains that 'in this fast-paced world of medical technology, what today may be an extraordinary procedure will be ordinary tomorrow' (Cox 1999:9). Furthermore, she maintains that ethicists argue against the ordinary and extraordinary distinction for deciding which treatments may be abated morally, or on the grounds that it is not the treatments that tend to be so characterised but the recipients of such treatments. It is this distinction which allows subjective standards to be applied under the guise of objectivity (Craig 1994).

The President's Commission (1983) reviewed the ordinary/extraordinary analysis to reach a conclusion of its usefulness in defining what care is obligatory for the patient to accept and others to provide, and what is volitional. It found a variety of usages: the most natural understanding of the distinction, the difference between ordinary and extraordinary care as applied to a patient in a particular condition; a technological distinction between simple (ordinary) and complex, elaborate, or artificial (extraordinary) care; and, an inquiry into the benefits and burdens of a treatment. The President's Commission concluded as follows:

*Despite its long history of frequent use, the distinction between ordinary and extraordinary treatments has now become so confused that its continued use in the formulation of public policy is no longer desirable (President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research 1983:88).*

Remarkably, the President's Commission found 'no particular treatments, including such 'ordinary' hospital interventions as PN or IV hydration, antibiotics, and transfusions of blood products to be universally warranted and thus obligatory for a patient to accept' (*ibid*: 90). It is within this framework that an ethical distinction begins to emerge. Jett (1995) provides an example of even when full parenteral or enteral feeding is not warranted, there still may exist a duty to make food available, perhaps as an expression of ongoing fidelity to the patient or to ensure that some amount of nourishment is ingested, perhaps to alleviate the suffering of hunger or thirst. Several other articles about life-sustaining nutrition (Hall 1994; Hodgson 1995; Sullivan 1993) reason that ethically, artificial nutritional support is optional, not mandatory, if it is not practicable, is of no medical benefit, or is disproportionately burdensome. In rare cases, as with patients with complete intestinal infarction, artificial nutritional support may be technically impossible and thus, is not required. Dunlop *et al* (1995) argue that artificial nutritional support is of no benefit when, combined with other treatments, it cannot change a patient's condition or course. However, when artificial nutritional support is practicable, as is the case in most situations, it is best evaluated by taking the patient's perspective.

### **Self-Determination and Suicide**

According to Daly (1995) a patient, in deciding whether artificial nutritional support is disproportionately and unacceptably burdensome, would weigh those burdens against the benefits of extended life. The notion of self-determination or autonomy is one that is deeply rooted in our culture (Boisaubin 1993). In general, this is the moral right to choose and follow one's own plan of life and action (Beauchamp and Childress 2001). Legally, these preferences are significant as certain legal systems recognise that individuals have a fundamental right to control their own bodies, and the right to be

protected from unwanted interventions. An important judicial opinion, that of Natanson versus Kline maintains:

*Anglo American law starts with the premise of thoroughgoing self-determination. It follows that each man is considered to be master of his own body, and he may, if he be of sound mind, prohibit the performance of life saving surgery or other medical treatment (Jonsen et al 1992:39).*

There is much in the literature regarding the right of the patient to refuse nutrition. Kleinman (1991) describes the patient's right to determine his or her treatment as fundamental and reflecting our respect for the autonomy of the individual. He warns that a strict adherence to the principle of autonomy can be problematic when patients appear to be cognitively competent but unable to make use of the information because of their emotional state. None of these reports, however, considers the right of competent patients to insist on a therapeutic modality that does not have clear benefit. The fundamental question posed here seems to be the extent to which any individual owns his or her own death. Rosner (1993:1892) asks 'Does a person have the right to select how and when to die? Is such a decision by the patient akin to suicide?' Dominant Judeo-Christian teaching is that life is a gift of God to be held in trust. One is duty bound to care for one's life and health. Only God gives life and, hence, only God can take it away. Secular ethics however, according to Rosner (1993) teaches that a patient has the right to determine what shall and shall not be done to preserve his/her health or prolong his/her life. Therefore, the patient has an absolute right to request the withdrawing or withholding of life-sustaining therapy such as artificial nutritional support.

### **Does Withdrawal Constitute Killing?**

Complex questions cannot be answered simplistically, and this question is far more complex than it looks. Nonetheless, many clinicians categorise this question under the general rubric of withdrawal of medical life support measures - which, according to Curtin (1994) only adds to the confusion. As Curtin explains, it is one thing to decide not to resuscitate a terminally ill patient, it is quite another to starve a person to death whether or not the patient has some hope of survival (1994). Holt (1991) suggests that since

death always results from the removal of nutrition/hydration supports, is it not euthanasia? In a sense, the question is partially deceptive. While it is true that the cessation of artificial nutritional support is inevitably fatal, so is the cessation of such other treatment procedures such as renal dialysis, mechanical ventilation, inotropic infusions, and chemotherapy, for those whose lives depend upon them. However, the crux of the question here is what really kills the patient? Is it the withdrawal of medical supports or the underlying disease process that rendered the supports necessary - or more simply, is death due to natural causes or a volitional act? This question remains unanswered within the available literature.

While maintaining adequate nutrition is a part of any medical regimen, adequate nourishment itself is not solely within the medical prerogative. As Curtin (1994) explains, a physician may prescribe a special diet, or provide nutrition through artificial means, or even order a temporary suspension of a nutritional regimen, yet the permanent suspension of a nutritional regimen is not a medical option in the ordinary sense of that term. Although the use of drugs, equipment, treatments including the use of ventilators and defibrillators, is initiated and discontinued by medical prescription as patient need dictates, the patient's need for nourishment continues regardless of his or her health state (*ibid.*).

Several writers including Callahan (1988) and Sielger and Wiesbard (1985) firmly uphold their positions of why artificial nutritional support should never be withheld or withdrawn. Rosner (1993) maintains this view yet accepts that his 'personal position' differs from that of most of the medical community. He resolutely claims that doctors are required to do everything in their power to alleviate suffering, cure sickness and disease, and prolong useful and productive life:

*...I firmly believe that a physician is obligated to provide handicapped newborns, including anencephalics, as well as dying patients supportive care, including psychosocial and emotional care, to the very end. Fluids and nutrition, whether given by mouth or 'artificially' by feeding tube or intravenous infusion, are part and parcel of that supportive care - no different*

*from walking, turning, talking, singing, reading, or just listening to the dying patient. There are times when specific medical and/or surgical therapy is neither indicated nor appropriate or desirable for a newborn with a lethal defect or a terminally, irreversibly ill, dying patient. There is no time, however, when general supportive measures can be abandoned, thereby hastening the patient's demise, unless the patient specifically requests such withholding or withdrawal because of severe pain and/or suffering. Patients in a coma or a persistent vegetative state are not suffering. Their families, friends, caregivers, and society may suffer emotionally and financially. But it is wrong to relieve the suffering of others by shortening the life of the patient. Withdrawing and/or withholding fluids and nutrition is a direct and proximate cause of death (Rosner 1993:1894).*

Rosner (1993) claims that the physician is given divine license to heal but not to shorten life by hastening death. Even if the courts legally sanction the withdrawal or withholding of artificial nutritional support from terminally ill and chronic PVS patients, and sanction the actions of those who choose to starve themselves to death, Rosner explains that what is 'legal' is not always 'moral' (1993:1894).

Withholding or withdrawing medical life support measures, as a rule, is justified on the basis of futility or human rights (patient's right to refuse treatment) or both. It is difficult to argue that feeding is futile or that deliberate starvation is a humanitarian endeavour. Ordinarily, to deprive a person of basic sustenance is 'to kill' (Curtin 1994:14). However, as the means of providing sustenance have become more sophisticated, who is included in this duty has become less clear. While few among us would consider bottle-feeding an infant or spoon-feeding a debilitated adult to be morally optional, each could be perceived as being an artificial means of feeding. Furthermore, a premature infant may not have sufficient strength or sucking reflex to feed efficiently thus necessitating the use of a special teat for his or her bottle. Similarly, a debilitated adult may require his or her food to be pureed. Do such adjustments in the feeding process (albeit not via tubes) justify a refusal to feed? From these examples, it is only a short step to the use of tube feeding in infant without a sucking reflex or for adults too debilitated to chew their food. The question is then raised as to whether or not artificial nutritional support (EN in this example) is a medical option or moral imperative? Similarly, if digestion is impaired, be it



temporarily or permanently, PN is the most effective means of feeding, yet is PN morally or legally required in all instances? These questions do not appear in the clinical/ethical literature reviewed for this project.

Here at least, some broad though reasonably clear distinctions are possible with regard to the distortions of artificial feeding as demonstrated by Curtin (1994) above. When feeding could be accomplished by mouth (e.g. bottle-feedings with or without a special teat or spoon feeding of pureed or nonpureed food), to deliberately withhold or withdraw is to kill. From an ethical and legal perspective, Curtin offers this explanation:

*From an ethical perspective, whether or not feedings ought to be forced would depend directly on the condition as well as the competence of the person refusing to eat. From a legal perspective, the safest course would be to consult the courts when in doubt - and perhaps even when not in doubt (Curtin 1994:15).*

Another related question regarding death which Curtin raises, is whether artificial nutritional support measures, or more specifically, artificial nutritional life support measures constitutes an inhumane prolongation of death in certain circumstances? Curtin (1994) believes that it does. She explains that in situations where death is inevitable and the condition of living is intolerable (extensive technological isolation from human touch, futile pain and pointless extensions of dying), highly sophisticated means of feeding not only are not in the patient's best interests, they may even be more risky to his or her suffering:

*In fact, even feeding by mouth may be more risky and/or more irritation than it is worth. Forced feeding in such circumstances is morally repugnant (Curtin 1994:15).*

Similarly, Bernat *et al* (1993) explain that physicians may educate patients in that they may refuse artificial nutritional support in a way that minimises suffering. Chronically or terminally ill patients who wish to gain more control over their deaths can then refuse nutrition and hydration. However, this assumption is somewhat thwarted by another

assumption that thirst and hunger remain strong drives in terminal illness, and the misconception that failing to satisfy these drives causes intractable suffering. The stereotypical image of a parched person crawling in the desert toward an oasis mirage of lush water pools, plus the images beamed onto millions of lounge room televisions of famine, as well as the narrative accounts of shipwrecked victims adrift without water, have contributed to the general assumption that life-threatening starvation and dehydration is unbearable. Although this is true in the above circumstances, according to Bernat *et al* (1993) it is the consensus of experienced physicians and nurses that terminally ill patients dying of dehydration or lack of nutrition do not suffer if treated properly. In fact, they go further to explain that maintaining physiologic hydration and adequate nutrition is difficult in most seriously ill patients because intrinsic thirst and hunger are usually diminished or absent. Physicians, and particularly nurses, have written many observational pieces describing peaceful deaths by starvation and dehydration (Andrews and Levine 1989; Zerweck 1983; Printz 1992). The scientific and clinical literature on this matter is scant. Systematic studies of the symptoms preceding death are hard to find, and those that do exist commonly do not separate suffering attributable to the underlying disease process from suffering attributable to starvation and dehydration (Mogielnicki *et al* 1990; Billings 1985; Morris *et al* 1986).

### **Burdens and Benefits**

Another ethical and legal issue that has been drawn into the feeding debate is the balancing of benefit versus burden. For example, would the implementation of PN be of overall benefit to a terminally ill patient when the risks (central venous catheter<sup>4</sup> placement, sepsis, metabolic complications) are weighed against the potential benefit of improved nutritional status and perhaps prolongation of life? The powerful rhetoric of 'death with dignity' has gained, according to Siegler and Weisbard (1985:129) 'intellectual currency and practical importance'. Initially, this rhetoric was a plea for more humane and individualised treatment in the face of the sometimes cold and impersonal technological imperatives of modern medicine. Hence the burdens versus benefits arguments began to appear in the literature around the late 1980's. The arguments

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<sup>4</sup> Commonly referred to as 'CVC' or 'central line'.

regarding burdens and benefits of artificial nutritional support, by and large, rest on the dual propositions that the provision of artificial nutritional support is a medical intervention guided by consideration similar to those governing other treatment methods and that judgements concerning the withdrawal of such interventions should be based on a reckoning of benefits and burdens associated with their intervention.

Placement of nasogastric or intravenous tubes requires medical training, and the use of such tubes has a nontrivial risk of iatrogenic illness; placement of a gastrostomy tube requires further medical training in endoscopy or surgery, and the risks of placement are the more serious risks of haemorrhage, infection, and peritoneal leakage (Meyers and Grodin 1991). For some patients, there are further burdens of treatment. For patients with terminal disease who are close to the end of life, the result may be a prolongation of suffering (Goldstein and Fuller 1994). For demented patients who cannot comprehend the purpose of the feeding tube, the burden of incessant irritation from a foreign device may be more severe. For patients in PVS who previously expressed a wish to be allowed to die, this burden may represent an insult to their dignity in such refusal to follow their prior instructions (*ibid.*).

Dorner *et al* (1997) maintain that the health care team may overestimate the benefits of medical intervention and prolonging life while underestimating the burdens. They provide a concise list of points when considering whether the patient will regain useful function and improved quality-of-life as a result of artificial nutritional support:

*Benefits may include:*

- *Increased life span*
- *Increased ability to recover*
- *Increased possibility of returning to useful functioning*
- *Improved quality-of-life*
- *Improved psychological and physiologic state*
- *Increased resistance to infection*
- *Improved healing of skin and wounds*

*Burdens may include:*

- *Physical pain*
- *Spiritual and emotional pain and suffering*

- *Invasive procedures*
- *Indignity*
- *Emotional and financial burden on the family (Dorner et al 1997:S176)*

Groher (1990) offers more definitive examples of the burdens associated with artificial nutritional support, yet does not concentrate on the associated benefits. With enteral feeding, he postulates that the known medical risks include but are not limited to:

*....nasal alar ulceration, sinus infection, bleeding, fistula, intolerance of fluid volume, pulmonary oedema, reflux and regurgitation, diarrhoea and gastrointestinal distress, and aspiration pneumonia. Aspiration is particularly prevalent in the elderly hospitalised population and needs to be considered a major risk in those with known oropharyngeal incompetence and/or history of prior reflux disease (Groher 1990:104).*

Ciocon *et al* (1988) found a 47% incidence of aspiration in patients who were fed by nasogastric tube in a chronic care setting. In addition, the placement of nasogastric tubes in some patients required that they must be restrained, putting them at a greater risk for decubitus ulcers. The risks associated with the placement of an enteral feeding tube in the gut, that is gastrostomy or jejunostomy tube placement include bleeding, infection at the tube insertion site, gastrointestinal distress, diarrhoea, and peritonitis (Groher 1990). Associated risks of feeding via the parenteral route, according to the same author, include pneumothorax, haemothorax, catheter embolus, sepsis, and electrolyte imbalance (*ibid.*).

Another related area of risk that deserves discussion is whether the provision of life-sustaining nutrients via PN or EN in those with terminal diseases causes the patient to continue to suffer by allowing him or her to survive longer than if the feeding was withheld. In other words, by maintaining physiological function through artificial nutritional support, is it fair to allow the patient to experience the pain that could be associated with end-stage disease? Lo *et al* (1986) argue that the assumption that most people would choose to forego artificial nutritional support if they understood that the

institution of 'feeding' would not improve their chances for recovery. Miscovitz *et al* (1988) argue that the maintenance of physiological function alone is not sufficient reason for prolonging life. Providing artificial nutritional support in these instances also may put the patient at psychological risk by providing the false hope of improvement, and the family at risk because they may come to feel that a feeding tube, be it enteral or parenteral, compromises the patient's dignity (Groher 1990). Furthermore, does the maintenance of physiological function by feeding put the patient at risk for another possibly more debilitating illness? There are few data within the literature to help the health care professional answer these questions. However, it is clear that these issues should be part of the decision to employ artificial nutritional support.

Concomitant to the burden encountered by letting a patient live and possibly suffer from terminal or irreversible illness is the issue that the act of withholding artificial feeding may cause the patient additional pain and suffering, having a negative impact on their quality-of-life. It is not an uncommon notion among health care providers, (Groher 1990), and supported in some court decisions (Dresser and Boisaubin 1985), that withholding artificial nutritional support induces pain and suffering beyond the disease that precipitated the need for intervention. According to Groher (1990) the courts have failed to focus on the data contrary to this view, even in patients in PVS and coma:

*Some testimony has centred on those patients in the persistent vegetative state who have normal wake/sleep cycles and exhibit abnormal reflexes, facial expressions, and movement patterns interpreted as an expression of pain. Unfortunately, the data on both sides of the issue are largely anecdotal (Groher 1990:104).*

In her experience with terminally ill patients, Zerwekh (1983) observed that those who were not 'fed' during the end of their illness seemed to experience less pain than those who did. Her observations are supported by Printz (1988), and by Dresser and Boisaubin (1985), both of whom provide somewhat more than anecdotal support for their claim. Dresser and Boisaubin (1985) note that dehydration will lead to death as a consequence of azotaemia, hypernatraemia, and hypercalcaemia, all of which produce a sedative, and therefore, an anaesthetic effect on the body. They also point out that by

drying secretions and excretions secondary to dehydration, the patient is more comfortable because there are fewer instances of congestion with apnoea, vomiting, and incontinence. Printz (1988) reviewed the literature pertaining to pain secondary to dehydration, noting that in her dying patients all appeared to be in less distress and pain than those who were artificially hydrated and nourished until death. She noted that even those patients who remain in metabolic balance produce ketones during calorie deprivation together with opioid peptides, both of which have an anaesthetic effect on the central nervous system. In a related animal study, Quill (1989) demonstrated that nutritional deprivation increases the opiate dynorphin, which acts as a strong anaesthetic to the central nervous system.

The prevalent argument for the institution of artificial feeding is that it may benefit the patient by reversing malnutrition and prolonging life, neither of which have been supported scientifically for patients in a chronic care setting. In a study relating to the benefits of artificial nutritional support (EN specifically), Quill (1989) found nasogastric tubes to be of limited value. In a retrospective review of 59 patients 70 years or older who were admitted to a community hospital with irreversible illness (severe cerebrovascular accident,<sup>5</sup> dementia, metastatic neoplastic disease), Quill (1989) found that 64% died whilst hospitalised. In only two percent of the 55 was the feeding tube removed because of improvement. In 55% of the patients, restraints had to be utilised, causing the author to conclude that feeding tube insertion in the group of patients severely compromised their quality-of-life. Quill also found that most of the physicians who inserted the tube did so for therapeutic reasons, even though the outcome did not suggest that this goal was met. Although it was not measured directly, Quill concluded that the insertion of a feeding tube in this patient population did not prevent death but seemed only to defer it (1989).

The benefits-and-burdens argument, albeit useful in a number of contexts, is not routinely accepted favourably. Meyers (1985) and Dresser and Boisaubin (1985) demonstrate the value of the argument and how it marks a clear analytic improvement

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<sup>5</sup> Commonly referred to as either CVA or 'stroke'.

over earlier references to extraordinary measures or artificial means which are terms that have brought much confusion into such discussion. However, as Siegler and Weisbard (1985) explain, the benefits-and-burdens argument is rendered problematic when the assertion that physicians, families, courts, or other third parties can properly conclude that the burdens of withdrawal of artificial nutritional support - an unconvincing catalogue of potential complications or side effects - outweigh the benefits, that is, sustaining life:

*We recognise that in rare cases, the provision of fluids and, particularly, nutritional support may be medically futile or even counterproductive in sustaining life. We do not recommend that such futile or counterproductive steps be mandated (Siegler and Weisbard 1985:130).*

Generally, the numerous 'compassionate calls' within the literature for the withdrawal of artificial nutritional support do so in the context of a few selected cases, which, if considered critically, could predispose to considerable abuse. The concept of medical futility, hinted on in the above passage, therefore deserves further exploration.

### **Medical Futility**

Considering the literature on medical futility is essential in such discussions on ethics and artificial nutritional support. The Hippocratic Corpus encourages physicians to recognise when medicine has reached its limit of usefulness. Mitchell and Lawson (1999: 1705) note that Plato emphasised the 'inappropriateness of persisting with treatments which leave the surviving patient with a useless life'. Today, ethics and the law give primacy to patient autonomy, defined as the right to be a fully informed participant in all aspects of medical decision-making and the right to refuse unwanted, even recommended and life-saving medical care. So powerful has this notion of autonomy become that its 'glare', as defined by Scheiderman *et al* (1990:3942), often blinds the physicians and bioethicists to the legitimacy of other ethical accounts that, for many years has shaped the range of physicians' obligations towards patients. Among these doctrines was the belief that futile treatment is not obligatory. Similarly, no ethical principle or law has ever required physicians to offer or accede to demands for treatments that are futile (Presidents Commission for the Study of Ethical Problems in Medicine and Biomedical and

Behavioral Research 1983). However, even when this doctrine is accepted in theory, Blackhall (1987) and Tomlinson and Brody (1988) argue that physicians frequently practice as though every available medical measure must be used to prolong life unless patients give definitive directions to the contrary.

A discussion regarding medical futility that appears in the American Journal of Medicine (Lantos *et al* 1989), highlights that therapy might be effective, in a limited sense, yet the goals that are achieved are not desirable, for example, when considering prolonged artificial nutritional support of a patient in PVS. The authors suggest that physicians should acknowledge that, in such situations, potentially achievable goals exists and therefore therapy is not futile. However, Schneiderman *et al* (1990) argue that the aim of medical treatment is not simply to cause an effect on some part of the patient's anatomy, physiology, or chemistry, but to benefit the patient as a whole:

*No physician would feel obligated to yield to a patient's demand to treat pneumonia with insulin. The physician would rightly argue that (in the absence of insulin-requiring diabetes) such treatment is inappropriate; insulin might have a physiologic effect on the patient's blood sugar, but would offer no benefit to the patient with respect to pneumonia. Similarly, nutritional support could effectively preserve a host of organ systems in a patient in persistent vegetative state, but fail to restore a conscious and salient life (Scheiderman et al 1990:950).*

In keeping with a qualitative notion of futility the same authors propose that any treatment that merely preserves permanent unconsciousness or that fails to end total dependence on intensive medical care should be regarded as nonbeneficial and, therefore, futile. Also, if survival requires the patient's entire preoccupation with intensive medical treatment, such as total parenteral nutrition, to the extent that he or she cannot achieve any other life goals, the treatment is effective but not beneficial, and according to Schneiderman *et al* (1990) need not be offered to the patient, and the patient's family has no right to demand it.



Regarding PN, Morse (1991) suggests that the ethics of offering this form of nutritional therapy when treating a terminally ill patient has some parallels with the debate over cardiopulmonary resuscitation (CPR) in terminally ill patients. Dickens (1990) argues that care which appears unlikely to be of assistance may be offered, such as life support for a terminally ill patient, but it may legitimately be withheld if it is considered futile. Brown and Chekryn (in De Ridder and Gastmans 1996) claim, via respect for the dying person and dignified process of death, that PN or EN must be progressively reduced when the patient has been determined to have reached the terminal stage or an irreversible decaying process.

The concept of futility according to Singer and Siegler (1991) and Stanley (1989) should however, be applied cautiously, since a possibly helpful medical therapy such as artificial nutrition may not be offered and might even be withheld if it is not beneficial. The way in which a clinician defines futility, therefore, is important, and is of paramount importance to this research.

### **Achieving Life Goals**

Specifically excluded from the above notions of futility is the medical care that offers the opportunity to achieve life goals, however limited. Thus, patients whose illnesses are severe enough to require frequent hospitalisation, patients confined to nursing homes, or patients with severe physical or mental handicaps are not, in themselves, recipients of futile treatments. Scheiderman *et al* (1990) argue that such patients have the right to receive or reject any medical treatment according to their own perceptions of benefits compared with burdens. The notion of achieving life goals appears in the literature under the subject of 'achieving life goals' yet appears infrequently. Scheiderman *et al* (1990) clearly define this notion by explaining that physicians are required only to provide medical benefits to patients, yet are permitted to offer other non-medical benefits. For example, a physician is not obligated to keep a patient alive in an irreversible vegetative state, because doing so does not medically benefit the patient, yet may do so on compassionate grounds, when continuance of biologic life achieved goals for the patient or family. The same authors provide another example:

*An exception could well be made out of compassion for the patient with terminal metastatic cancer who requires resuscitation in the event of cardiac arrest to survive long enough to see a son or daughter who has not yet arrived from afar to pay last respects (Schneiderman 1990:953).*

Bozzetti (1989) agrees that at least for a limited time, artificial nutritional support can prevent further nutritional deterioration in cancer patients. Since most cancer patients die from causes other than cachexia alone, nutritional support could have an impact that is limited with time. Fawcett (1993) similarly explains that prolonging artificial nutritional support has been used to enable patients with terminal acquired immune deficiency syndrome (AIDS), to go home for the short period of time left before they die. In such instances, PN gave patients the strength to finalise any legal and personal matters that needed to be dealt with before they died. In such cases, Fawcett claims that quality and not quantity of life is paramount (1993). No other descriptions or discussions of the concept of achieving life goals was located in the literature, and poses as a significant gap in knowledge which is addressed later in the interpretation chapters of this thesis under the heading of 'Buying Time'.

### **Symbolic Treatment**

The use of artificial nutritional support carries an assortment of ethical implications. Many theories defend the use of artificial nutritional support on ethical rather than on scientific grounds (Seedhouse 1990). One of these theories regards artificial nutritional support as a symbolic message to a person, especially one who is 'vulnerable' (explained by Cox (1998:8) and Kayser-Jones (1990:399) as being the elderly, patients who are mentally impaired, comatose or terminally ill). It holds that withholding such support hastens the person's death, resulting in loss of integrity for the health service and the destruction of a symbol of human interdependence and caring (Wurzbach 1990). It is within this paradigm that others argue for the provision of artificial nutritional support for all vulnerable populations.

The most compelling argument in favour of providing artificial nutritional support is that this action is a symbolic expression of caring and compassion. The symbolism of food

cannot be ignored, and the meaning of feeding must be explored with each patient and family. However, the provision of enteral and parenteral nutritional support is qualitatively different from the provision of food and water by mouth (American Nurses Association 1992). Ahronheim and Gasner (1990) argue that medical procedures for supplying nutrients should not be invested with social, religious, or symbolic meanings normally associated with food or with the acts of eating or feeding. Holt (1991) asserts that it is virtually impossible for us to consider artificial feeding devices with the same emotional detachment as a respirator or a dialysis machine claiming that nourishment is not a simple action, rather a transaction consisting of reciprocal actions - the offering and taking of food. Miles (1987) claims that though physicians may prescribe artificial nutritional support as a medical therapy, families are much more likely to view it as eating and drinking, as a communal act that maintains solidarity and affirms dignity. Such distortions require further synthesis.

### **Distortions**

The use of artificial nutritional support, like other decisions facing the health care team, should have a sound justification. The decision of whether to start, to continue, or to stop PN/EN is justified by a common reasoning (Presidents Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research 1982). Hammes (1990) argues that good ethical decisions begin with pertinent data. This data includes not merely the information about diagnosis, prognosis, and treatment, but also psychological outlook, and personal values. Yet information is not always straightforward. What we refer to as 'facts' are shaped by our culture and concepts. In the case of PN specifically, some of these 'facts' are easily misunderstood or distorted (Caspar 1988) when PN is called food. Another distortion may ensue when the use of PN is justified by virtue of the symbolism of feeding and eating. There is little doubt that food and drink are significant symbols that evoke important emotions in humans. As discussed earlier in this review, from the earliest care of infants to our family and religious rituals, food and drink play a central role in the meaning of our social behaviour. As Hammes (1988:402) explains, 'when we share or give food and drink, we nurture, we deepen relationships, we celebrate, and we commemorate'. There is a problem,

however, when these meanings are applied to a new technology like PN. Like other medical treatments, PN is a form of caring for an ill individual, but it should not be employed to symbolise our values of nurturing in the same way as food is (*ibid.*).

There is little within the related literature to be found on this confusion of the social meanings of food and drink with the medical use of nutritional support. This confusion however, can seriously distort our actions, attitudes, and decisions. Hammes (1990) however, does make up for this deficit by exploring this confusion with veracity. He explores the problems of when family members might demand that a patient be 'fed' by artificial means (PN specifically), citing reasons of love, or as a symbol of nurturing. In this instance an appeal is made to a powerful symbol; yet the action, rather than conveying the meaning of love or nurturing, could impart a sense of disrespect, isolation, or a denial of death.

Hammes (1990) offers another distortion of when an appeal is made to the sanctity of human life. He argues that it is clear that the medical tradition views the individual life as a value in itself. This recognition, however, does not tell us that we must always provide nutritional support. If we were always required to provide it, we would end up disregarding human life by showing no respect for individual values or by making mere biological existence a central purpose of human life (*ibid.*).

A final distortion can arise when we are faced with charges like: 'You are starving the patient to death!' (Ahronheim and Gasner 1990:278). It is important that we recognise that this verb, 'to starve', has several meanings. These include (firstly) to be malnourished; (secondly) to experience hunger; (thirdly) to kill or be killed by withholding food. Plainly, all three meanings apply to some individuals who go without food. In contrast, many ill or injured individuals may become malnourished and dehydrated and even die, but as Cox (1987), Billings (1985) and Schmitz and O'Brien (1986) remind us, they may neither experience discomfort, nor have they been 'killed'. Hammes (1990) maintains that the arguments and descriptions that use the concept of 'starvation' are

often effective because of the multiple meanings of the word. We, therefore, must look carefully at our use of this concept and perhaps be careful in our choice of wording. Holt (1991) clarifies the distortion of symbolic eating and medical feeding simply by explaining that artificial feeding devices require the supervision of highly trained personnel, are bodily invasive and contain inherent risks and side effects. Also, such devices are more akin to other mechanical supports than they are to a sip of cold water or a spoon of broth. When seen this way, nutrition by such means, like other life-sustaining treatment, is not ethically mandated to be universally warranted for every patient. Holt (1991) further explains that as treatment modalities, they are subject to indications and counter-indications and must be continually evaluated regarding their proportionate value to accepted therapeutic goals.

Getting the facts straight, an important beginning for ethically justified decisions, must include a clear understanding of what PN and EN are, and what they are not. Hammes (1990) argues that the appeals to ordinary care, to the meanings of food and drink, to the sanctity of life, and to the horrors of starvation often confuse the facts rather than clarify them. These distortions must be eliminated without either destroying important, traditional values and meaning or investing PN and EN with value and meaning that they should not have. Although exploration of such distortions is not provided by the literature, and such a deficiency is addressed in the empirical body of this thesis.

### **The Sloganism of Starvation**

The debate about the withdrawal of life-sustaining treatments has acquired a discourse of its own. The use of the word 'starvation' is especially provocative when it is applied to the clinical consequences of withholding or withdrawing artificial nutritional support from patients with terminal illnesses or profound neurological impairment. The picture it conjures up is a powerful one, associated with wasting, cracked and ulcerated skin, impaired wound healing, infection, ascites, and a '...listlessness of protracted protein-calorie malnutrition in the third world so vividly portrayed on television' (Ahronheim and Gasner 1990:278). Likewise, as Holt (1991) explains, television pictures of bread and soup lines, refugee camps, famine victims with gaunt marasmic bodies evoke powerful

emotions. These negative symbols remind us of the proportionate discomfort we have all experienced at relatively low levels of hunger and thirst. Based on those brief transitory states, we can easily conjure up images of unremitting agony caused by severe malnutrition and dehydration. Rightly so, such images are disturbing to the well-fed population in the developed western world, yet according to the above authors, they are irrelevant to discussions of feeding patients who are hopelessly ill (Ahronheim and Gasner 1990). In all such images however, we need to keep in mind that we are not talking about food or water, rather suspended flasks, polyurethane, silicone and plastic tubes inserted into noses, stomachs, small intestines, and veins of patients who often are unconscious or semiconscious, confused and/or noncommunicative.

Holt (1991:10) who writes from the perspective of hospital based pastoral care reminds us that we cannot and should not dismiss the symbolism of eating and drinking which vividly reminds us that as humans 'we are not only embodied, but embedded in a network of caring relationships'. He does, however, go on to explain that despite this, we cannot use this symbolism to mandate the provision of artificial nutritional support for every patient. Hence, the question arises as to whether or not such feeding procedures and treatment modalities are common standards of care? If we believe that they are rudimentary standards of care along with hygiene, safety and comfort, then the debate ends here. The conflicting assumptions within the literature however, do not dismiss the debate so easily.

It is probably useful to briefly explain the consequences of withdrawal of artificial nutrition in these vulnerable patient populations. The patient with PVS or comatose is without cognitive function and according to Cranford (1984), incapable of experiencing pain and suffering. Patients with end-stage dementia are neurologically not far from this state (Cranford 1984; American Medical Association Council on Scientific Affairs and Council on Ethical and Judicial Affairs 1989), but find themselves in a devastating, terminal state that has long been recognised as common to a variety of severe neurological impairments (Walshe and Leonard 1985). Ahronheim and Gasner (1990) argue that when such patients do not quite satisfy the criteria of PVS, they are not technically

unconscious. Nor, however, are they alert as is often asserted in court arguments (Rhoden 1988). Deprivation of hydration promptly results in further depression of consciousness and then coma (Rowe 1985). The experience of observers is that this process is not painful (Billings 1985; Printz 1988; Schmitz and O'Brien 1986). Also, there is some evidence for impaired thirst in the setting of advanced age or neurological impairment (Billings 1985; Miller *et al* 1982; Phillips *et al* 1984), and for endogenous production of substances producing natural analgesia (Printz 1988; Schmitz *et al* 1986; Miller *et al* 1982; Phillips *et al* 1984). It is this endogenous production of natural analgesia which is thwarted in the instigation of providing artificial nutrition and hydration (Printz 1992; Billings 1985).

### **The Decision-Making Process**

One of the ethical issues relating to artificial nutritional support within the literature arises in the process of deciding whether to prescribe PN or EN for a patient. Ethical concerns in the decision-making process encompass identifying and integrating relevant human values, identifying the decision makers, implementing the decision to use either/or EN and PN, and in some cases, deciding to withdraw the same. The capacity of the patient to make decisions with regards to artificial nutritional support can be problematic when the health status of the patient is seriously impaired by poor nutrition or debilitating disease.

Once the decision to use artificial nutritional support has been made, ethical issues arise in the interpretation of the benefits and costs of the therapy. Pain, suffering, cost, hardships imposed on loved ones, and the undermining of purposefulness have been cited as factors in the assessment of benefits and costs of therapy (Jonsen 1979; Hastings Center 1987). One ethicist points out that a patient survives on home PN, not merely by organic function, but by having control over the essential activities of life (Jonsen 1979). Having primary control of the technology and supporting activities restores purposefulness to the patient, thus may enhance the quality of the patient's life and increase the benefits from the technology. Consequently, there are important ethical considerations in the manner in which PN for instance, is initiated and administered to

the patient, especially in home treatment and long term care. If a time-limited trial of EN and/or PN is not beneficial to the patient, or if the costs of continuing treatment are too high, withdrawal of artificial nutritional support may be considered. Little appears to be known about the circumstances that influence this decision by individual patients and health professionals.

One of the most significant predicaments of the decision-making process involves the meaning of starvation and the symbolic and psychological significance of feeding to patients, family members, and caregivers. Some clinicians claim that seriously debilitated patients seldom experience the symptoms of dehydration beyond a dry mouth and slight thirst (Billings 1985). Therefore, in their view, maintaining fluids and nourishment is not morally required in patient care. Other clinicians and ethicists argue for continued feeding for symbolic significance, for legal reasons, or for reasons of compassion or professional conscience (Callahan 1983; Meyers 1985; Seigler and Weisbard 1985). Others consider nutrition as one form of treatment that may be initiated or withdrawn under the same conditions as any other medical treatment (Dresser and Boisaubin 1985; Micetch *et al* 1983; Wanzer *et al* 1984; Wanzer 1989). Theoretical considerations of withdrawing treatment in the form of artificial nutrition have not been studied adequately and deserve further investigation.

Although numerous ethical issues have been identified with the use of artificial nutritional support, the most compelling issues include equitable access to the technology; potential injustices toward other members of society because of the cost of the technology; quality-of-life issues, including prolongation of life; and decision-making of the use of artificial nutritional support. Adequate ethical assessment of any technology relies partly, on empirical studies in the field, the sophistication of the ethical literature, and the careful delineation of the conceptual and methodological issues associated with a particular technology's employment. To the extent that these aspects can be addressed in the use of enteral and parenteral feeding, there is reason to believe that an adequate ethical assessment can be made, but such an assessment is not yet available, hence this research project.



The decision-making process nevertheless, does appear to be reflected in the many guidelines on nutritional support in the non-critical/perioperative environment. In reviewing these guidelines concerning artificial nutritional support (American Academy of Neurology 1989; American Dietetic Association 1987; American Medical Association Council on Ethical and Judicial Affairs 1989; American Nurses Association 1988; American Society of Enteral and Parenteral Nutrition 1986) three points seem to be central. The ethical guidelines concerning artificial nutrition and its withholding or refusal can be summarised as follows:

1. There is a strong presumption to provide food and water.
2. Agreement that nutrition may be forgone when (a) it is biologically ineffective in prolonging life, enhancing recovery, or providing comfort; or (b) it will cause more physical harm than good; e.g. shorten life or prolong the suffering of a dying patient.
3. There is consensus that nutrition may be forgone when the patient's values and wishes are reliably known and consider nutritional support to be either of no benefit or of excessive burden.

Generally speaking, from the associated literature, this analysis is relatively simple. Difficulties occur however when the scientific research has conflicting or no information about the benefits or burdens of a particular use of a treatment. Also, the particular facts of a case (e.g. diagnosis, patient wishes) are difficult to interpret, plus, the physician's obligations to the patient may seem to conflict with social responsibilities. Such ethical guidelines therefore do appear to have their limitations.

### **Justice: Resources, Access and Economic Considerations**

The other issue of relevance is that of justice, which according to Fainsinger *et al* (1992) define what patients are legitimately entitled to and what they may claim. The question of whether cost should be a factor in clinical ethical decision-making is intensifying as resources become more scarce. No articles were found dealing with justice issues pertaining to the provision of artificial nutritional support generally, apart from broad reviews of the concept of justice in the terminally ill. Parenteral nutritional support

specifically, however, attracted more literary attention - of cost analysis that is. According to Goel (1990) and Bruera and MacDonald (1988) PN is generally regarded as a costly medical intervention. Substantial costs can be attributed to the solutions, the equipment needed to deliver them, and the human resources involved in the preparation of the materials by pharmacists and in the selection and monitoring by physicians and nurses. Additional costs are generated by many other services required, for example maintenance of durable medical equipment, pathology monitoring, and medical consumables. Because PN is not an inexpensive modality, this is a factor that has to be considered, although as Latimer (1991) warns, life-prolonging care should not be denied, cut short, or grudgingly continued on the basis of policy, protocol, or generalisations about age and diagnosis. Callahan (1983) warns that the denial of nutritional support may in the long run become the only effective way to ensure that a large number of biologically tenacious patients actually die. This is a legitimate concern which is shared by Knox (1989) and Sanstead (1990).

Ofman and Koretz (1997) review the economics of nutritional support and conclude that it currently accounts for approximately one percent of the total health care costs in the USA. They concluded that preoperative PN may produce a small absolute reduction in post-operative morbidity, but its cost becomes prohibitive. Similarly, Eisenberg *et al* (1993), in an economic analysis of perioperative PN concluded that on the basis of the hospital-based method of administering PN that was used in the clinical trial (Department of Veterans Affairs Study 1991), perioperative PN did not result in decreased costs for any subgroup of patients. Preoperative EN on the contrary, especially if carried out in the home, may be of benefit and therefore is an economically defensible intervention (*ibid.*). However these authors maintain that nutritional support generally, is one area of medicine in which there has been far more enthusiasm than the data justify:

*Disease-associated malnutrition probably is a secondary phenomenon, not an important cause of morbidity. The widespread use of this modality cannot be justified in a cost-constrained health care system (Ofman and Koretz 1997:453).*

May (cited in Schiller and O'Sullivan-Maillet 1999) mentions several types of ethical issues facing dietitians that have fiscal implications, those being nutritional support for the terminally ill; use of costly specialised nutritional support for the uninsured; early discharge of patients who need specialised nutritional support; and reductions in quality care due to staff shortages and budget cuts. Veatch (1988:34-35) writes in detail regarding the justice and economics of terminal illness and the concept of 'useless versus marginally beneficial care', yet does not explore the specifics of particular treatment(s). This represents a significant deficit within the associated literature that warrants in-depth analysis. In fact, the entire withdrawal and withholding debate(s) does not explore the justice/economic issues within any notable 'ethical' context. This is representative of the extent of controversy associated with the issue of cost and justice and nutritional support. Another possible difficulty associated with general discussion regarding this issue is the enormous differences in health economics and prospective payment systems versus reimbursement between the USA and the rest of the world.

The concept of justice and nutrition is however, discussed specifically by Macfie (1997) albeit briefly. He maintains that some would argue that the availability of resources should not be considered as part of the ethical debate over the instigation or cessation of any given medical therapy, citing Levinsky (1977). Macfie claims that this must be wrong, as justice, which is the fair and equitable provision of resources to all, is vital to any ethical debate (1997). With regards to artificial nutritional support it is noteworthy that recent guidelines on parenteral and enteral nutritional support, published by the American Society of Parenteral and Enteral Nutrition (ASPEN) in 1996 stated that 'health care providers should not make unilateral decisions to provide, withhold or withdraw nutritional support on the basis of limiting costs or of rationing scarce resources for the benefit of society unless required by law' (ASPEN 1996: [www.clinnutr.org](http://www.clinnutr.org)).

Once again, Macfie stands out as being the exclusive contributor of a particular ethical issue (being justice) regarding artificial feeding. In his article published in the *Wien Klinische Wochenschrift* (1997), Macfie discloses this somewhat controversial notion of cost-containment:

*Whilst it is an attractive proposition that doctors should be able to work in the best interests of their patients, paying scant regard to resource implications, in reality this is a naïve and unacceptable abrogation of a doctor's responsibilities... The moral question is no longer whether to participate in cost-containment but how to do so in a morally creditable way. Although economic constraints may force physicians to weigh more carefully the cost of each benefit they do not require that the physician appraises the value of the patient himself or weigh his benefit to society (Macfie 1997:853).*

Macfie maintains that the application of the ethical principle of justice as this applies to the treatment of malnutrition or the provision of artificial nutritional support necessitates that physicians carefully appraise these treatments for each and every individual (1996). He offers simple explanations of how physicians can help control costs by choosing the most economic way of delivering optimal care:

*Why use parenteral nutrition if enteral nutrition will do? Why use percutaneous endoscopic gastrostomy<sup>6</sup> if short-term enteral nutrition or sip feeding will suffice? Further doctors should be obligated to take on board those aspects of research, which have clearly shown to reduce costs (Macfie 1997: 853).*

Evidence exists to show that the use of a nutrition team provides substantial savings in the costs of artificial nutritional support (Elia 1993). Despite this, only 30% of hospitals in the United Kingdom where this evidence was generated had a properly established nutrition support team in 1995 (Payne-James *et al* 1995).

When life-sustaining technologies are expensive, the issue of equitable access to them is a concern. The End Stage Renal Disease (ESRD) program of Medicare in the USA is a good example of how concern for access resulted in federal funding to make costly technology available and accessible to citizens in an equitable fashion (Caplan 1981), yet federal funding alone does not eliminate potential injustice in the distribution of a technology. If technologies are expensive, continued injustices occur in three ways: needy patients will not be served because the technology is not easily available to them;

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<sup>6</sup> Percutaneous Endoscopic Gastrostomy, commonly abbreviated and referred to as a PEG and/or G-Tube (Gastrostomy Tube).

patients, even though they are able to pay or may qualify for public assistance, will do so at a prohibitive cost in the form of burdens to themselves and the family (Fry 1990); and patients who might benefit from the technology will not fit the therapeutic criteria and therefore will not be eligible to receive it (Jonsen 1979). The issue of potential injustices because of the high price of a technology has been well addressed in the ethical literature (Churchill 1987; Daniels 1985; President's Commission on the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research 1983; Veatch 1986), yet the potential injustices in artificial nutritional support use among certain individuals are not well defined, possibly because it is still considered an emerging technology. Continued analysis and evaluation are therefore needed on the impact of cost and equitable access to this form of medical therapy.

### **Quality-of-Life Issues**

Quality-of-life is a concept that 'focused on the good of the individual what kind of life is possible given the person's condition, and whether that condition will allow the individual to have a life that he or she views as worth living' (Hastings Center in Fry 1990:330). It is a subjective evaluation of individual worth made by the individual himself or herself and not by anyone else. Goodhall (1997) claims that the term 'quality-of-life' is frequently used by health care professionals, but it is a complex concept that lacks a common definition, resulting in inconsistencies in its interpretation. Whereas the term supports the notion that a worthwhile life can be a life with the most serious illness or an extremely disabling condition, it also suggests that an assessment of life can differ from one person to the next and defies a singular description or claim to universal experience (Fry 1990).

Monzon (1998) claims that if quality-of-life is defined as being the social, physiological, mental, spiritual, intellectual, and general well-being of people, we realise that there is no known health care system that is able to guarantee that well-being in all its possible aspects. A decision to limit nutritional therapy raises difficult questions about the value of life (Singer cited in Watts and Cassel 1984). Where such questions arise, the conditions of living have generally reached extreme debility or misery. Standards of human life such as intelligence (Fletcher 1982), or potential for interaction (McCormick 1974) have

been applied to justify the decision to allow death without heroic medical interventions. Such standards reflect the subjective values of each particular author.

Questions of quality-of-life for patients present an ethical challenge to health professionals, who often are tempted to make decisions that they believe enhance the patient's quality-of-life and who, in any event, judge the patient's quality-of-life by their own standards. A health care professional can scarcely avoid making quality-of-life judgements to some extent if the goal of health care is the good of the patients. The mere determination of good - even the desire to create good - encompasses a subjective evaluation of a particular quality-of-life. However, this is not necessarily an ethical problem unless the decisions are made without consulting the patient. In the case of artificial nutritional support, the technology may enable an individual to maintain and prolong life, even though this life is not considered worth living by the individual. Fry (1990) explains that the decision to implement artificial nutritional support needs to be as free as possible of quality-of-life judgements on the behalf of the care provider.

The issue of quality-of-life has periodically been addressed by the courts (Boisaubin 1993) and appears throughout the literature in terms of those patients deemed either terminally ill or in PVS. This concept of quality-of-life, is fraught with problems because of the subjectivity and human variability involved in its determination, as Boisaubin (1993) explains:

*For example, many people while healthy, when questioned, would reject the prospect of continued life with a profound disability such as quadriplegia. On the other hand, the majority living with this condition desire to go on living rather than request death (Boisaubin 1993:136).*

The extent to which quality-of-life judgements enter into health care decisions and patients' choices of treatment is hard to determine accurately. This topic is of primary concern in the use of artificial nutritional support for patients who are terminally ill, permanently unconscious, cognitively impaired (Norberg and Hirschfield 1987), elderly (Norberg *et al* 1980), or who are receiving long-term support at home (Detsky *et al* 1987;

Herfindal *et al* 1989). One study reported decreased quality-of-life assessments by patients on PN (Herfindal *et al* 1989) whereas another suggested increased levels of patient-reported quality-of-life while receiving PN in comparison with alternative approaches (Detsky *et al* 1987). However, the designs of these studies and the difficulties in developing quality-of-life measures indicate the need for more extensive study of the technology before conclusive statements are made about quality-of-life factors in the decision to use artificial nutritional support.

The limitations and compromise in quality-of-life that unwarranted artificial nutritional support and access for the same imposes on patients, especially if they are restrained to prevent removing the devices, are unacceptable according to Scofield (1991). Tube feeding regimens in the elderly specifically, increase the patient's isolation from family, friends and residents (for example in a nursing home environment), and can lead to psychosocial deterioration and withdrawal. Medically unwarranted artificial feeding makes it more difficult for patients to regain lost function, assuming they are ever offered this chance (*ibid.*).

### **A Natural Death is a Peaceful Death**

Whilst considering the previously mentioned sloganism of starvation and revisiting some of the established palliative medicine arguments, it is important to consider the notion of a natural death when discussing withdrawal (of nutrition and hydration) issues at the end of life. According to Ahronheim and Gasner, since time began, until very recently, 'people who grew too old, too disabled, too weak, or too sick to eat and drink died without a feeding tube in place (1990:279). Although superimposed medical illness in such people can now frequently be cured, it is logical to assume that rejection of food is a physiological component of the illness and the active process of dying. Oral intake is volitional, and subject to rejection in the presence of anorexia of whatever origin. Artificial nutritional support, on the contrary, is provided in amounts calculated to satisfy nutritional requirements. The body cannot block its entry but can only reject it by malabsorption and regurgitation which are well-known complications of tube feeding (Bastow 1986; Campbell-Taylor and Fischer 1987).

For those who cannot accept a negative answer to the question 'is withdrawal of artificial nutritional support painful?' we must pose the question differently, and ask 'do the benefits of artificial feeding in hopelessly ill patients outweigh the burdens?' This question, and similar questions with regard to the provision of artificial nutritional support in hopelessly ill patients has been explored in detail by ethicists, health professionals and lawyers (Carson 1986; Derr 1986; Lo and Dornbrand 1984; Siegler and Wiesbard 1985).

Artificial nutritional support itself may cause pain. Central venous catheterisation necessary for parenteral feeding, even with the administration of local anaesthesia is still a surgical procedure that is uncomfortable and for some patients, painful. Howard (1990) argues that PN, for example, is not an innocuous treatment, with complications relating to catheter placement, infection, metabolic abnormalities, hepatic abnormalities, and other complications stemming from long term treatment. This is also supported by Maki (1992) and Lipman (1998). Enteral feeding itself may produce pain. Erosions or haemorrhage of the nasal septum, oesophagus, and gastric mucosa have been reported (Bastow 1986; Campbell-Taylor and Fisher 1987; Ciocon *et al* 1988), and nasogastric feeding as well as gastrostomy feeding has been associated with aspiration pneumonia (Campbell-Taylor and Fisher 1987; Ciocon *et al* 1988; Metheny *et al* 1986). According to Ahronheim and Gasner (1990:279) the provision of artificial nutrition may become an act of forced feeding, resisted through the 'primitive mode of expression that remains - struggling to pull the tube out'. The image of physical restraint is one that follows a patient struggling to pull out their own feeding tube. The same authors confront us with the thought-provoking concept of a patient who is tied down to a bed, intubated with enteral feeding devices. It is this image of physical restraint and forced feeding which, in a patient who is immobile and travelling a downhill journey, is just as disturbing as that of 'starvation'. Jett (1995) encourages us to similarly confront this issue of unnecessary suffering associated with burdensome feeding. She explains that pointless suffering may in fact be alleviated by a thoughtful look at our assumptions and biases about proper medical care during the terminal phase of life - and acting to change care that does not contribute to a peaceful death. This essentially introduces us to discussions on the



recognition of appropriate end-of-life care, which is especially relevant when withholding and withdrawing treatments are discussed within the context of critical care.

### **Withholding and Withdrawing Issues in the Critically Ill**

A decision to withdraw life support, according to the overwhelming bulk of the literature, is best made by patients themselves, and the right of competent adults (or their proxies) to make such decisions is well established. The manner by which critically ill patients should die, however, is usually entrusted to physicians. Christakis and Asch (1993) claim that since most physicians are uncomfortable with euthanasia, such patients are usually allowed to die by physicians tempering efforts to prolong life and withholding or withdrawing life-sustaining therapy. Little has also been written within the critical care nursing literature that specifically deals with ethics and artificial nutritional support. Daly (1990) utilised the exploration of narrative to determine critical care nurses' understandings of withdrawing and withholding nutrition. The outcome of this qualitative study was that the general consensus of critical care nurses maintained that there is no absolute obligation to provide artificial nutrition in all cases. However, once again there was not clear delineation between artificial nutritional support and other critical care modalities as the participants gave conflicting views on whether it was extraordinary medical care or ordinary comfort care.

### **Malnutrition, Ethics and Artificial Nutritional Support**

What of artificial nutritional support under other circumstances – the perioperative patient, the cancer patient and the chronically ill? As previously mentioned there is a wealth of literature available on the potential benefits of artificial nutritional support using different means and in a wide variety of patient groups. Some have shown obvious benefit, others have produced ambiguous results, and in some groups, such as parenteral feeding in perioperative patients without severe malnutrition, positive harm. It is not surprising, therefore, that a consensus regarding the value of artificial nutritional support does not exist and that many clinicians remain confused. One problem assessing the benefit as opposed to the burden of nutritional support in these types of

studies is that they do not separate the benefits of treating the underlying illness from the consequences of mitigating the effects of starvation.

Death from protein-energy malnutrition occurs within 60-70 days of total starvation in normal adults. Functional metabolic deficits occur after some 10-15 days of semi-starvation in previously healthy adults and after shorter periods in those already compromised by disease (Meguid *et al* 1988). The consequences of starvation are well known and, apart from weight loss, include impairment of the immune response, alterations in organ function, malaise, lethargy, and changes in cognitive function (Elia 1993). Against this background of information on the causes and consequences of malnutrition, it is a relatively elementary matter to make recommendations for treatment. For instance, in 1993, ASPEN published guidelines for the use of parenteral and enteral nutritional support and recommended that a maximum period of seven days of a severely limited nutrient intake is the empirical absolute most investigators set for hospitalised patients (ASPEN 1993). Macfie (1995) maintains that most would add that a weight loss of 10-15% recalled pre-illness weight was also an indication for nutritional support. In spite of this wealth of data indicating the deleterious effects of malnutrition and worthy evidence demonstrating that we can reverse this, Macfie (1995) specifically maintains that nutritional therapy is underused.

Why then is starvation not treated and is it unethical not to do so? Macfie (1995) gives three primary reasons for this: first, inadequate education of health care professionals; second, inadequate education of the general public; and third, resource implications. The fact that many health care professionals still do not recognise the significance of malnutrition is a reflection on medical and postgraduate education (*ibid.*). Until recently most patients have remained ignorant of developments in medical technology that ensures that starvation need not occur. Finally, as we are all aware during these days of financial restraint, health service managers exert an ever-increasing influence on medical treatment in an attempt to contain costs. It is Macfie's view that the influence of ethical debate will radically change our practice with regard to the provision of artificial nutritional support. He states:

*We should not and cannot underestimate the influence of patient demand in our clinical practice. With regard to ethics it is axiomatic that the rights of the patient must be upheld and as there is an increasing awareness as to the consequences of starvation then an increasing number of patients will seek from their medical attendants reassurance that this will be avoided in their case (Macfie 1995:215).*

With regard to resource implications, Macfie (1995) recognises that these are colossal particularly if all patients with a 10-15% weight loss or with seven days inadequate oral intake are to receive nutritional support. He concedes that this will inevitably lead to some conflicts within the professions and with management. Nonetheless, from the ethical standpoint, there is no precedent that resources should be seen as a reason not to treat (*ibid.*) This is succinctly summarised in the guidelines for parenteral and enteral nutritional support published by ASPEN in 1999. To quote, 'Health care providers should not make unilateral decisions to provide, withhold or withdraw nutrition support on the basis of limiting costs or rationing scarce resources for the benefit of society unless required by the law. No such laws exist at this time' (ASPEN 1999:[www.clinnutri.org](http://www.clinnutri.org)). Macfie (1995) responds to this by suggesting that the inability of clinicians to provide nutritional support either because of personal beliefs or institutional policy will necessitate the clinician making reasonable efforts to arrange for the timely transfer of the patient's care to a practitioner or facility willing to implement appropriate treatment.

The application of the ethical principle of justice as this applies to the treatment of malnutrition or the provision of artificial nutritional support necessitates that physicians carefully appraise these treatments for each and every individual. The question arises therefore of whether or not physicians can help contain costs by choosing the most economic way of delivering optimal care, for example, why use PN if EN will do?

### **Multidisciplinary Interpretations**

Only one article was identified that offered a multidisciplinary interpretation of issues in nutritional support. Srp *et al* (1989) provide a psychosocial interpretation of nutrition support related issues with a clear emphasis on the long-term home PN patient. Perspectives of long term home PN are given by the physician, dietitian, liaison

psychiatrist, social worker, nutrition support nurse, pharmacist, and patient. Interestingly, the least amount of emphasis in this article is placed on the patient. As this was the only article retrieved from an exhaustive literature search across all health care professions, there is a demonstrable deficit in multidisciplinary interpretations of artificial nutritional support. This article did not reflect on any ethical issues *per se*. Consequently, this deficiency justifies a multidisciplinary inquiry, such as the nature of this project.

Another lone author distinctly describes a short fall in interdisciplinary decision-making, suggesting that families confronted with difficult choices will turn to the physician for guidance. Sanstead (1990) suggests that those people, be they family members, caregivers, physicians, who do not have essential experience and insights for decision-making related to the withdrawal/withholding issues surrounding artificial nutritional support, obtain counsel and guidance from clergy and other scholars of ethics and morality. He stipulates that the use of such expertise can help in planning management. This concept brings us back to the clinical versus ethical argument of what is deemed appropriate. Sanstead (1990) possibly introduces another variable to this dichotomy, that is, what is economically appropriate. Sanstead frames an issue which, despite being extremely controversial and ripe for contemporary debate, is not reflected in the rest of the associated literature. He expresses concern that withholding or withdrawing artificial nutritional support measures could be abused by those who are more concerned with the economics of health care than with the patient care. Through vigilance, Sanstead claims that physicians and other health care providers must prevent economic considerations from influencing decisions that determine care:

*Appeals to society regarding the cost of health care by planners and budget-conscious officials must be countered by emphasising the humanitarian dimensions of medicine and by making society at large aware of the sometimes inhumane outcomes that occur when the welfare of patients becomes secondary (Sanstead 1990:768).*

Gillon (1994) warns that there is no obvious reason however, that doctors and medical teams are always right regarding the provision or non-provision of artificial nutritional

support - if indeed there is a right answer. Again, this shortfall in multidisciplinary interpretation and collaboration regarding difficult decision-making as suggested by the above author does well to justify further inquiry of a multidisciplinary nature.

Liaschenko and Davis (1991:271) discuss the similarities and differences between the practices of medicine and nursing where nutritional support is concerned. Their analysis of the medical and nursing literature indicates that the 'practices of both professions share a similar tension'. No specific information however, is provided regarding the distinct ethical issues as they pertain to the provision of artificial nutritional support. One area however, that is explored by these authors that warrants mention here is that a formal and rational approach to ethics is inadequate to the demands of medicine and nursing. Carson (cited in Liaschenko and Davis 1991) claims that an overemphasis on obligation, or what he calls the morality system is only part of our ethical lives. Similarly, Williams (cited in Liaschenko and Davis 1991) suggests that thick descriptions of our ethical language as it is used in practice may be a much more fruitful approach. This leads to the question of how we might best explore the ethical issues of artificial nutritional support, from a multidisciplinary perspective, without being hindered by such formal and rational approaches to ethics. Such a multidisciplinary approach to ethics research is therefore warranted.

## **Conclusion**

The ethical issues and questions that surround the various issues of artificial nutritional support are obviously multifaceted. Professional viewpoints may vary, and include diverse philosophical, religious, cultural, and political perspectives. The implications of recognising artificial nutritional support as a medical therapy and thus assessing its appropriate provision on the basis of accepted ethical principles are far reaching. The application of ethical principles in the use of artificial nutritional support is likely to have a significant impact on the clinical practice particularly in Western society where the morality of different treatment strategies are increasingly being subjected to public scrutiny. Application of the ethical themes discussed in this review do however give very different recommendations for the actual provision of artificial nutritional support, thereby

providing no consensus whatsoever. The duty-based moralist who would invariably feed the patient whatever the anticipated outcome (because to do otherwise would be murder) on the basis that this was the right and responsibility of the doctor. The goal-based or utilitarian doctor would feed the patient when appropriate in their health care setting and if the results of such intervention were merited on the basis of scientific evidence. The rights-based moralist would maintain that the patient should always be offered artificial nutritional support and if requested by the patient, then the moral responsibility must be to provide it. By the same token, if the patient or their surrogate(s) refuses artificial nutritional support then the patient's wishes must be respected. Evidently, there is conflict between these three themes as well as with the fundamental moral obligations of autonomy, beneficence, nonmaleficence and justice. These conflicts help to emphasise that ethics is a process of reasoning whereby a respectable and defensible position is sought, which protects the interests of the patient. We are perpetually reminded in the ethics literature that there are no absolutely satisfactory resolutions of ethical dilemmas and that the most one can hope to achieve is a balance between the conflicting interests and goals of different individuals involved in patient care. Thus, pursuing a multidisciplinary approach toward ethics and artificial nutritional support seems to be one way of reaching some kind of resolution, by way of accommodating those different individuals.

It must be recognised that there is no such thing as a single and absolute ethical rule that can be applied in every conceivable situation. The literature teaches us that almost every ethical dilemma will necessarily pose the problem of competing and conflicting ethical obligations. It is because of this that an alternative method of inquiry should be sought to accommodate the variables that the application of the ethical principles are unable to because they do not allow for the idiosyncratic realities of complex clinical situations in multitudinous health care settings. By way of employing a qualitative method of inquiry, it is hoped that the gaps identified within this review of the literature will be explored, examined and theorised. The theoretical and practical explanations of such a methodology are discussed in detail in the following chapter.

## **CHAPTER TWO**

### **METHODOLOGY**

#### **Introduction**

This inquiry will be of a qualitative nature thereby excluding the quantitative necessities of a control group, and statistical analysis. A methodology of narrative and knowledge development in bioethics has been chosen which will be referred to hereinafter as narrative ethics. This method is discussed in detail with a certain emphasis afforded to the art and method of qualitative interview studies, as well a synopsis of the computer software application utilised in the management and interpretation of the qualitative data in this project. Methodological considerations including the determinants of rigor and ethical considerations are also discussed.

#### **Narrative Ethics**

Drawing on such theorists as Lyotard (1984), who argues for narrative as an alternative mode of knowledge to science, and Bruner (1986) who demonstrates that narrative is a universal mode of cognition, narrative is currently enjoying unprecedented prestige as an avenue through which substantive meaning and working knowledge can be developed. Two central assumptions which underpin qualitative approaches are: That ideological positions are revealed which propose that reality can be apprehended by capturing the individual's point of view (subjectivity); and that qualitative researchers can directly represent this experience in language (linguistic representation). These assumptions suggest that subjectivity and language are not natural yet rather cultural, therefore providing such research with the possibility of challenging existing assumptions and power structures which shape the individual's experience of health and illness (Crowe 1998). In the case of this research project, the method of employing a narrative approach exposed certain challenges both personally and professionally to the researcher. The confronting and controversial ventures were also challenging to the existing structures, theories and literary perceptions that had so far shaped the researcher's experiences and assumptions of the ethical provision of artificial nutritional support.

Crowe (1998) maintains that the power of the word in both its written and spoken form is a primary determinant in how we experience ourselves and others within the world, and how we interpret those experiences. Roof (1993:304) considers narrative approaches to research as holding the potential to move researchers beyond 'methodological individualism' and 'attention to simply individual attributes', and to push them to look at cultural narratives more broadly:

*Peoples' stories are never just their stories. Stories connect us with larger stories, with cultural narratives that shape our shared meanings (Roof 1993:304).*

Personal narratives are ways of expressing experience, and as reality can only manifest itself in us as experience, narratives are fundamental to human existence (Steffen 1997). As Oliver Sacks claimed, 'I've never been very good at learning from texts or lectures. My only texts have been individuals, have been patients' (1993:127). Consequently, people are central to narrative research, yet peoples' experiences may seem insignificant to them as they think of them as simply part of living their lives. However, narrative has an interest in commonplace experiences and points of view. It encourages people to delve into these, and to realise that it is through their accounts that personal and practical knowledge may be generated for themselves and others (Roberts and Taylor 1998).

### **Theoretical Framework**

Medical ethics has been dominated by the four principles approach (autonomy, beneficence, non-maleficence, and justice), and by the application of these general normative principles to concrete cases (Beauchamp and Childress 2001) including those discussed in the preceding chapter. There is little doubt that this has provided us with some useful tools for analysis of situations, and a common language that names important issues. The four principles operate as an ethical grid, which structures the presentation of a case and guides the discussion. Its wide level of acceptance demonstrates its application and accessibility. The emphasis is on preferences, risks, and rational decision-making. Ethical reasoning is considered as following a calculus, which ideally results in one good solution. However, the limitations of principles are now



becoming apparent (Nicholas and Gillett 1997). Clouser and Gert (1990) also claim that there is unease amongst practitioners emerging from the realisation that the realities and practicalities of clinical practice are not paid sufficient attention. Criticism of the principle-based approach (or what Baker (1998) refers to as 'principlist'; and what Loewy and Loewy (2001) term 'principlism') is that the approach is abstract in that it originates from general principles, attempts to eliminate emotional issues, and aims at a universally valid conclusion. Tomlinson (1997) explains that the immediate criticism lodged against principlism is that ethical principles are too removed from, and insensitive to, the specifics of the very particular living cases to which they are applied. Widdershoven and Smits (1996) argue that ethical issues cannot be solved by an act of reason, and that they require involvement and intuition. This intuition can be sustained, according to Nussbaum (1986) by stories, or narrative. Nussbaum (1986) contends that people should read stories, and analyse narratives to learn about conflicts, and to become engaged in ethical practices. The limitations of the principle-based method of ethical analysis will be further demonstrated in the interpretation chapters in this thesis whereby surprising omissions and inclusions in the ethical discussions are highlighted and explored.

Narratives tell us more about ethics than any other philosophical treatise can, and show us the tragic character of life and make us aware of the subtle tensions within ethical practice (Chase 1996). Similarly, Benner (1991) tells us that ethics is in need of narrative about real people because narrative provides the room for doubt, anxiety, and hope as elements of human interactions. Tomlinson (1997) maintains that narrative places a part in moral and professional development. The reading and study of narratives has salutary effects on moral development through the enhancement of perceptiveness, sensitivity, sympathy, or other virtues. Narrative serves a pivotal function in the discovery, justification, or application of ethical knowledge - a role that fills the gaps inherent in any analytic-principle based method. It can expand our understandings of other people and perhaps ourselves so that our ethical judgements become more realistically informed. Tomlinson (1997) also claims that narrative may awaken ethical sensibilities so that we

are more sensitive to the wrongfulness of circumstances we had become hardened to. And so 'narrative ethics' is born.

The narrative turn in medical ethics is based on the conviction that we need stories to get to a more elaborate view on ethical issues in health care. Tomlinson (1997:123) asks 'what might stories provide for us besides the pleasure of reading them and telling them?' Could narratives deepen our understanding of ethical problems and choices? Widdershoven and Smits (1996) claim that general normative principles are too abstract and crude to come to grips with practical problems. Consequently, as a theoretical tenet shaping this research, the researcher wanted to understand the ethical issues in providing artificial nutritional support. The researcher therefore needed to start from the way in which participants gave meaning to the situation by sharing narratives that expressed concrete commitments, emotions, and doubts. As Widdershoven and Smits (1996:278) declare 'we can only hope to find adequate ways of dealing with ethical problems if we are prepared to listen to the stories of the people involved'. This approach to ethics recognises that our understanding is socially situated, that we develop our sense of what is right and appropriate, what is good or to be avoided, out of total life experiences - and not necessarily an abstract set of principles (Nicholas and Gillett 1997). This was the essential impetus for utilising a narrative approach to inquiry of an ethical nature.

Reference to narrative in regard to medical ethics characteristically occurs in relation to what has been described as 'narrative ethics' (Brody 1994:207). A substantial literature has been established on a magnitude of issues relating to narrative ethics including discussion of: the meaning(s) of the term itself (Newton 1995); its relationship with phenomenology (Ellos 1994); its relationship with Christian ethics (McClendon 1986); the relevance of post-modernist analysis (McKinney 1995); and, of course, its relationship with literature (Hudson-Jones 1996). There is therefore some resemblance between the essentially philosophical approach (narrative ethics); the fundamentally sociological one (life-story); and the lived experience (phenomenology). Throughout this thesis the primary reference is to those phenomenological underpinnings of the personal narrative

that fundamentally inform the methodology. It is imperative at this point to recognise the possible interpretation of this method as what has been referred to by Rose *et al* (1995:556) as 'method slurring'. Remaining true to a methodology ensures academic rigor in this respect, however as narrative ethics research (as a method) draws heavily from phenomenology, the application of phenomenological intent is highly appropriate. Polkinghorne (1988) points to the congruence between narrative analysis and phenomenological analysis. A narrative research approach thus meets the condition of congruity with the researcher's basic phenomenological research interests, and established skills.

Four elements of narrative ethics form the basis of the methodology employed in this study. First, the personal narrative rather than a re-identified framework is central to the analysis. Second, this narrative is central in the decision-making/dilemma-resolution process. Third, the approach is all about the achievement of an understanding of the meaning of the situation for those involved. And fourth, there is identification that it is only through knowledge of the personal, cultural and social context that the most befitting ethical resolution can be reached. As Hunter (1991) explains, narrative structures the conversation between health professionals and provides a major vehicle for the transmission of knowledge and information of the profession. It is this latter point that underpins the primary aim of the narrative process in this research project.

Hunsaker-Hawkins (1997) argues that physicians are mindful of the breach between ethical discourse and ethical practice whereby in reality, decisions are usually not made exclusively through a process of skilled deductive reasoning:

*Many other factors are also involved whenever we make important decisions about our own lives or the lives of others – and in this medical decisions are no different from any others. Furthermore, it would seem that this is the way we should make decisions. Moral choice is an act of the whole person: It should involve all our mental faculties – reason, intuition, emotion, imagination – working in concert. Epiphanic knowledge does, and should, coexist with the kind of knowledge that is arrived at through deductive reasoning (Hunsaker-Hawkins 1997).*

The role of individual life accounts has been recommended as important to the practice of bioethics for a number of years (Tovey 1998). Despite being a relatively contemporary concept in health research, narrative ethics represents a valuable method for researching ethical dilemmas and the settings in which these dilemmas are played out. Personal accounts need not simply provide an impetus to scientific research yet can in themselves yield intellectually robust evidence on the general as well as the particular. By drawing on the rigorous methods developed elsewhere in qualitative research (primarily phenomenology), personal accounts not only allow us to enter the world of the sick person, but allow us to do so in such a way as to contribute to empirical and theoretical knowledge. Tovey (1998) maintains that the integration of narrative ethics with rigorous methods formulated within sociology provides the capacity for narrative to be a valuable component of academic inquiry in what are frequently complex and sensitive areas. The area of artificial nutritional support is by no means an exception.

It is important to note that narrative ethics research does not replace other approaches to medical ethics. Principle-based ethics can provide some important tools of analysis, however a narrative ethic adds to the discussion of the ethics of health care. It creates an opportunity for critical reflection upon our theoretical frameworks and taken-for-granted assumptions that are grounded in our professional lives. As Nicholas and Gillett (1997:299) remind us, 'We are talking about actual lives, real people.' Narrative ethics reminds us of this and alerts us to how our institutional and professional practices are experienced by both health care provider and health care recipient.

The aim of utilising this approach, then, is not in itself to solve the ethical dilemmas surrounding artificial nutritional support, or to promote 'appropriate' values and consequent action. The approach is instead a means to expand knowledge about 'patient worlds' and 'provider worlds', in order to enter those worlds empirically and thereby contribute to a multidisciplinary and multifaceted approach to the complex issues of artificial feeding which is simultaneously incorporating qualitative data.

## Sample

An alternative approach, often found in qualitative research and often misunderstood in medical circles (May and Pope 1995) is to use systematic, non-probabilistic sampling. The purpose is not to establish a random or representative sample drawn from a population but rather to identify specific groups of people who either possess characteristics or live in circumstances relevant to the social phenomenon being studied. Participants are identified because they will enable exploration of a particular aspect of behaviour relevant to the research (May and Pope 1995). This approach to sampling allows the researcher deliberately to include a wide range of types of participants, and also to select key participants with access to important sources of knowledge. One of the major differences between qualitative and quantitative research is that qualitative approaches typically involve purposeful sampling, while quantitative approaches usually involve probability sampling (Kuzel 1995; Morse 1989; Patton 1990). Patton (1990:169) described 14 different types of purposeful sampling involving the selection for in-depth study of typical, atypical, or 'information rich cases'. When qualitative researchers decide to seek out people because of their vocation and anticipated experience, it is because they consider them good sources of information that will advance them toward an analytic goal. While the sample is statistically nonrepresentative, it is informationally representative in that data will be obtained from persons who can stand for other persons with similar characteristics (Sandelowski 1995).

Using 'purposive' or purposeful sampling as described by Appleton (1995), the researcher approached selected health professionals who consented to take part in this study. Participants from the following multidisciplinary spectrum within Australia, the UK and the USA were approached:

- Bioethics
- Surgery – general, trauma, neurosurgery
- Medicine – internal medicine, critical care, gerontology, oncology, palliative care
- Pastoral Care
- Nursing - palliative care, oncology, clinical nutrition, critical care, gerontology
- Pharmacy
- Social Work
- Occupational Therapy
- Law

- Health Service Management/Administration

The sampling approach employed in this research was determined by the purpose of the project as statistical representativeness is not normally sought for qualitative research (Field and Morse 1989). Similarly, the sample size was not determined by hard and fast rules, but by other factors such as depth and duration of the interview and what is deemed feasible for a single interviewer. Taking into account the scope of the research and its in-depth/multidisciplinary nature, a sample size of approximately 30 participants was sought. This number was deemed more than adequate for appropriate deliberation within the confines of a Ph.D. thesis after expert consultation from two renowned qualitative researchers – one in Australia and one in the USA.

Concerns about sample size were also addressed via the related literature. Inadequate sample size can undermine the credibility of research findings (Sandelowski 1995) or too small to support claims of having achieved either information redundancy (Lincoln and Guba 1985) or theoretical saturation (Strauss and Corbin 1990). On the contrary, sample sizes may be too large to support claims of having completed detailed analysis of the data, especially the microanalysis necessitated by narrative research (Sandelowski 1995).

Sandelowski (1995) claims that purposeful sampling for selected phenomenological variation is a way a researcher working alone with limited resources can reduce the minimum number of sampling units required within the confines of a single research project, yet still produce credible and analytically significant findings. Determining an adequate sample size in qualitative research is ultimately a matter of judgement and experience in evaluating the quality of information collected against the uses to which it will be put. The following principle was therefore utilised in determining both an adequate and appropriate sample size for the research:

*An adequate sample size in qualitative research is one that permits – by virtue of not being too large – the deep, case oriented analysis that is the hallmark of all qualitative inquiry, and that results in – by virtue of not being too small – a new and*

*richly textured understanding of experience (Sandelowski 1995:183).*

The total of 32 participants was deemed both adequate and appropriate, having reached 'saturation point' of data and recurring themes by approximately the 28<sup>th</sup> interview. Tovey (1998) explains this saturation as a stage at which new narratives make sense within existing narratives and therefore do not require those propositions to be modified further.

### **Data Collection: The In - Depth Interview**

The focus of the qualitative researcher's concern when using narrative is to discover knowledge through the grasping of the individual's subjective experience employing a diverse range of strategies – case study, personal experience, observation, and interviews (Crowe 1998). The latter was chosen as the strategy for discovering knowledge in this project. This was the primary means of data collection, that is, the in-depth interview. These interviews were of a semi-structured nature thereby granting a notable level of autonomy to the participant in order to shape the nature of the analysis. The in-depth interview context allows for more than a rigid exchange of questions and answers, and becomes an interactive process of telling, listening, clarifying, and understanding (Chase and Bell 1994). Although qualitative interviews are often described as being unstructured in order to distinguish them with formalised quantitative interviews, the term 'unstructured' is misleading as no interview is completely devoid of structure. Britten (1995) explains that if it were, there would be no guarantee that the data gathered would be appropriate to the research question. The semi-structured interviews were conducted on the basis of a loose structure incorporating open-ended questions that outlined the area being explored, at least initially, and from which the interviewer or interviewee deviated in order to pursue an idea in more detail. Appleton (1995) suggests that by using open-ended questions, participants are encouraged to expand on their own experiences. Consequently, a wealth of information was contributed by the various participants in this study. Sorrell and Redmond (1995) maintain that open-ended questioning elicits a narrative directly related to an important experience of the respondent, who then becomes engrossed in the unfolding narrative, as the vividness of the original experience returns.

A semi-structured interview schedule was employed to facilitate in-depth exploration of the multidisciplinary participants' perspectives of the ethics of artificial nutritional support. The aim of the interview was to discover the interviewee's own framework of meanings. The research obligation was to avoid imposing the researcher's structures and assumptions as far as possible. During the course of the research the researcher needed to remain open to the possibility that the concepts and variables that emerged may be very different from those that might have been predicted at the outset (Britten 1995). This resulted in both surprising omissions and interesting inclusions in the overall data that are discussed in detail throughout the interpretation chapters.

Britten (1995) suggests that most qualitative interviewers should have a list of core questions that define the areas to be covered. Unlike quantitative interviews based on highly structured questionnaires, the order in which questions were asked varied, as did the questions designed to probe the participant's meaning. Wording cannot be standardised in the narrative approach because the researcher will try to use the participant's own vocabulary when framing supplementary questions. Also, during the course of the interview, the researcher may introduce further questions as she becomes more familiar with the topic being discussed (Britten 1995). Thoughtful probes by the researcher may assist the participant to bring forth contextual details important to meanings embedded in the narrative. Questions such as the following can help the participant reflect on the experience of interest (Van Manen 1990): 'How were you feeling at that time?' 'What else was going on?' and 'Can you tell me more about that?' – were often utilised during the interviews.

Periods of silence were used to establish a comfortable pace during the interviews, which encouraged the participants to follow their own path of associations by telling their story their own way. Some ideas or feelings of the participants were not able to be captured in words, for example, certain nuances and tones of speech. It was important for the researcher, in these situations, to be comfortable with silence in order to listen to the powerful silence that may speak more than words.



In the initial data analysis phase of the research, the opportunity existed to explore unanticipated themes. While the participants were offered broad themes in the interview which they addressed, it should be clarified that the interpretation of what was important rested ultimately with them. An essential component of the interview process was to ensure that the researcher checked that she understood the participants' meanings instead of depending on her own assumptions. This was particularly significant if there was obvious potential for misunderstanding – for example, when interviewing a participant who may be unfamiliar with medical terminology. It was the researcher's objective to ask questions that were open-ended, neutral, sensitive, and clear to the participant. This started with questions that the participant could answer easily and then proceeded to more difficult or sensitive topics.

Participants were met at a mutually agreed location, usually in the participant's 'natural setting'. As Denzin and Lincoln (1994) argue, qualitative research is multi-method in focus, involving an interpretive, naturalistic approach to its subject matter. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret phenomena in terms of the meanings participants give to them. Information for participants and informed consent were discussed at this time. If informed consent was obtained, a return visit was arranged to conduct the initial in-depth interview. This was then followed up by second meeting for confirmation of the interview transcript and the opportunity to discuss/reflect on the researcher's interpretation of themes arising from the initial interview. This meeting also provided the opportunity for the participant for 'debriefing'. It was anticipated that these interviews would take between half an hour to one hour. Overall, this assumption proved correct with the shortest interview lasting 28 minutes, and the longest 72 minutes. A cautioning from Weiss (1994) regarding the time consuming and labour intensive nature of qualitative interviewing was taken on board:

*Indeed, if undertaken as a Ph.D. thesis, where there are likely to be large ambitions and limited resources, a qualitative study can stretch on and on. Several months may be required for the interviewing, and the analysis of the interview can take even longer (Weiss 1994:11).*

The data collection phase lasted approximately four months, and the interpretation was ongoing for the following 12 months as a reflexive activity. The investment of time was not of concern to the researcher as it was clear from the related literature (primarily Weiss 1994 and Emerson 1987) that time required by qualitative interview studies tends to be well invested.

The interviews between the participants and the researcher were recorded verbatim and preserved as text through the use of a dictaphone and interview transcripts. By this method the narrative ethics of artificial nutritional support were captured in the text and preserved for interpretation. According to Gadamer (1975), text is located within a world that embodies historical, social and cultural dimensions as a segment of time. It is by way of language that understanding occurs, through the process of interpretation.

### **Phenomenological Questioning**

Questioning in the research was essentially phenomenological in nature. Sorrel and Redmond (1995) explain that phenomenological questioning is concerned with uncovering knowledge related to a specific phenomena. The interviewer shapes the interview yet is also shaped by the process, thus they are not conducted but rather they are participated in by the interviewer and interviewee (*ibid.*). The questions used to trigger the conversation were not planned or executed rigidly, yet included propositions such as:

- Thank you for agreeing to be part of this research. I am interested in your perceptions of artificial nutritional support, and the ethical issues in the provision of such treatment. Think of an instance that you have been involved in, in which you were confronted with ethical issues such as: withholding or withdrawing of artificial nutritional support; related complications; provision of artificial nutritional support in a terminally ill patient; persistent vegetative state patient. Tell me about it please.
- What was your part in this/these situations? What else was happening? How did that make you feel?
- Do you consider artificial nutritional support as the same as food and drink? Can you tell me why you think that?

- Do you consider artificial nutritional support as being different from other forms of medical treatment?
- If you could give advice to health care professionals on what you thought was ethical provision of artificial nutritional support, what would it be?

### **Ensuring A Quality Interview**

According to Guba and Lincoln (1981) the quality of data to be generated will be predominantly dependent on the skills and expertise of the interviewer. The researcher was masters-prepared having facilitated phenomenological interviews to research participants previously and considered herself to possess valuable first hand experience in the sound facilitation of quality in-depth interviews. Some common pitfalls for researchers that have been identified by qualitative researchers, namely Field and Morse (1989) were taken into account in order to facilitate only the highest quality interview.

The following factors were addressed with utmost consideration:

- Ensuring an interruption free environment, that is, no outside interruptions such as telephones, pagers, people entering the room, public address announcements;
- Ensuring no competing distractions, for example, children, radio, television;
- Refraining from asking the participant embarrassing or awkward questions;
- Refraining from jumping from one question to another;
- Refraining from giving the participant medical advice or 'teaching';
- Refraining from counselling, for example, summarising responses too early;
- Refraining from presenting one's own perspective, thus potentially biasing the interview;
- Ensuring accuracy of the interview by way of a translator if needed.

### **Analysis and Interpretation**

The approach to data analysis in this research has similarities with that used in other qualitative methodologies such as case studies, ethnography and phenomenology (Glaser and Strauss 1967). However, in the 1980's Bertaux (1981) adapted these principles specifically for the analysis of personal accounts, and these have since been modified and extended for use in settings beyond those originally identified (Tovey 1993;

Tovey 1992). The analysis and interpretation of the data became a reflective narrative in itself – one that avoided the split between mind and body which, according to Price (1994), is imposed by medical training. With each narrative the objective was to subject that narrative to rigorous inquiry, and to a constant search for themes. Tovey (1998) suggests that if this is appropriately performed, what results is not a 'yes/no' response to a simple hypothesis but a complex narrative or set of related narratives, which incorporate and account for the range of actions relating to each theme. The aim of this procedure is to reach saturation (Tovey 1998). Reflecting on the previously mentioned concern of sample size, saturation point was being reached between the 28<sup>th</sup> and 30<sup>th</sup> interview.

The audiotaped conversations were transcribed verbatim, and/or notes were transferred to a computer disk copy. It was decided that quotations, or excerpts of narratives would not be edited, thus presenting the original speech in such a way to reproduce the sounds of the tape as much as possible. Weiss (1994:192) terms this as a 'preservationist' philosophy in the treatment of interview transcripts. An argument in support of this preservationist approach is that speech communicates not only the dictionary meaning of its words but also the speaker's feelings, passions and uncertainties (De Vault 1990). The rationale for utilising this approach is that every element in a participant's expression – hesitations, colloquialisms and pronunciations – has value in communication. As Riessman (1987:189) explains, speech that has been 'cleaned up' to be more readable loses important information. Both these arguments hold only that the original speech, pristine and without editorial change, can adequately represent the participant's meaning and self. Anything else is a distortion (Weiss 1994).

After reading and re-reading the transcriptions, analysis proceeded using a combination of manual thematic analysis and a computer-assisted analysis program. After reviewing several of the currently available computer-assisted qualitative data analysis software packages, it was decided that the most appropriate program to employ was 'ATLAS/ti'. This program was deemed highly appropriate in the management and subsequent analysis of the vast amounts of textual data that was anticipated in the research. Added

to this, a manual method of thematic analysis was also used, which allowed for the researcher to find the finer nuances of human communication that were not conveyed in verbally explicit ways. That is, some meanings came forward as the result of an interpretation of the full context of what was said, rather than by the discrete words used. Each interview transcript was read through carefully prior to coding to gain 'a feel' for the participants' responses to questions or spontaneous offerings of information. These responses or 'offerings' were based on the individual participants' experiences, basic assumptions, views, thoughts, biases, and preconceived ideas. Passages of text (quotations) that signified a distinct theme were 'selected' electronically and assigned an according code.<sup>7</sup> Code titles were chosen according to the nature of the contribution. For example, if a participant was talking about the distortion of artificial nutritional support being compared to simple food and water, then that passage of text was selected and coded as 'food and water'. Code titles were named according to the participants' explanations therefore giving the participants a certain ownership of the interpretation. The ATLAS/ti program allowed this naming of the codes via a function called 'in-vivo' coding, that is, when the text itself contains a good name for the code.

By the end of the 32<sup>nd</sup> interview coding process, a total of 49 codes were identified. These were: *Advance Directives; Autonomy; Autonomy - Patient Empowerment; Basic Care; Benefits and Burdens; Buying Time; Cancer; Complications from Feeding; Conflict Regarding Feeding; Consent; Convenience; Critical Care; Curing and Caring; Decision-Making; Do No Harm; Education Issues; Elderly; EN versus PN; Equity of Access; Ethical Dilemma; Ethics Consults/Committees; Extraordinary versus Ordinary Care; Family; Food And Water; Futility; Generating Revenue; Guilt; Health System Differences; Inappropriate Treatment; Legal Issues; Malnutrition in Hospital; Multicultural Differences; Nutrition Not Sexy Enough; Overtreatment; Palliative Care; Paternity; Payment Issues; Possible Abuses; Process Of Dying – Death; Quality-of-life; Racial Differences; Reluctance to Change Practice; Research Regarding Nutrition; Responsibility for*

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<sup>7</sup> A note on the use of quotations from the interviews is in order. These quotations or excerpts from narratives that appear throughout the interpretation chapters of this thesis are direct transcriptions and capture all figures of speech, pauses, and colloquialisms (including those considered vulgar) thus maintaining true narrative and participant ownership of the data.

*Nutrition; Sloganism of Starvation; Tube Feeding; Using the Gut; Who Pays? – Resources; and Withdrawal of Nutrition.*

Essentially, these 49 codes arose as the main repetitive themes arising from the interview discussions. A list of all codes was generated, as was a list of all individual codes with their corresponding quotations. This latter document was extensive in itself (in excess of 80 000 words), yet it clearly demonstrated an obvious 'overlapping' of codes which assisted in the next methodological process, that being the merging of codes into major themes. This process of merging codes was also aided by the application of the ATLAS/ti program. Through this overlapping, eight major themes were formed. These major themes became the foundation of the interpretation chapters of this thesis and have been entitled according to their subject matter and emphasis as afforded by the participants in this research. The major themes are: **Principles, Money, Death, Culture, Dilemmas, Futility, Technology and Responsibility.**

Codes and major themes derived from the narratives were identified that gave insights into the essence of what was being communicated about the experiences of ethical issues of artificial nutritional support. A code was included as informative if it made a unique contribution to the total description of the experience. The codes were defined according to the meanings they reflected in the research, and they were set out clearly for validation by each participant. Following validation of the codes and major themes by the participants, the research report was electronically generated, which displayed the connections between the participant's narratives and the interpretations made by the researcher. A detailed synopsis of this process is explained in the following segment on computer assisted qualitative data analysis.

### **Computer-Assisted Qualitative Data Analysis (CAQDAS)**

Computers in research are seen by many to support the principles upheld by the positivist/quantitative tradition. It is only relatively recently that computers have been available to assist qualitative researchers in their work, and have yet to be accepted as an essential tool (Pateman 1998). This is surprising considering the vast amount of data

that the qualitative researcher has to keep track of. As mentioned previously, the output of all coded quotations in this project alone culminated in an 80, 000-word document. The use of computers in qualitative research, according to Aljunid (1996) results from the increase in sample sizes for qualitative study and from efforts by researchers to dismiss scepticism on the validity and reliability of results from manual processing of the data. Computers certainly possess great potential for easing the researcher's workload when collating, indexing and analysing large amounts of textual data – as in the case of this research project. Yet, the actual interpretation of the data still resides with the researcher. As Morse and Field (1996) explain, the meaning of text cannot be analysed by computer. Consequently it is still necessary for the researcher to read cognitively, engage with and code the text, although it is possible to set up an automatic coding and retrieval system.

The main criticism of CAQDAS is that it can alienate researchers from their data. This criticism is also expressed as a fear that the context of the data will be lost if the researcher begins to work exclusively on the codes in isolation from the text, so that the codes appear as things in themselves (Seidel and Kelle 1995). Richards and Richards (1991) suggest that CAQDAS may be more rigorous and that computerisation removes the constraints associated with large amounts of data and the complexities of demanding analyses. Despite the debate, there is general agreement that textual analysis packages can ease the researcher's workload, save time and generally enhance the power of qualitative analysis that far exceeds manual methods in terms of efficiency, consistency, and rigor. This occurs with the provision that the burden of interpretation still rests on the researcher (Webb 1999; Weitzman 1999; Pateman 1998; Morison and Moir 1998).

### **Introduction to ATLAS/ti**

ATLAS/ti is a software application developed in Berlin by Thomas Muhr of Scientific Software Development in 1993. It is an effective workbench for the qualitative analysis of large bodies of textual, graphical and audio data. It offers a variety of tools for accomplishing the tasks associated with any systematic approach to 'soft' data, for example, material which cannot be analysed by formal, statistical approaches in

meaningful ways. In the course of such qualitative analysis as the chosen methodology, ATLAS/ti helped to uncover the complex phenomena hidden in the vast amounts of textual data in an exploratory way. For coping with the inherent complexity of the interpretive tasks at hand, ATLAS/ti offered a powerful and intuitive environment that provided a continuous focus on the research materials. It offered tools to manage, extract, compare, explore, and reassemble meaningful pieces from the data in a creative, yet systematic way. Fortunately, this program imposed no restriction on the size of, or amount of data, the number of entities created, or the complexity of the structures and themes derived.

### **The VISE Principle**

The main principle of the ATLAS/ti method is termed VISE: Visualisation, Integration, Serendipity, and Exploration.

*Visualisation* means the direct support of the way human beings think, arrange and approach solutions in creative, yet methodical ways. Tools are offered to visualise complex properties and relations between the objects (quotations, codes and memos), which accumulate during the process of eliciting meaning and structure from the data.

*Integration* describes the analytical operations needed especially in the early stages of interpretation. The main 'container' object integrating all the other entities of the research is the 'Hermeneutic Unit'. Only one Hermeneutic Unit was created for the research and was aptly named 'Interview Analysis'.

*Serendipity* is defined in Collins Dictionary as 'a seeming gift for making fortunate discoveries accidentally' (1996:549). The term 'serendipity' describes the intuitive approach to data. A common operation making use of the serendipitous effect was 'browsing' which occurred during the reading, re-reading and subsequent coding of all the interview transcripts.



*Exploration* is achieved through an exploratory yet methodical approach to the data as opposed to a more bureaucratic handling of the data, assuming that the generation of themes and theories will greatly benefit the overall process. The conception of the ATLAS/ti program, including getting acquainted with its own idiosyncrasies, is aimed towards an exploratory, discovery-oriented approach (Muhr 1997).

### **Why ATLAS/ti ?**

The fundamental design objective utilised in the creation of ATLAS/ti was to develop a tool, which effectively supports the human interpreter, particularly in dealing with relatively large amounts of research information (Muhr 1997). Although this program facilitates many of the activities involved in qualitative data analysis and interpretation (particularly selecting, coding and annotating), its purpose is not to automatise these methods. As the software developer cautions, automatic interpretation of text cannot succeed in grasping the complexity, lack of explicitness, and contextuality of everyday or scientific knowledge (Muhr 1997). Thus, the main objective of employing such a program is fundamentally to do with data management. Data management was essentially accomplished via two basic concepts: textual level work and conceptual level work. The textual level included activities like segmentation of data, coding of text, audio passages and the writing of memos. The conceptual level focused on model building activities such as linking codes to form semantic networks and the merging of codes to form major themes. These are further explained as follows:

### **Textual Level Work**

Textual research activities included the breaking down, or segmenting of the interview transcripts into passages, the adding of comments to respective passages (note-making, annotating), as well as the filing or indexing of all selected transcript passages, secondary text materials (such as topical newspaper articles and lecture notes from presentations and grand rounds attended during the data collection phase), annotations, and memos to expedite their retrieval.

### **Conceptual Level Work**

Beyond mere code and retrieval functions, ATLAS/ti's networking feature allowed for the visual correlation of selected passages, memos, and codes, into diagrams which graphically outlined complex relations. This feature virtually transforms the text-based workspace into a graphical 'playground' for constructing concepts and relations apparent from within the data.

### **General Steps**

The following sequence of steps, although not mandatory, describes in brief terms the process of employing ATLAS/ti for the management of data in this research project:

1. Project creation (a 'container') which was to enclose the data, all research findings, transcripts of interviews, quotations, codes, memos. This container is called the 'Hermeneutic Unit'. The sole Hermeneutic Unit used in this research was entitled 'Interview Analysis'.
2. The association of all data files or 'Primary Documents' (text, graphics, audio) located anywhere in the Hermeneutic Unit.
3. Reading and selection of text passages that were of interest and pertinence to the research, assigning codes and memos simultaneously (not simply the interview transcripts – field notes, journal entries, topical newspaper articles and lecture notes were included).
4. Comparison of data segments differently or equally coded, assigning links and nodes simultaneously.
5. Building semantic networks from codes. These networks together with codes and memos became the cornerstones of the emerging theory/themes.
6. Finally, compilation of a written report.

## Coding

The procedures of coding using ATLAS/ti do not grasp the complexity of the intellectual efforts of coding as understood in the framework of manually rigorous qualitative methods, for example, grounded theory (Glaser and Strauss 1967). However, they are more than mere indexing procedures as annotating and commenting in every stage of the coding process was undertaken electronically. A variety of coding techniques was available, however the 'open coding' and 'code-by-list' techniques were used primarily. Open coding was initially used to assign a code for the first time, that is, creating a new code at the same time a section of the primary document was being coded. Thereafter, the code-by-list technique was utilised whereby an existing code could be assigned to a primary document selection. Any number of codes from the code list could be chosen. All coding resulted in quotations being linked with the assigned code. There was no restriction on the number of codes assigned to a quotation, and visa versa, a code could be assigned to an arbitrary number of quotations. For example, the following excerpt from a participant's narrative demonstrates how a number of codes could be assigned:

Codes: [ethics consults/committees] [futility] [withdrawal of nutrition]

*It is the same process – if the physician thinks that this is nonbeneficial treatment, medically futile treatment they recommend withdrawal and change to comfort. If the family persists, then the physician takes it to the facility ethics committee, if the ethics committee agrees, now, as of September 1st, by State Law the family has 10 days during which we have to continue full treatment, but they have 10 days to find another physician and/or a facility that will provide nonbeneficial/futile treatment, or we can withdraw treatment, or the family can go to court and try to get an extension of the time, but it is written in the law, the judge can't extend the time unless that in the judge's opinion there is some reasonable expectation that some facility will take this person, and if there is not, then that it is it. But I mean, it is too bad that you have to resort to legal manoeuvres.*

This quotation was assigned the codes: [ethics consults/committees] [futility] [withdrawal of nutrition] simultaneously. The use of 'Free Codes' was useful as an additional coding-

related housekeeping function. Just as quotations did not necessarily have to be coded to justify their existence, codes could be created that had not (yet) been used for coding purposes. For example, codes could be created that came to mind during the routine coding work which could not yet be applied to the current segment of work, yet would be helpful later on.

### **Writing Memos**

The writing of memos is an important task in every working phase of a qualitative research project (Muhr 1997). What was captured in memos were often the 'puzzle pieces' to be put together in the phase of writing the final report. The difference between codes and memos in this research project was that codes were a succinct, dense description of concepts emerging during the stage of closely examining the data.

Like primary documents, codes could be commented on. This function was employed to clarify the meaning of a code, or to explain how it was to be used for coding. For example, when assigning the code 'Responsibility for Nutrition' the following comment/memo was attached to that code to further clarify its meaning: *This code refers to whose responsibility it is to care for/manage and maintain the nutritional status of the patient – to avoid malnutrition, to ensure monitoring, assessment, safety and ensuring quality of care.*

### **Creating Reports**

The main strength of ATLAS/ti was the support of online activities like searching, browsing, and creating links. However, infrequently it was necessary to create something on paper or at least assemble results to be included in a report which could be studied offline. There was not one single location to find report related commands, yet for every object class there was an output menu which offered different options for creating printed materials. Besides generating and printing numerous primary documents, lists of quotations, and codes, a more complex report could be generated by using the HTML generator. All textual output could be directed to one of three devices: printer, text editor, and ASCII-file. With output redirected to the text editor, the contents

could be studied and modified on-screen before finally printing or saving the output to an ASCII-file. All output was preceded by a header containing the name of the Hermeneutic Unit ('Interview Analysis'), the current date and the name of the author. A textual output of quotations included a report of all quotations attached to either the selected primary text; all current quotations contained in the Hermeneutic Unit; and/or all quotations referring to a selected code.

### **Generating Code Lists and Retrieval**

This procedure created an alphabetically sorted list of all current codes. Such a list was useful in two ways. It could be used to obtain a print-out of all codes used in the Hermeneutic Unit, or it could be used as a collection of codes which could be later imported into another Hermeneutic Unit, should one be established. The operation of retrieving coded quotes offered immediate access to the primary data even when the researcher was already concerned with higher textual tasks such as merging codes to major themes and theory construction.

### **Conceptualizing: Networks, Codes and Links**

A network was essentially defined as a set of nodes and links, with a node being a network that could be linked to an arbitrary number of other nodes. For example, in the network entitled 'Principles', the nodes linked were: *autonomy; autonomy-patient empowerment; consent; decision-making, paternalism; and equity of access*. Links were then drawn as lines or arcs between the connected nodes in graphical presentations of networks. ATALS/ti also allowed for these links to be named enabling a distinct expression of the nature of the relationships between the concepts. In essence, this function produced a graphical representation of the initial codes merging into major themes and the theorising behind such connections. These connections culminated into what ultimately became the basis for thorough exploration and interpretation of the data. The 'Network Editor' function offered an intuitive and powerful method to create and manipulate network structures. It favoured a direct manipulation technique whereby the objects (codes, quotations, and memos) could be literally grabbed by using the mouse and then moved around the screen, drawing and/or severing links between them.

Essentially, the employment of this application proved to be relatively easy, reliable and practical considering the nature of the data collected.

### **Determinants of Rigor: Ensuring Rigor in the Initial Phase**

Various means of determining rigor in qualitative research have been suggested (Sandelowski 1989; Denzin 1989; Hall and Stevens 1991; Beck 1993). There is no accepted test of rigor in qualitative research just as there is no one way of doing qualitative research. This means that researchers must use the most appropriate means of assessing rigor in qualitative projects to reflect the methodological assumptions of the project. After a lengthy and expansive review of the qualitative methodology literature, the following points were considered crucial to contributing to rigor in this project:

- Reflexivity - by continually critiquing the research process
- Credibility - by assessing initial progress via member checks (returning the transcripts to the participants for verification)
- Rapport - experienced as open, trusting dynamics between researcher and participant
- Acknowledging complexity in the research and the participants
- Achieving consensus in decision-making
- Addressing relevance to participants' concerns
- Attaining honesty and mutuality
- Naming - using participant's own terms and concepts to denote the project's objectives, processes and outcomes
- Achieving rationality by forming collaborative interpersonal relationships to challenge ideas and respect differences (with research supervisor).

Burns and Grove (2000) argue that rigor in qualitative research is associated with openness, scrupulous adherence to a philosophical perspective, thoroughness in collecting data, and consideration of all data in the subjective theory development phase. They suggest that, in order to be rigorous, the researcher needs to be open to new ideas and be willing to let go of old ones, and to examine many dimensions to form new ideas.

The early literature reveals that the concepts of validity and reliability, as understood from the positivist perspective, are somewhat inappropriate and inadequate when applied to interpretive research such as narrative analysis (Hill Bailey 1996). More contemporary literature suggests that because the positivist and interpretative paradigms are epistemologically anomalous, the transfer of quality criteria from one perspective to the other is not automatic or even reasonable. That is, the experimental model presupposes an objective and measurable reality or truth, whereas the interpretive approach is interested not in truth but in meaning (Chinn 1994). Traditionally, the quality of any research finding is determined by critiquing the validity and reliability of the research process. Lincoln and Guba (1985:300) offer alternative terminology to the concepts of rigor as purported in quantitative research. They renamed these concepts as 'trustworthiness' criteria. Their trustworthiness criteria initially acknowledged the established positivist rigor criteria as superior and were, therefore, an attempt at ensuring some scientific acceptability of qualitative findings (Hill Bailey 1996). In their model 'internal validity' was replaced with 'credibility', 'external validity' with 'transferability', 'reliability' with 'dependability', and 'objectivity' with 'confirmability' (Lincoln and Guba 1985:300). In demonstrating that the findings generated were trustworthy, it was crucial to show that the method employed was rigorous. Demonstrating analytical rigor of the data collection process was accomplished via the following steps:

1. Being present at the interview
2. Listening to the tape
3. Transcribing
4. Reading the transcription
5. Repeating steps 1 and 2 to ensure familiarity
6. Thinking/assimilating/intuiting - forming initial interpretations of themes
7. Returning transcriptions to participants for confirmation/validation/debriefing
8. Interpretation and understanding

Essentially, this was a relatively simple process, which was hinged on familiarity of the data. The researcher chose to transcribe the interviews herself (a task which consumed

approximately four to five hours transcription per interview), so that earlier and later transcriptions could be simultaneously compared and annotated, with modifications of interpretations made if necessary. Ultimately this lead to an intimate understanding of the participant's issues, and/or experiences that were important to them. This is not to suggest that the findings represented the definitive truths about the ethical issues of the provision of artificial nutritional support, but they may constitute a justifiable interpretation, representing what Jackson Knight (1969) refers to as the 'truth of art' and not the 'trivial truth of fact' (cited in Rose and Webb 1998:561). Interviews were also transcribed as soon as possible after the actual interview in an attempt to 'stay as close to the data' as possible. In the majority of cases, the interview tape was transcribed within 24-48 hours of the actual interview meeting.

In recent years, an extensive dialogue concerning the value or quality of qualitative research has occurred (Guba 1990). As a result, alternative strategies of defining the quality of knowledge generated within the interpretative paradigm have emerged. These strategies are grounded on recognition of paradigmatic epistemological differences (Hill Bailey 1996). The language of this dialogue reflects the evolution in the understanding of this concern. In this literature, research findings are now evaluated for credibility, dependability, confirmability, and transferability. These concepts of determining qualitative rigor in narrative analysis as defined by Lincoln and Guba (1985) will essentially inform the determinants of rigor in this research project.

### **Credibility**

Credibility is a criterion that equates, to some extent, to internal validity in traditional positivistic research. The criterion deals with whether credible and truthful findings and interpretation will be generated, that is, credibility will apply to the collection of data as well as to the analysis. Guba and Lincoln (1981) suggest that the determination of credibility can be accomplished only by taking data and interpretations to the sources from which they were drawn and asking the participants whether they believe, or, find the results plausible.



Credibility was achieved via the following activities:

- Repeated contact with the participants enhanced closeness and confidence with the researcher;
- Each participant had the opportunity to read through their individual transcripts and to comment, change or make any addition that they wanted to. In this way the participants confirmed their interviews to be adequate and fair descriptions of their situation;
- Credibility in the data collection depended upon the degree of closeness and mutual respect established, the interviewing skill of the researcher, motives and strategies of the participants, and the impact of the fact that the researcher may be a colleague/former colleague;
- The researcher did not look for ready-made concepts in the text, but rather for codes and expressions for what the participant described.

Member validation, or member checking was essentially the means of achieving credibility. Member validation is a technique scholars have proposed for establishing validity of a researcher's interpretations of data collected from research participants and for ensuring that these participants have access to what has been made of their experiences. This accordingly involves a professional obligation to 'do good science' and specifically an ethical obligation to support the participants' right to know (Sandelowski 1993:4). It has also been defined by Roberts and Taylor (1998) as a procedure employed within qualitative research methods to ensure that participants validate their contributions to the overall project, as a source of determining the trustworthiness of the project. Similarly, Stake (1994) claims that member checking is a measure for ensuring honesty and identifying researcher biases that might skew the interpretation. On a practical level, this means that the participants were given the transcripts of their interviews to ensure that the information was complete and accurate, and provided the participant with the opportunity to comment on the initial interpretations.

### **Dependability**

A qualitative approach is preferable when the aim is to explore complex connections in an ever-changing surrounding, such as the provision of artificial nutritional support in

acute and post-acute settings. A scientific indicator for solidly performed research is dependability. This means that the study adapts to changes in the studied environment and to new information obtained during the study period.

Dependability was achieved via the following activities:

- Collection of data and the analysis occurred simultaneously. This, according to Hamberg *et al* (1994) supports dependability and enhances flexibility. It gave the researcher an opportunity to use new ideas and analytical codes from interview to interview;
- The number of participants was not decided in advance. Instead, the sample size was governed by the degree of saturation in the analytic phase;
- Consistent contact with the participants over a 12 month period meant that the research process will not be based on just one snap-shot of life. Instead, it will change and adapt as time goes by;
- It is important that the research process can be followed by others. The researcher therefore made notes and memos of her thoughts and ideas in a reflexive journal during the study period. These memos were necessary for another criterion of sound interpretive research, that is, confirmability.

### **Confirmability**

This criterion correlates to, but is not the same as objectivity in quantitative designs. Both define the neutrality, that is, the research shall not distort the reality it sets out to describe. This means that the research should include procedures to verify that the findings and concepts described are established in the data and not a result of poorly performed analytic work or preconceived assumptions. Confirmability means that the evaluation of the neutrality of a research project is moved from the researcher as a subject, and instead is focused on the data and the interpretation of the data. This is how confirmability opens the way to intersubjective knowledge (Hamberg *et al* 1994). It should be possible for other researchers to consider findings and results as reasonable and fair by looking into the data (Lincoln and Guba 1985). This required a method so systematic and thorough that the researcher continuously had to question the findings,

rethink and critically review the material. Essentially the entire research process was a critique in progress.

Confirmability was achieved by:

- Choosing a method of analysis (qualitative methodology - narrative ethics) that by definition begins in the data and tries to identify what the data can reveal;
- Comparing analytical codes with a senior researcher with expertise in narrative ethics;
- Searching for negative data in the material that could either strengthen the researcher's interpretations or cause the researcher to question her codings and classifications;
- Testing confirmability by having the research supervisor scrutinise the transcripts, the researcher's codings, classifications, and memos.

Mays and Pope (1995) maintain that the reliability of the analysis of this research data will be enhanced by having an independent assessment of the transcripts and comparing agreement between the raters of the research.

The concepts of the determinants of rigor of research ensure that independent researchers will reach the same findings based on the same data. To the principle researcher, this is a test of confirmability, that is, that the findings/interpretations are truly grounded in the data and not fabrications in the researcher's head. The researcher engaged her supervisor in checking the data during the analysis. This was performed to reduce the risk that her own theoretical framework would cause her to overlook data not agreeable to her way of thinking.

### **Transferability**

Conclusions made in a qualitative study are not proof but are descriptions and interpretations. They must be evaluated for their plausibility, syllogism and ability to be communicated to others (Hamberg *et al* 1994). The eventual findings of this research must be comprehensible to others and regarded as reasonable, and the relations found must be recognisable in a clinical setting. Findings in narrative ethics research cannot be generalised as quantitative results but transferability relates to generalizability.

To make transferability judgements possible, it was necessary to:

- Describe the context in which the study took place;
- Describe the demographics such as gender, ethnicity, family situation, professional affiliation; geographical location.

This will enable others to decide whether the findings are relevant in other situations, for example, will there be anything to learn from this study of ethical issues in artificial nutritional support for those interested in parenterally supporting terminal cancer patients in varying demographics.

A potential drawback of transferability lies in the fact that the responsibility for judgement is left to the potential users of the findings (Hamberg *et al* 1995). The researcher's responsibility therefore, was to give a comprehensive description of the context and findings. However, the researcher will have no control over how the data may be interpreted by others, other than to communicate the findings to the wider research community. It is the researcher's intention to eventually publish the findings in a peer reviewed journal(s).

### **Methodological Considerations: Validity, Reliability, and Generalizability**

The autonomy granted to the research participants results in the emergence of subject-directed themes and propositions to sit alongside those identified at the outset. Given the relatively small number of participants and the essentially inductive nature of the method, questions about the generalizability of results, and the reliability/validity of the approach might well be raised. Tovey (1998) argues that no collection of narratives is ever likely to be gathered in such a way as to constitute a representative sample. Because no population is being mirrored, no generalization to any given population is attempted. Instead, what the rigor of the method is directed towards is a generalization of theory – a means by which an existing expectation, understanding, or body of knowledge is exposed to, and revised on the basis of new empirical evidence drawn from a particular site of activity.

Generalizability of the research deserves special consideration. Qualitative research employing small and purposefully selected samples has historically been considered nonrepresentative of the population and its findings not generalizable. Morse (1999) in defence of this obvious limitation declares that generalizability is not the purpose of qualitative inquiry. She defends qualitative research as being generalizable in that each participant in the relatively small sample has been purposefully selected for the contribution he or she can make toward the emerging theory. Therefore, the knowledge gained from the theory derived from this research should fit all scenarios that may be identified in the larger population. The theory is also applicable beyond this immediate group and is applicable to all similar situations, questions and problems, regardless of the comparability of the demographic composition of the groups (Morse 1991).

Positivists may characterise results from research as anecdotal, because they rely on accounts provided by a relatively small sample of participants, or as impressionistic. This implication that not only are results imprecise, but also that they are more of a product of art than of objective scientific method (Priore cited in Weiss 1994). However, another argument in support of generalizability of findings via a qualitative method employing purposeful sampling is that it is possible to maximise the range of health care related disciplines thus providing an important variation under study. The participants were not confined to one geographical location, country, culture, health care delivery system - thus providing breadth and depth of experience and perspective.

The question of relevance of notions of reliability and validity of the narrative has been neatly summarised by Plummer (1983):

*...validity [ensuring that the study is measuring what it purports to] should come first, reliability second. There is no point in being very precise about nothing. If the subjective story is what the researcher is after, the life history approach becomes the most valid method...It simply will not do to classify, catalogue and standardise everything in advance, for this would be a distorted and hence invalid story (Plummer 1983:162).*

The contemporary writings of researchers engaged in narrative analysis reflect the evolving understanding and complexity of the quality issue within the interpretive literature (Riessman 1993). Researchers employing this methodology allude to the reconceptualization of validity and reliability within the interpretive paradigm as a process. For these researchers, this refashioning using terms such as *trustworthiness* and *credibility* has positively changed validity from an objective reality to the process of confirmation/validations:

*Validation, the process through which we make claims for the trustworthiness of our interpretations, is the critical issue. Trustworthiness not truth is a key semantic difference: the latter assumes an objective reality, whereas the former moves the process into the social world (Riessman 1993:65).*

Through the process of validation, the researcher allows the readers to judge the authenticity and trustworthiness of his or her work (Hill Bailey 1996). This process is not merely the employment of two or more raters during the analysis of data to ensure equivalence (Brink 1987) or member checking to affirm the researcher's interpretation (Riessman 1993). Rather, to date, the predominant strategy in narrative analysis of the confirmation or validation activity is simply to make the research process visible, allowing systematic scrutiny (Mishler 1990; Riessman 1993; Sandelowski 1993).

For narrativists, credible and valuable narrative interpretation presents:

*...data in the form of texts used in the analysis, with full transcripts and tapes that can be made available to other researchers; ...methods that transform the texts into findings; and ...the direct linkages shown between data, findings, and interpretation (Mishler 1990:429).*

Hill Bailey (1996) explains that the presentation of data in this manner enhances the authenticity of the finding by not privileging the researcher as the sole interpreter. For the purpose of this research the intention was to include the participants in the analysis process as there was not just one correct interpretation of the structures, meanings, or

context of narratives considering the multidisciplinary nature of the participant sample. Moreover, there is no specific set of rules that if followed confer credibility, rather:

*Trustworthiness becomes a matter of persuasion whereby the scientist is viewed as having made those practices visible, and, therefore, auditable; it is less a matter of claiming to be right than to have practiced good science (Sandelowski 1993:2).*

This closeness and attention in the researcher-participant relationship and research is well suited to narrative ethics research. However, the researcher remained ever cognisant of the combination of being a researcher and clinician simultaneously as there may have been situations in which the researcher had to shift from one role to the other.

### **Reflections on Data Quality: The Question of Memory**

Crowe (1998) warns that qualitative methods which rely on interview for data collection also rely on memory processes. There is a general consensus in the related literature that past experiences can be recalled and communicated as a true representation of past events. Taussig (1992:84) however, challenges this assumption by arguing that our minds do not '...function like carbon paper or cameras to faithfully register the facts of life'. Memory processes and retrieval are reconstructed rather than recalled, and this reconstruction takes place within the specific and formative circumstances of the present (Frow 1995). Van der Kolk (1987) asserts that because some experiences, especially traumatic ones, are stored in memory in non-verbal modes such as sensations and images which may be difficult to retrieve and communicate in linguistic forms. This has implications (in terms of challenging the participants' memory) for the qualitative narrative approaches that have a tendency to assume that the participant provides a description of events that actually happened (Crowe 1998). Taking these constructive criticisms on board, it is of paramount concern to the overall quality of the research and rigor of data collection and subsequent interpretation that the narratives of all participants are regarded as true and non-fictional. These are essentially their stories, and these are honoured as factual accounts, impressions, perspectives and experiences.

### **The Whole Truth?**

Weiss (1994) contends that while interviewers can anticipate that they will be told the truth they cannot assume that they will be told the whole truth, nor the precise truth. The vagaries of respondent memory make for reports in which some observations are crystal clear while others are obscured, distorted or blocked. Respondents may also shade their responses to present a positive picture of themselves. Yet despite all the ways in which interview data can be problematic, richly detailed accounts of vividly remembered events are likely to be trustworthy. Ultimately our best guarantee of the validity of interview material is careful and concrete interviewing within the context of a good interview partnership (Weiss 1994). This partnership was achieved essentially by carefully following the aforementioned interview strategies.

### **Minimising Researcher Bias in the Presentation of Results**

Although it is not normally appropriate to write up qualitative research in the conventional format of the scientific paper, with a rigid distinction between the results and the discussion section of the account, it is important that the presentation of the research allows the reader as far as possible to distinguish the data, the analytic framework used, and the interpretation (Dingwall 1992). The problem with qualitative interpretations is the sheer volume of data customarily available and the relatively greater difficulty faced by the researcher in summarising this data (Mays and Pope 1995). Anticipating up to 32 lengthy in-depth interviews in this research was by no means an exception. A partial solution to this problem was achieved by presenting extensive sequences from the original data, followed by a detailed commentary.

By virtue of the multidisciplinary nature of the data contribution, a form of 'bracketing' occurred thereby freeing the researcher from bias to a considerable extent. Oiler (1982) suggests that bias comes from the retrospective interpretation of experience built on inaccurate memories. Cohen (1987) adds prejudices and personal commitments as forms of bias. Bracketing involves deliberately seeing the other side of arguments, allowing thoughts to wander, to be confused and uncertain, and seeking the opinions of others (Rose *et al* 1995). Despite these attempts of minimising bias, it was understood



that being totally detached from researcher bias as such was impossible. As Crotty explains 'researchers cannot deny that they all come armed with prior knowledge, their own beliefs and judgement, preconceived ideas and theories, or personal and theoretical bias' (1996:16).

### **Ethical Considerations: Theory**

Miller (1996) contends that narrative research is the quintessential ethical project, as well as in support of self-reflection. Habermas (1993:118) claims that narrative research addresses the perennial ethical concern and goal of sensitive, aware human beings – answering the existential question of the 'wherefore in our lives'. From this perspective, narrative research in itself is an ethical endeavour (Widdershoven and Smits 1996). The act of exploring the narrative therefore gives meaning, and it is the act of such narrative exploration that both meaningful and ethical consequences can arise (Miller 1996).

Interview-based research affords people the opportunity to explore themselves, to increase their awareness, to find meaning and to be understood. According to Miller (1996), this work is fundamental and ethical in its own right, and the dialogue that takes place is therefore inherently ethical. In support of this, Widdershoven and Smits (1996) claim that ethical issues cannot be dealt with unless one thoroughly knows the situation and focuses on the meaning of the issue for the people involved, thus deriving meaning that can be established only by the interpretation of the stories they tell. Thus, the ethics of employing narrative research to the question(s) of the provision of artificial nutritional support is theoretically justified, if not encouraged.

### **Ethical Considerations: Practice**

In the course of this research, attempts were made to safeguard human rights and a number of processes and procedures were employed to ensure the ethical standards of the research. Research participants had the right to full disclosure. All participants received a detailed explanation, verbally and in writing, of what the research involved, including the aims and processes of the research, and the participants' involvement. They were offered the right to refuse to participate or to withdraw at any time, without

penalty of any kind. They had the opportunity to ask questions, make comments, and voice concerns that they may have concerning the project. A copy of the Consent Form and a Plain Language Statement (Information Sheet) can be viewed in the Appendices located at the rear of this thesis. For the purposes of some of the USA interviews, relevant documentation from the respective Institutional Review Board is also located in the Appendices.

Privacy, confidentiality and anonymity were ensured throughout the research. Strategies included the use of pseudonyms, instead of personally identifiable information.

Audiotaped interviews did not include the real names of participants, or any other identifiable information, as these were protected by the use of pseudonyms. Participants have been simply referred to throughout the text as their profession and country. For example, 'Trauma Surgeon USA', 'Nutrition Nurse Specialist AUST, and 'Critical Care Physician UK' – so as to maintain anonymity yet provide both a professional and geographical dimension to the data. These professional titles were both assigned and described by the participants themselves.<sup>8</sup>

The participants had the right not to be harmed by the study. Due to the personal nature of the disclosures there was the potential in which the participants could experience some emotional discomfort related to sensitive issues. Strategies to alleviate this were to assure participants of their anonymity and privacy as mentioned previously, to provide open access to research information concerning themselves only, to allow them opportunities to comment upon, and to validate the accounts.

The processes in this research make a strong commitment to minimising power differences between the researcher and the participants. This was achieved by encouraging openness and trust, especially in relation to participants divulging their perceptions about ethical dilemmas inherent in artificial nutritional support.

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<sup>8</sup> To protect the anonymity of participants, the researcher has removed or changed certain information that may identify the participants.

All data collected in this research will be stored in a locked storage compartment for seven years and the responsibility for the safety and security of it will reside with the researcher.

## **Conclusion**

Narrative gives us insight into the nature of practices as ethical endeavours (Widdershoven and Smits 1996). The same authors also challenge us not to focus on principles but study narrative as told by practitioners. The assembling of narratives and their subsequent interpretation as expressions of what is at stake in practices dealing with ethical issues forms the basis of the following interpretation chapters. Such narrative research however, is not ethically neutral. The narratives contributed in this research have required both interpretation and exegesis in order to become meaningful. From this perspective, the ensuing narrative research is in itself an ethical endeavour. The aim, therefore, of the following eight interpretation chapters is to offer a new perspective(s) on how to deal with a problematic issue in health care today, that is, the provision of artificial nutritional support.

## **CHAPTER THREE**

### **PRINCIPLES**

#### **Introduction**

The major theme entitled 'Principles' was created by the merging of the following codes: autonomy; patient empowerment; consent; decision-making; paternalism; equity of access; and ethics committees/consults. The title of this major theme reflects in essence the contributions of the participants on areas of their practice and experience that dealt with ethical principles, or the closest thing to them. Interestingly the participants only touched on this area very lightly, with terms such as beneficence, non-maleficence, autonomy and justice only being verbalised a few times throughout the entire data collection process. The term 'principles' was chosen by the researcher as the most succinct and encapsulating heading for this area, although it is understood that there are other ways of 'doing' ethics other than the principlist approach. However, the ethical principles were embraced by the participants therefore reflecting the dominant discourse of principlism as espoused by such writers as Beauchamp and Childress (2001). Subheadings or 'discussion points' were chosen and prioritised according to the emphasis placed on them by the participants themselves, and the incidence of discussion occurring in the data itself. Consequently, interesting omissions and surprising inclusions of discussion topics are the foundation of this chapter. The discussion points are: autonomy; medical paternalism; ethics committees; access; consent; and beneficence.

#### **Autonomy**

A total of 15 quotes for autonomy and patient empowerment were coded out of the 32 interviews. The participants contributing to discussions on autonomy and patient empowerment consisted of: a Law Professor (USA); a Trauma Surgeon (USA); a Hospital Chaplain/Ethicist (USA); three Occupational Therapists (two USA and one AUST); a Nutrition Nurse Specialist (AUST); a General Surgeon (UK); an Oncologist (USA); and an Oncology Nurse Specialist (USA). The context in which autonomy was discussed was primarily that of honouring the wishes of the patient, for example:

*Understanding that most of the patients we work with have terminal diagnoses, and their request might be to eat, to have a normal oral intake – now that might not be the safest medical thing for them to do, but understanding that people have those rights and those choices, and are able to make informed decisions is paramount (Occupational Therapist, USA).*

And:

*Now if the patient is competent and the patient says that they want to be fed, then doctors have an ethical obligation to feed them – you know, having outlined the disadvantages and complications. This is never a problem for me – like in a department store when the customer knows best. Well I believe that if the patients say they want to be fed then we have to feed them. The problem only arises when you have an incompetent patient meaning someone unconscious in the ICU or someone who has had a stroke, or in PVS. In most cases, family has never talked about it, so you have absolutely no idea what that person would have wanted – as an autonomous individual (General Surgeon UK).*

This participant was the only one that broached the concept of 'ethical principles' being non-workable in certain clinical situations, for example, patient autonomy in a critical care setting being virtually non-existent more often than not, whereby the patient is rendered unconscious and non-responsive due to their illness/ and/or sedation. Similarly, the lack of communication between the patient and their family members/proxies is raised, thereby complicating a decision-making process that would be honouring the wishes of the patient. Lack of such dialogue however does not appear to be as big a problem in environments where advance care planning and making one's wishes known through processes such as living wills, durable power of attorney for health care and advance directives are the norm.

*It is actually unusual but occasionally we have a case where the patient clearly wants everything done, and I mean everything. If his last words are 'do everything' or in his advance directive he clearly states that he wants everything to be done that could be done, then you gotta decide on whether you honour autonomy or do you honour non-maleficence which is to do no harm,*

*because in fact by doing everything and providing that kind of treatment you are actually harming this person – so do we override patient autonomy by not doing harm?....well in most cases we do....we say I know this is what he wanted because he wanted everything but that doesn't mean we are going to harm him (Hospital Chaplain/Ethicist USA)*

This quote embraces the principle of beneficence yet not in so many words. It also touches on the dilemma of harming the patient in order to honour their wishes. This conflict of interests is explored in more detail in a later chapter entitled 'Futility' where the benefit versus burden dichotomy is discussed. However, in those circumstances where the wishes of the patient are not known to family, the decision-making process was described in two ways. Firstly, from handing that responsibility on to the family, thereby honouring autonomy:

*Well, if the patient is not capable of making an autonomous decision, and let's face it, in most circumstances they are not because then we wouldn't have these ethics discussions, then in the name of autonomy, we have to put it on the family's shoulders.....but now they have got the monkey on their back. They have to address something that we would have addressed already (in our own minds) and the eventual outcome will be the same (Trauma Surgeon USA).*

Secondly, the decision-making process in a case where the patient's wishes were not known, was described in more paternalistic terms by a UK Surgeon:

*It is worth bearing in mind that there is no legal precedent - ethical or moral - for relatives to make decisions for their family members when their wishes are not known. These decisions are left up to the treating physician. That may sound arrogant but in reality most of the time the family cannot decide anyway, I mean, they have never taken it on board, you know, to discuss it with each other while they are all competent – so they leave it up to us, and the end result is almost always the same. Sometimes they demand intervention, consequently I think we have a few patients around the place who are being inappropriately fed (General Surgeon UK).*

The concept of having similar end results of treatment regardless of an autonomous or paternalistic decision-making process was also mentioned by a Law Professor (USA), who explained that the notion of autonomy is in some ways granted too much importance:

*From some perspectives, including mine, that we credit autonomy a little too much in some cases, because the default is set in favour of the autonomous choice, in favour of self-determination...and I think that from my perspective it looks like it is a pretty humane view that choreographs the treatment and the inevitable death of the patient. I mean the end point is going to be the same no matter what – it really is a question of how you get there and what kind of support you can provide for the patient. If the patient is aware then great, but if not, then it is the family who really needs to be responsible and accept the same end point (Law Professor USA)*

Being responsible for having one's wishes known (be it an individual or family), and being responsible for one's health state was similarly discussed by a Nutrition Nurse Specialist:

*Despite people becoming a bit more aware of their rights as autonomous decision-makers, your general population needs to take some ownership and responsibility for their own well being and consequences in case they get really sick. You still see these patients laying in bed who want some kind of magic wand to be waved over them and are told 'yes off you go, you are cured now'..they have to realise they have to participate in how they are actually going to get better, and have a positive attitude which doesn't just involve themselves, but getting their carers, their families involved too (Nutrition Nurse Specialist, AUST).*

In comparison, an American Oncologist commented on responsibility and empowerment within a different health care delivery system, that is, a 'privatised' system<sup>9</sup>:

*In this system, the patient is an empowered consumer – they have had to be to realise what goes on. Especially with the Internet, we have people come in the clinics with a pile of*

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<sup>9</sup> See Chapter Five 'Money' (p. 137-138) for explanations of 'privatised' and 'socialised' health care systems.

*reprints downloaded and they do know more about the disease and treatments than we do sometimes (Oncologist, USA).*

This was the extent of discussions on the principle of autonomy, which essentially viewed autonomy as being a patient's right and not a doctor's prerogative. Physician autonomy as such was not mentioned by the participants, yet was alluded to in terms of 'medical paternalism'.

### **Medical Paternalism**

In contrast to the discussion of autonomy, an unexpected inclusion in the participant's experiences and views on the provision of artificial nutritional support included the concept of paternalism, or, as it has been described by Nuland as 'medical paternalism' (1995:258). Nuland explains that people become doctors because '...our ability to cure gives us power over the death of which we are so afraid', and that 'In an attempt to maintain control, a doctor, usually without being aware of it, convinces himself that he knows better than the patient what course is proper' (*ibid*: 258). Knowing what is best for the patient could be in sharp contrast with the wishes of the patient. This notion of medical arrogance or paternalism was mentioned throughout the 32 by the following participants: a Medical Social Worker (USA); a General Surgeon (UK); a Hospital Chaplain/Ethicist (USA); a Nutrition Nurse Specialist (AUST); a Law Professor (USA); a Nutrition Nurse Specialist (UK); and two Oncologists (USA).

In its simplest form, medical paternalism was discussed as 'doctor knows best' – with or without consultation from other health care professionals or the patient/family. The assumption that the doctor knows best was also made within the clinical and unrealistic confines of the hospital. As a Medical Social Worker commented:

*They [the doctors] prescribe a lot of stuff, go ahead and place the feeding tube, and never go into the patient's home to see what their real world is really like, or what it is that is actually going on for the patient and the family. They only think of the patient kind of like a car or something that breaks down and they are just attaching a new part, putting a new part on it to keep all the things running and the gas going through the parts.*



*They don't think of the patient going home to this community that they once lived with this family in this setting. I guess its kind of arrogant but it happens all the time (Medical Social Worker USA).*

Decision-making as a separate entity only appeared in the data once, and upon re-reading and reflection it was obvious that it could be tied into the notion of paternalism. In discussing treatment decisions, a Hospital Pharmacist (AUST) explained in similar terms, the power of the treating doctor in relation to feeding issues:

*It is very much the way we work here, that is, the final decision is within the physician's court, and as to whether it happens or as to whether it doesn't happen, and when and how it happens is the physician's call (Hospital Pharmacist AUST).*

Arrogance, within the discussion of medical paternalism, was alluded to by another participant, yet in conjunction with patient complicity:

*Most of our surgeons and physicians, despite being old school or fresh out, all think they know best....I mean, some of our older doctors are still into the 'I own the patient and all of their care' mentality, so they will not refer patients to palliative care, or home hospice unless they have exercised every bit of their so-called ownership to treat them up to their eyeballs...but certainly there are still a lot of older people who think that exactly what the doctor says is exactly right, and um...there is no deviation from that, and if Dr. X tells you to jump off the top of the Sydney Harbour Bridge, then that is exactly what you do – no questions asked (Nutrition Nurse Specialist AUST).*

Correspondingly, complicity with medical paternalism in relation to feeding decisions was explained in terms of 'passing the buck' onto family members. This notion was not found in the literature, on the contrary, most medical ethics texts espoused the doctrine that all individuals should be given practical assistance to maximise their decision-making capacity. For example, the British Medical Association's (BMA) recently published guidelines on withholding or withdrawing life-prolonging medical treatment clearly states that this should include providing information in broad terms and simple language, and that patients/families should not be regarded as incapable of making or communicating a

decision (BMA 2001). This however, does not always appear to be the case as the following quote suggests:

*For many of these patients there is no hope of recovery – be they brain injured or advanced dementia, critically ill, whatever...you can give the family the best case scenario and the worst case scenario – and it can be left up to the family although the family will often need a lot of guidance as they find the decision-making for all of this hi-tech stuff very difficult, so it is a bit like the doctors passing the buck. The doctors put all these decisions on to the family, and will make no recommendation, and will show no leniency one way or the other about the provision of support (Nutrition Nurse Specialist AUST).*

The reality of practices differing markedly between health care delivery systems was eloquently captured by a Hospital Chaplain/Ethicist who had practiced in numerous countries outside the USA. In reflecting on the informed consumer of health care in the USA, he pondered:

*I'm wondering too if it isn't a kind of typical American thing. I think that American patients tolerate less paternalism than other cultures, and my guess is that medicine in the UK, Australia, certainly in Japan I know, and other countries is much more paternalistic, like...'I am the doctor and I am telling you what to do and you go do this'. And in the United States we tend to be 'You are the doctor, and I don't like what you are doing, so you are fired, and I am going to get somebody else who I do like what they do' (Hospital Ethicist USA).*

This culture of health care delivery systems concerning medical paternalism was also experienced by a Law Professor (USA) who regarded being in charge of decision-making regarding a patient's treatment was a shared responsibility, that is, shared with the autonomous patient or surrogate. However, when reflecting on the experience of one of his relatives in the UK, he explained the decision-making process somewhat differently:

*Over there - England - the doctors just made up their decision to withdraw nutritional support and my relative died within a few days, but I just couldn't believe it...I mean, I was just floored...the family just all went along with it and never*

*questioned the decision or said a thing. Now that wouldn't happen here in the US (Law Professor USA).*

The lack of opportunity for family members not only to question medical decision-making, but to simply be involved in discussions regarding treatment plans was inadvertently exposed by an UK Nutrition Nurse Specialist. She similarly demonstrated a strong culture of medical paternity, and the complicity of patients and their families in the following:

*We will all meet to discuss feeding options for the patient, like the doctor, myself, the dietitian and the pharmacist, and the doctor heads up that meeting...and if he says 'no you shouldn't feed this person, then, at the end of the day, the doctor is in charge of things and takes that responsibility (Nutrition Nurse Specialist UK).*

The obvious comparison between these selected quotations reflect not only the dichotomy that exists between autonomy and paternalism, but also the sharp contrast between geographical margins, that is, the essentially socialised nature of health care delivery in the UK, and Australia, and the private system in the USA. This dichotomy is explored in more detail in a later chapter entitled 'Money'.

### **Ethics Committees**

Several quotes were coded for 'ethics committees', two of which overlapped with codes for 'legal issues' and 'futility'. Only two participants spoke of ethics committees, ethics consults, their use and utilisation. They were a Law Professor and Hospital Chaplain/Ethicist from the USA, and were serving as members of several ethics committees at large metropolitan hospitals, including one not-for-profit teaching hospital attached to a major state university medical school. The advent of such committees was explained as being a consequence of the landmark Karen Quinlan case:

*Interestingly, and I doubt whether you know this but the judge in the Quinlan case read a paper by Karen Teale, who at the time was a resident at Baylor Waco – anyway, she wrote this paper where she used the term 'ethics committee' as one way to solve these ethical/critical issues. The judge read that paper and said 'what you need here (in the Quinlan case) is an ethics*

*committee'. So she actually coined the term. So by now, most hospitals have ethics committees to deal with the issues (Hospital Chaplain/Ethicist USA).*

The process of convening an ethics committee was explained by the Hospital Chaplain/Ethicist (USA) as:

*You can convene pretty quickly...an hours notice to get three or four of us together like for an emergency sitting, and we always get someone from the community attending the committee for 'arms length' so it is not just us going on...the person from the community could be a social worker, could be a retired physician – um, we have a psychiatrist, we have an attorney, and someone from the consumer health forum, and if they can't be there in person, then we have had them on speakerphone (Hospital Chaplain/Ethicist USA).*

This raises an interesting deficiency in those hospitals that do not employ such a committee to deal with ethical consultations. The nature of the 'ethics committee' in the UK and Australia by and large only convene for monthly or bi-monthly meetings to review research proposals, and are essentially for the ethics review of research. This involves clinical trials, ethical conduct in research involving humans, and animal subject research ethics issues. The nature of their work does not involve discussing those 'ethics consults' as described by the USA participants, which includes those cases requested by patients and their families. Once again, the power of the health consumer is clearly visible within the context of privatised health care.

The assumption that the function of ethics committees outside the USA is deficient in terms of providing a function beyond the review and critique of research is supported in the literature by its very absence. For example, the BMA refers to ethics committees as the mechanism for monitoring and approving research. The function and composition of these committees pertain only to research; whether the scientific quality of the protocol is properly assessed; whether the investigator is competent; possible hazards to trial subjects and precautions taken to deal with these; measures for providing information and seeking consent; recruitment of subjects; and, storage of data (BMA 1998). In the

USA, the forum utilised for these purposes is termed the 'Institutional Review Board' (IRB). There is possibly the danger of trans-Atlantic differences in terminology in this comparison, however there is a notable shortfall in the literature outside the USA that describes institutional committees that provide a forum that is multidisciplinary in composition and deliberately designed to be only advisory in nature, for the consideration of clinical cases of ethical conflict (Singer *et al* 2001).

The legal practitioner participating in this research maintained that most members of ethics committees would more likely take the side of the patient with the view that the patient and family have different values and goals than their treating doctors:

*It is just another way of saying who gets to define the values of medicine and the goals of medicine – is that a professional standard that doctors get to write for themselves or is it a social standard that patients could influence treatment decisions as much as the doctors do? (Law Professor USA).*

This not only highlights the active role of the patient/family as a powerful consumer of health care, albeit in a predominantly private setting such as the USA, and similarly exposes a deficit within the function of ethics committees within socialised health care settings. Another possible deficit could be the actual composition of such committees. A King's Fund report remarked on the dominance of hospital doctors who constituted more than half the total membership of 222 ethics committees in the UK, and the under-representation of lay-people, women and nurses in the overall membership (BMA 1998).

The success of such committees was emphasised by both participants, and both described the utilisation of the committees as increasing. For example, in one hospital the ethics committee had already met 32 times in an eight month period at the time of interview (that is, January to August) which was a record compared to the 29 times for the entire year before. Both described the advantage of the ethics committee was that 'everybody wins' including the family, the patient, and the hospital:

*It is a win-win situation – like, if the patient wants a good death, they get it, or they get treated if they want (Hospital Chaplain/Ethicist USA).*

And:

*I think that they are a really good thing, and not because of the quality of decision-making, not because we get to the right answers more often than not or anything like that. There is more to it than that...I think though that in terms of what benefits the patient and benefits the family, um, we provide a process for dispute resolution, joint decision-making that brings people into the discussion that clears up factual misconception and allows people a forum to express preferences and beliefs, shows those preferences and beliefs a healthy amount of respect...airs differences, finds areas of agreement, narrows areas of disputation, and um, finds more often than not at least some narrow basis of agreement to proceed with. Then we can reassess it if it is necessary and see how we all feel about it, and at that, that is a pretty beneficial process for most of the disciplines (Law Professor USA).*

The other advantage of the ethics committee was explained in terms of the law. With the advent of futility policies in some institutions and their absence in others, the role of the ethics committee was described as important in terms of legal consequence especially in those cases where the hospital was being sued for withdrawing life-sustaining support such as the provision of artificial nutrition. One participant stressed emphatically that ethics committees do not make treatment decisions, nor do they decide a patient's quality-of-life:

*About a month ago I was involved in a case where the hospital and physicians were being sued, and the ethics committee had met on this case, and basically said that they thought that it was ethical to make the patient a category three which, with the family's consent, would allow for the withdrawal of aggressive treatment allowing the patient to die a natural death. Well then the family had second thoughts later on and got an attorney...he tried in every which way to get me to say that we had made a treatment decision – which we don't – the ethics committee does not make actual treatment decisions. For the treatment to be withdrawn the family had to go to the doctor and say 'yeah,*

*we want everything to be withdrawn' .....we did not do that, the family did.....so the physicians and the hospital were backed up by the ethics committee so it is one more plug for decent support for them. The ethics committee helps out a lot – for everyone. And I think that is the reason everybody is using us a lot more (Hospital Ethicist/Chaplain USA).*

Clearly, the benefits of employing such a forum as explained above are obvious, yet such forums are only discussed in the literature pertaining to USA institutions (Skeel and Self 1989; Danis 1998; La Puma and Stocking 1993; Fine 1998) which raises the question as to why 'ethics consults' do not appear in the other systems/countries? One explanation could be that the 'ethics consult' represents a stronger consumer expectation. This possibility is discussed in the Chapter Five 'Money'.

### **Access**

This discussion point was raised several times by the following participants: a Gerontologist (USA); a General Surgeon (USA); a Nutrition Nurse Specialist (AUST); and a Hospital Pharmacist (AUST). Access to basic care such as feeding was raised only once, and the remainder of comments regarding access was to do with resources. Basic care, that is, the simple provision of nourishment to a patient was considered a fundamental right in the eyes of the family:

*People, sick or not sick, need access to food for survival...we can never deny anyone that – be it via a tube or a plate of food in front of them (Gerontologist USA).*

This description of a person's fundamental right to be fed was associated with a fear of starvation. In a later discussion of the symbolism of 'food' and 'starvation' (in Chapter Six 'Culture'), the denial of such basic care evoked powerful and emotive responses. Not having access to nutrition was deemed cruel and inhumane by a variety of participants. Yet the above participant's view was the sole contribution in the data of access to basic care. The remaining participants mentioned access to expensive technologies and the possible discrepancies or injustices between public and private health care delivery systems. Essentially, this was related to the ethical principle of justice, which overlapped

with the code 'Who Pays? – Resources'. One surgeon explained the possibilities of expensive nutritional support (TPN specifically) being denied to patients in an attempt to save money:

*I can see certain environments where they are really into cost cutting...like what Managed Care is doing...I mean, I think it is a real concern that if a person really needs TPN, and it is not a matter of having it or not, don't get it. That is bad...and yeah, there maybe some situations where people might do that. We don't do that here. We just don't do that. We think that if a person needs it we are going to recommend and fight like hell to make sure that they get it (General Surgeon USA).*

Similar views of cost cutting were explained by a Nutrition Nurse Specialist who commented on those patients who might really need TPN for survival. She shared an experience of a man who was terminally ill and essentially dying yet would be able to survive for a few more weeks (in order to celebrate his daughter's 12<sup>th</sup> birthday) if he received TPN. At a cost of approximately \$1500 a week for the provision of home treatment and back-up nursing care, the man said that he would pay for it himself as he was not privately insured and the treating hospital did not provide TPN to dying patients:

*He said he would pay for it out of his own pocket, and at first I thought that all of the problems had gone (because it had been a real bun fight sorting it out)...and then I thought about it and thought about it and realised that we were getting ourselves into a horrible mess about equity of access – I mean what would happen to another person without the funds? We would not provide it, and ethically to me, that is a problem (Nutrition Nurse Specialist AUST).*

This occurred within a strictly capitated health care region under severe budgetary constraints where finite funds were allocated annually for the provision of home TPN to suitable patients. Although it was not mentioned at the time, this problem correlated with experiences shared elsewhere in the data about patients forced to 'live off' their children's inheritance in order to pay for certain treatments that could prolong their lives. Paradoxically, another participant explained a common occurrence whereby private patients did not have the same access to nutritional technologies as public patients, and



were thereby clinically disadvantaged. His experience stemmed from that fact that most private hospitals (in Australia) do not have the facilities to manufacture and provide TPN, and that the expertise in doing so is considered to reside within the public hospitals:

*A situation that is not uncommon to us is when a privately insured patient who has had their procedure in the private hospital runs into problems and really needs TPN...yet doesn't get it because they don't have the same facilities. So what happens is that these patients get right behind the eight ball and the wheels fall off. They then get transferred to the public hospital and we bail them out ...usually in the intensive care unit which means that we have to move a public patient out of the ICU to accommodate the private patient...and ethically, well I don't know how to feel about that (Hospital Pharmacist AUST).*

This interesting contrast raises other sceptical possibilities regarding the potential for the public hospital to generate revenue from the transferred private hospital patient to the public hospital campus for expensive treatment. Despite an exhaustive search, these possibilities of questionable access to expensive nutritional technologies for privately insured patients, and the premature discharge of public patients from the ICU in order to accommodate revenue generating patients transferred from private hospitals were not found in any of the literature reviewed for this project. Despite this 'evidence' as contributed above being anecdotal, the mere suggestion deserves further inquiry.

## **Consent**

The question of consent was raised only twice – both times by Nutrition Nurse Specialists, one from the UK and the other from Australia. In both cases, consent was discussed within the context of commencing artificial nutritional support. Firstly, the participant from the UK explained the reality of no legally binding form of consent by way of a family member to support the provision of artificial nutritional support. Her comments also embody certain overtones of previously described medical paternalism:

*Well sometimes the family can be very difficult, I mean...we know that starting feeding in particular patients just isn't fair on anybody, and the relatives are demanding that the patient be fed (and we don't want to do that)...so sometimes they think that*

*you are putting up barriers up just to make life very difficult. In a court of law, their consent is not legally binding, but their insistence still makes it very difficult to treat the patient properly (Nutrition Nurse Specialist UK).*

Not surprisingly, the view of the British Medical Association on the autonomy of doctors supports this experience. Consent and autonomy are explained as not being the sole prerogatives of patients and it is not only the patient who has rights of consent and refusal. Doctors provide treatment, not simply because it is requested or consented to, but because in their view it is clinically appropriate (BMA 1998).

The technicalities of consent, be they legal or discursive deserve a certain analysis within the context of commencing and then providing artificial nutritional support. Consent to provide a particular procedure, for example, the surgical placement of a percutaneous feeding tube, does not necessarily mean that consent is provided for the actual feeding of the patient. This was explained by the Australian Nutrition Nurse Specialist:

*When the patient can't take anything by mouth then a drip is initiated, but there is never consent given for that drip. Nor is there consent given for the nasogastric tube placed a few days later when the patient needs more than IV fluids. It is really only when we get to the provision of more invasive access such as a PEG, or a long term central line, or port – that we actually start initiating consent...and then it is for the actual procedure rather than the actual provision of nutritional support. So the consent is for the invasive procedure rather than for the artificial feeding, and I think that as far as explanations to relatives, patients, families and that go, I think that often it is assumed that they realise what the access is for (that is, artificial means and high technology means for the provision of nutritional support), however, often they don't. And, quite often it is not until they have been having the feeding for some time that the family will query as to whether the patient should be having it, and whether they actually asked for, or wanted it in the first place (Nutrition Nurse Specialist AUST).*

The consequences of consent, such as in the case above, being somewhat misconstrued, have not been described in the literature reviewed for this project. The

clarity of communicating such consent would appear as being the deciding factor in avoiding such conflict. The above narrative also implies a notion of tacit consent or a 'taken-for-grantedness' in that what might constitute ordinary care (that is, 'a drip') for a clinician might be extraordinary for the patient. Undoubtedly the recognition by doctors that patients usually know better than anyone else what is best for them imposes a duty upon doctors to empower patients to make their own decisions. These decisions however, need to be based on information and support that is not beyond their comprehension. As one Oncologist (USA) lamented - *'there would be no ethical problems encountered by doctors at all if they only communicated with their patients'*.

### **Beneficence**

Undoubtedly, the most surprising omission in the data was the principle of beneficence. Despite several explanations of 'benefit versus burden' within the context of medically futile treatments,<sup>10</sup> only one participant alluded to beneficence in terms of nutritional therapies being of benefit to patients. This participant was a clinical dietitian who specialised in enteral feeding access devices. Her main ethical problem was that nutritional support was potentially harmful to many patients:

*My main concern is to do no harm, and all treatments can be potentially harmful, and TPN can be far more harmful than many people realise...and enteral feeding can be harmful too if we talk about aspiration and tube site breakdown, but the metabolic effects of TPN can kill you too. We gotta realise what we could be doing to these patients...by thinking that we are treating them we could be harming them. We gotta be mindful of the complications (Dietitian USA).*

The many complications associated with artificial nutritional support were discussed elsewhere in the data yet not specifically with harming the patient. In a subsequent review of the literature of enteral feeding tubes and mortality rates post tube placement in the elderly, it was discovered that mortality rates as high as 40% post insertion have been reported.<sup>11</sup> The failure of the participants to mention these complications could be

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<sup>10</sup> The subject of medical futility is explored and discussed in detail in Chapter Eight 'Futility'.

<sup>11</sup> See Chapter One 'Review of the Literature' (p.19) and Chapter Nine 'Technology' (p. 244) regarding complications of artificial nutritional support.

indicative of a certain ignorance amongst professionals of the realities of the complications associated with artificial nutritional support.

## Conclusion

A closer analysis of the narratives in this chapter exposes a certain complexity as to what is implied by the participants' discussions on the 'ethical principles'. Ethics, as a discursively shaped and negotiated construct is not solely about principlism. Despite the participants embracing the principlist language, they may also be seen to be exhibiting virtuous behaviour as well as what Braunack-Mayer (1999) describes as casuistry. Therefore, the analysis of the narratives shared in this chapter highlights an interesting paradox in that the participants incorporate tacit notions of principlism yet attest to virtuous behaviour.

Amongst the most quoted principles in the history of codes in medical ethics is the maxim *primum non nocere* – above all do no harm. The fact that only one participant mentioned this possibly suggests the lack of 'ethics' awareness across the health related disciplines. Similarly, despite the doctrine that autonomy, beneficence/non-maleficence and justice are ethical principles rooted in Western tradition, the lack of what was an expected emphasis on these principles raises some interesting questions. Could this reflect the realities of the professional perceptions of ethical principles as being derived from practice and not from theory? Instead, the experiences and viewpoints derived from practice shape the relevance of ethical principles and the emphasis afforded to these. An interesting inclusion was the discussion of medical paternalism, which permeated the other discussion points. Could it be that medical paternalism is alive and well throughout the experience of health care to the point where it is tacitly taken for granted? In relation to the provision of artificial nutritional support, it appears so and therefore is worthy of further exploration. So too is the discrepancy between health care systems relating to the functions of ethics committees.

Ethics 'at the bedside' with regard to the clinical function of the ethics consultation as explained by the American participants certainly lends itself to a more thorough

appreciation of the ethical principles than the somewhat staunch and limited 'IRB' function of the ethics committee as explained by the UK and Australian participants. This restricted view does not appear to be developing further, as a recent publication demonstrates the finite role of the ethics committee in Australia within the bounds of research ethics mechanisms (Komesaroff and Cohen 2001).

There is much to be said for the development of multidisciplinary ethics committees in Australia which serve as an advisory forum with regard to clinical decision-making in a variety of health care settings. Like the USA, Australian human research committees need to recognise lay participation as important and to affirm the diversity of views with regard to the contested socio-political spaces which are discursively shaped as ethics, quality and clinical practice. There is not a better illustration of the variety of views in health care than is to be found in those discussions of the concept of 'death', which is the subject of the next chapter.

## CHAPTER FOUR

### DEATH

#### Introduction

The major theme entitled 'Death' was formed by the merging of the overlapping codes: Process of Dying – Death; Palliative Care; Buying Time; and Cancer. Artificial nutritional support was considered by the majority of participants as being one of the most difficult life-sustaining treatments to withdraw in an end-of-life situation. This subject of death, (and/or end-of-life issues), was granted more emphasis than the researcher expected, and permeated other related subjects, or discussion points that also were not anticipated. These included the influence of film and television media on peoples' perceptions on death, the 'medicalization' of death, the lack of acceptance of palliative care by other medical specialties, and primarily, the notion of 'buying time' in end-of-life situations. Another interesting discussion point arising from the interviews was that of education and the lack of acceptance of dying as a normal physiological end point of life, and the possible origin of that being a notable shortfall in current medical education on death and dying.

The following discussion points that are explored in this chapter were named according to the participants' own wording and descriptions. These are: Medicalizing Death; Good Death Care; Buying Time; and Demystifying Death and the Media. Not all participants considered death and dying as relevant to the provision of artificial nutritional support. Those who did consisted of: Two Palliative Care Physicians (AUST); two Oncologists (USA); a Hospital Chaplain/Ethicist (USA); a Nutrition Nurse Specialist (AUST); a Medical Social Worker (USA); an ICU Nurse Specialist (USA); a Gerontologist (USA); a Critical Care Physician (AUST); a General Surgeon (AUST); a Nutrition Nurse Specialist (UK); a Hospital Pharmacist (AUST); a Health Services Administrator (USA); a General Surgeon (UK); and a Dietitian (USA).

## Medicalizing Death

This discussion point encompassed several related issues, mainly overtreatment and ignorance in providing appropriate end-of-life care. Essentially the participants described death as being unnecessarily medicalized by the inappropriate continuation of aggressive nutritional support, which often led to more clinical complications thus expediting the patient's death, or creating increased discomfort. Several reasons were provided by the participants as to why this might occur with a 'lack of acceptance' and 'ignorance' being given. Participants who spoke of this included: a Hospital Chaplain/Ethicist (USA); a Medical Social Worker (USA); two Palliative Care Physicians (AUST); a General Surgeon (USA); a Dietitian (USA); and a Health Services Administrator (USA).

The act of medicalizing someone's death was explained by one participant as being possibly inadvertent due to a lack of understanding of the physiological process of dying. He explained that regarding nutrition, many dietitians would be concerned that patients (those who were actually dying) were not getting enough nourishment by mouth to meet their requirements and would need to have either enteral or parenteral alimentation. His disbelief of the ignorance associated with a dying person's nutritional needs was poignantly captured in the following quote:

*Well of course they can't meet their nutritional requirements...they are azotaemic!! They aren't supposed to be eating anything because that is the way people die, and I think that we have largely forgotten how people die in the last 50 years because we have medicalized death and confined it to medical settings. So if anything, I think that the emphasis on clinical nutrition is way overdone – and that is not well understood by most professionals, let alone patients and families (Hospital Chaplain/Ethicist USA).*

Several supporting arguments were located in the literature regarding dying being associated with increasing institutionalisation. Lerner (1970) claims that an estimated 80% to 90% of all deaths take place in hospital or a long-term care facility. This is echoed by Meyer (1998). Corr (1993) argues that 100 years ago, roughly the same percentage

of all deaths would have taken place in the home, and that most people now die in a strange place, in a strange bed, surrounded mostly by sights, sounds, smells, and people who are strangers to them. In short, direct encounters with all facets of death have been diminished in our modern society. Care for the dying and care of the dead has been moved away from the family and out of the home into a medical setting.

Azotaemia is described by Meyer (1997) as a condition in the which the body's waste nitrogen products become elevated in the blood. The role of azotaemia is described by the same author in a later publication as being something that results in a good death. As dehydration occurs, waste products build up in the body and serve as natural analgesics to insulate the body from pain. The patient becomes tired, sleepy, less and less conscious, falls into a coma where all pain ceases, and eventually dies. Attempts at medically reversing this process by maintaining artificial nutritional support creates a bad death by waking up the patient so he or she can fully experience suffering and death (Meyer 1998). Similarly, Jett (1995) claims that decreased nutritional intake and dehydration are the natural state of the dying organism. This process was mentioned by only two other participants in the entire research.

This sentiment was also reiterated throughout those comments coded under 'Palliative Care'. For example, one Palliative Care Physician (AUST) explained that occasionally medicine will prolong people's suffering inadvertently through the provision of artificial nutritional support. She explained that as a normal part of the dying process, the person will stop eating and drinking as the body finally begins to wind down. If artificial measures to both nourish and hydrate the patient are commenced at this stage, it can cause undue pain and suffering:

*They should just be allowed to fade out...which is what they would be doing if we didn't interfere in that process (Palliative Care Physician AUST).*

Another Palliative Care Physician (AUST) expressed an identical view on not interfering with the patient's natural process of dying, yet in more physiological terms:



*When somebody enters that active stage of dying and stops eating, drinking...well there is a lot of work that has been done to show that the body kicks in with natural endorphins, encephalins that are produced when people begin to die – like natural pain relief....which we switch off as soon as we put up a drip or put in a feeding tube...and why should we be stopping a natural process? (Palliative Care Physician AUST).*

This process was also mentioned by an Oncologist (USA) whereby the initiation of artificial nutritional support in a dying person would render the patient more alert to the point that they would lapse back out of a comfortable slumber and realise that they ‘...were in pain, dying and very uncomfortable’. A General Surgeon (USA) also upheld the patient’s right to be protected from a medicalized death:

*The feeding of a terminally ill patient is in many ways detrimental to a peaceful death, and, in many ways, that feeding causes far more complications than the patient deserves (General Surgeon USA).*

There is ample evidence in the literature that minimal nutritional intake and dehydration may enhance the comfort of the dying patient by decreasing secretions, oedema, pain, incontinence, cardiac load, and pulmonary distress (Andrews et al 1993; Billings 1985; Musgrave 1990; Stone 1993). However, as the participants continued with their stories, it became clear that their experiences involved continuous aggressive feeding in dying patients. Ignorance of the realities of dying that was evidenced by the medicalizing of a debilitated nursing home patient’s death was also expressed with a degree of sarcasm and disbelief:

*[gestures with eyes rolling and holding up hands]...I mean...HELLO, is any one home??? It can't be that difficult for these people to realise that a debilitated demented frail aged person who needs to have their legs broken to get the PEG in is probably not going to do too well. I see this all the time. Why can't they just let them go – I mean, excuse me but when someone is in their 90's, has terminal everything and has been circling the drain for years, why the heck would you want to put them through more suffering and treat, treat, treat? (Hospital Chaplain/Ethicist USA).*

The incidence of frustrating encounters such as the above was higher than anticipated. A Medical Social Worker explained that she dealt with death being medicalized everyday. Her experiences were more to do with dealing with the consequences of complications of when aggressive medical treatments went wrong in dying patients:

*I deal with it everyday, and I am sure that these patients die prematurely because they get aspiration problems from their feeding tubes and end up choking to death...or their tube gets infected and then they get septic and die in pain. Both the family and the doctors are at fault here...they just don't accept the fact that these people are dying and should be made comfortable (Medical Social Worker USA).*

The sole Health Service Administrator interviewed for this study reflected on her experience in caring for her father who was dying with lung cancer, close to death, yet the physician caring for him ordered nasogastric feeds. The following quote captures similar tones of disbelief in unnecessary medicalization of what is clearly a process of active dying:

*Just before he died it happened – they put a tube in and started feeds. It woke him up and he was so wild and aggressive to all of us. We held his hands to stop him from pulling the tube (at first), and they were going to restrain him. I couldn't believe it, so I let his hands go and he pulled the tube out...he pulled the tube (smiling)...it didn't impress the doctors but too bad I thought. It was a good thing (Health Service Administrator USA).*

The patient's death therefore could then be possibly prolonged and unnecessarily medicalized due to what essentially is an ignorance of palliative care, or as one participant described as 'good death care'. A subsequent review of the literature found that measures to improve such ignorance and lack of end-of-life education on how people actually die were only just being recently incorporated into medical education. This surprisingly was only occurring in the USA where programs (such as the EPEC Project)<sup>12</sup> were being implemented into medical curricula and continuing education

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<sup>12</sup> Education for Physicians on End-of-life Care which is sponsored by the Robert Wood Johnson Foundation, and reviewed by the American College of Medical Education.

programs thereafter to address the knowledge deficit in end-of-life care. In February 1999 the American Medical Association launched the EPEC Project which facilitated subjects including but not limited to:

- Decisions about life-sustaining treatment
- Discussing poor prognosis
- Accountability and quality of care at the end of life
- Grief and bereavement
- Accommodating religious and cultural diversity
- Addressing concerns about the law
- Caring for the dying
- Do-not-resuscitate orders
- Forgoing medically supplied nutrition and hydration
- Medical futility
- Ethical decision-making
- Management of pain
- The physiology of dying
- Organ donation
- Family issues
- Communication skills

However, such attempts to improve end-of-life education was more the exception than the rule. The general assumption via the literature (compounded by the absence of similar programs in the UK and Australia) suggests that there is little or no teaching on the subject of what to do when a disease cannot be reversed. According to Seravelli (1988), most medical schools do not teach palliative medicine in undergraduate curricula and as a result, most medical students evolve into doctors who are keen to treat the curable conditions, yet have little training in what to do with chronic irreversible conditions. Seravelli (1988) argues that this omission makes it difficult for doctors to deal with their own sense of therapeutic failure. Doctors are consequently socialised to consider medicine's technological 'rescue imperative' (Meyer 1988:10).

### **Good Death Care**

The title of this discussion point is essentially the very foundation of what palliative care strives for, yet in a subsequent literature review following the data collection phase, this term was located only once (Meyer 1998). Eleven participants considered palliative care as a medical specialty to be paramount in the ethical decision-making of the provision of

artificial nutritional support. They included: a Gerontologist (USA); two Palliative Care Physicians (AUST); a Health Service Administrator (USA); an Oncologist (USA); two Dietitians (USA); a Hospital Chaplain/Ethicist (USA); a General Surgeon (UK); an Oncology Nurse Specialist; and a Hospital Pharmacist (AUST).

The success of striving for a good death in terms of the ideals of palliation were sometimes thwarted by the unrealistic demands of the patients' relatives to continue with artificial nutritional support which they considered to be a life preserving treatment. Most participants agreed that this was a particularly difficult scenario to deal with, yet the important thing was to convey to people the reality that withholding such support would not contribute to the death of the patient. For example, a Gerontologist (USA) explained that:

*I know for a fact that nutrition will not keep them alive...I mean if we give them tube or IV feeding they will die in a few days and maybe weigh 42kgs versus not feeding and they die in a few days and weigh 40kgs. Nutrition cannot prolong a patient's life when they have end stage malignancy (Gerontologist USA).*

The idea of the disease killing the patient and not 'starvation' was also suggested by the following three participants:

*The cancer will kill them and not the fact that they are not being fed. Sure you can feed them but the cancer will eventually spread to the bronchus and they can't breathe and die. No nutritional treatment is going to stop that from happening (General Surgeon UK).*

*The biological process of the cancer or the degenerative disease like motor neurone disease, that is going to ultimately bring about the person's death – the disease process is inevitable irrespective of what we do, we cannot stop the actual process of death as an outcome (Palliative Care Physician AUST).*

*The malignant disease will cause the patient's death, but so could enteral feeding where you cause aspiration pneumonia. It*

*is not a life saving measure and has no role in palliative care of a dying patient (General Surgeon USA).*

The premise that artificial nutritional support did not have a role in the provision of good death care was agreed upon by most participants. Comments such as '*the use of artificial feeding is not really part of the palliative care culture*' (Palliative Care Physician AUST), and '*feeding is not an issue in palliative care – it is usually stopped before the patient is transferred to the palliative care unit*' (Palliative Care Physician AUST) sum up the basic assumptions that PN or EN did not have a role in palliative care. Bruera and Fainsinger (1993) support this assumption by maintaining that with the exception of extraordinary cases, the use of artificial nutritional support does not have a role in palliative medicine. This view was also supported by the belief that palliative care needed to be acknowledged as a medical specialty with a discreet body of knowledge and wisdom which was unfortunately, for some participants, not recognised:

*Unlike most other specialties, we in palliative care do know the endpoint – we know the outcome, so we actually have a bit more authority in the practice of doing no harm. Unfortunately we often don't get taken seriously. Other units refer to us to clean up their mess. That is a shame, and I hope it is changing (Palliative Care Physician AUST).*

Avoiding the provision of artificial nutritional support yet still providing good palliative care was explained by one participant as something very basic, that is, good mouth care. Oral hygiene is described in most nursing texts as being basic care to ensure a feeling of well being (Ferrel and Coyle 2001; Laporte and Witt 2001; Norlander 2001). The act of providing the same in a dying patient was described as being potentially life prolonging by one participant:

*Mouth care is so important in these people...they can absorb all the fluid they need through their mouth. If someone can't drink, then you sit with them with a little bowl of water, some ice, some swabs, and keep the mouth moist, keep their lips moist. They can't get as much water as they can through artificial means, but what you are doing is replacing the insensible losses and they*

*have their mouths beautifully cared for, and they can survive comfortably for weeks without anything else because they have good mouth care going on (Oncology Nurse Specialist USA).*

The provision of mouth care was mentioned just once yet alluded to other forms of basic comfort care that would be given in lieu of complex treatments, for example, parenteral feeding. Avoiding the initiation of artificial nutritional support has already been explained in terms of avoiding the unnecessary medicalization of death, and avoiding the associated complications of such treatments, yet in the palliative care setting, the participants gave a further reason. The difficulties experienced in withdrawing a treatment once it had already been started, was problematic for most participants. It was much easier not to start treatment than to cease it. For example:

*It is much easier to not commence nutritional support than to reason with family about discontinuing it....it is difficult once you are in an established mode of treatment to work out how to get out of it when it is clear that it is either not working or doing more harm than good (Palliative Care Physician AUST).*

This opinion is resounded throughout the medical futility literature regarding the withholding and/or withdrawing of artificial nutritional support. Yet in terms of when patients were referred to palliative care settings with artificial nutritional therapies in place created a hurdle for those involved:

*Despite making it one of our stipulations that before we take anybody on to our unit that PN or EN will not be continued, and although we make very clear to the referring medical unit, that unit occasionally fails to communicate to the patient that this is what happens. It is like they cannot bring themselves to discuss withdrawal with them – so they dump it on us, and it makes for a very awkward situation (Palliative Care Physician AUST).*

The 'fallout' generated by the lack of communication was described as being destructive both in terms of ongoing palliative care treatment of the patient and their family, and the continued relationship with the referring unit. This could essentially be the result of a process of denial, which is related to the lack of acceptance and ignorance of the dying

process as described earlier in this chapter. By and large, the role of artificial nutritional support in palliative care was agreed upon by the contributing participants as being inappropriate. However the withholding or withdrawing of such treatment was not viewed as cruel, or clinically problematic, and as the following quote suggests, be far more beneficial to the patient in terms of prolongation of life and comfort care:

*Withdrawing feeding from someone who is dying often prolongs their life – with good mouth care and sublingual absorption keeps them comfortable and free from feeding related discomfort. It is good care. That is what it is all about (Palliative Care Physician AUST).*

The concept of good death care was not confined to discussions of dying in a palliative care setting. An interesting aspect of death in hospital was that of death in a critical care setting. Several participants spoke of 'hi-tech' deaths in intensive care units which were both common and predictable. As one participant stated '*a lot of people die in ICU*' (ICU Nurse Specialist USA). The notion that death occurs frequently in this setting, yet is devoid of the same 'palliation' as would occur in a palliative care setting, was suggested in several ways by one Oncologist. He explained that patients were not supposed to die in critical care settings, meaning that 'intensive care' meant exactly that – intensive caring to ensure that life was preserved at all costs. He went further to justify the difficulties inherent in providing good death care in these settings due to nature of sudden and/or catastrophic illness that renders a patient in a critical condition with no warning:

*In order to prepare for death, and to do it well, you almost need the involvement of the patient, and a lot of the time in the ICU setting...you don't have that kind of time...so you are left with the family to do that on their own. It is one of the advantages of oncology – if there is an advantage...that we have some time to involve the patient so that they can take the lead in preparing for dying. But in the ICU you don't have that – plus you have a catastrophe in which the family is not prepared for. Consequently death in the ICU has a tendency to be...um...not so good (Oncologist USA).*

It is interesting here to reflect back to the principles of autonomy, beneficence, nonmaleficence and justice when discussing the concept of death (and lack of palliation) in the ICU setting. Firstly, the patient is not autonomous in that they are, more often than not, heavily sedated, nonresponsive and comatose. Secondly, many of the hi-tech treatments provided to sustain life are coupled with significant adverse reactions and side effects, therefore potentially doing the patient harm. And thirdly, the monetary nature of many treatments is exorbitant. Therefore it is casuistry and/or virtue ethics at work here. Consequently, the treatment of a critically ill patient in the ICU setting significantly challenges the fundamental principles of medical ethics in many ways. This view does not feature the literature, albeit one source which was located during a subsequent literature search post data collection (Downie 1996). Whether this paradox contributes to the deficiency in 'palliation' for patients who are essentially dying in the ICU is a theory warranting further inquiry.

In relation to withdrawing treatments such as artificial nutritional support in a critical care setting where the patient is dying was considered more difficult than in oncology and palliative care settings. An interesting notion of 'not on my watch' was insinuated by one participant who explained that physicians do not want the responsibility of withdrawing treatment and often avoided making those decisions. This was explained also in the context of moving dying patients out of the critical care setting to die elsewhere:

*It is awful to think that the ICU can't take that kind of responsibility and give good death care...like they might want to keep their unit mortality rates down, and ship them downstairs to another ward where another group of strangers will look after them. I can't prove that, but I know it goes on (Hospital Chaplain/Ethicist USA).*

Another interesting inclusion to the discussion of good death care was a term coined by one of the participants, that is, 'Life's Short...Eat Dessert First' (Palliative Care Physician AUST). Apart from seeing this quote printed on a bumper sticker and parfait glass since the time of the interview, it was nowhere to be found in the related literature. This



expression was described as being both a nutritionally sound and enjoyable method of maintaining a well nourished state in the terminally ill person:

*I tell people, life's short, eat dessert first...it is a nice way of telling people how to feed someone with cancer...their energy levels are going to be low, their only means of getting sustainable energy is through the sugar/glucose cycle, so let them have their dessert...they can eat whatever they want to from their main course after that, and make sure they get all the rubbish they ever wanted to eat but were never allowed to. Giving someone with advanced cancer a health diet to prevent cancer is ludicrous (Palliative Care Physician AUST).*

The complex oncological specialty of bone marrow transplant (BMT) was highlighted by one participant as being worthy of special consideration with regard to aggressive nutritional support. However he explained that these patients were extraordinary in that the treatment should always be short term with a finite end point:

*The finite end point is that the patient is going to die...and that doesn't make that much sense after all the aggressive treatment that they may be going through with BMT, or have already gone through, and TPN or enteral feeding may or may not make the patient more comfortable. It certainly ties them to the hospital and ties them to procedures that they may be better off without (Oncologist USA).*

Despite the general agreement that artificial nutritional support was indicated in the treatment of patients undergoing BMT (agreement via the participants and related literature), the above quote reminds us that such treatment is not without its drawbacks. Serious illness (namely septicaemia leading to death) related to parenteral feeding via central venous access in the BMT patient is well documented in the related literature (Kennedy *et al* 2000; Lina *et al* 1995). This raises serious questions as to whether there is a gap in the treatment ideals and aims between acute oncology care and good death care. Acute oncology has been described as being dedicated to the preservation of life with little tolerance for the inevitable flow of life toward death (Jett 1995). It is important here to differentiate between treating a patient with a diagnosis of cancer (yet is not deemed terminal), and one who is at the end stages of an advanced malignant disease.

It is also important to be mindful of how we define the word 'terminal'. Doyle *et al* (1997:11) claim that 'terminal' suggests that all is finished, that there is neither the time nor the opportunity to do more, and that active treatment is unjustified and might well be 'undignified'. The Encyclopaedia and Dictionary of Medicine, Nursing and Allied Health (1983) defines 'terminal' as forming or pertaining to an end. Similarly, the Australian Oxford Dictionary defines 'terminal' as forming or undergoing the last stage of a fatal disease (Sykes 1987). The word 'fatal' is paramount in how we utilise the term 'terminal' as not all cancers are actually fatal.

### **Buying Time**

The concept of 'buying time' was explained by several participants as the continuation of artificial nutritional support in those patients who were terminally ill in order to prolong life for a specific period of time. The prolongation of life in these patients was described as an extraordinary measure in order to reach a certain goal, for example, a birthday, an anniversary, or to allow time for relatives from afar to bid their loved one farewell. This concept was not anticipated, and did not feature in the review of the literature prior to the commencement of the research. 'Buying Time' was mentioned by nine participants who comprised of: Two Palliative Care Physicians (AUST); a Critical Care Physician (AUST); two Oncologists (USA); a Medical Social Worker (USA); a Nutrition Nurse Specialist (AUST); and a Hospital Pharmacist (AUST). Essentially, the participants were clear in offering strict practice guidelines in the implementation of a 'buying time' strategy and some shared detailed stories from practice where 'buying time' with artificial nutritional support had been employed in extraordinary circumstances.

The establishment of clearly identified goals for 'buying time' was expressed by most of the participants as being the deciding factor in continuing aggressive nutritional treatment in the terminally ill patient. One Palliative Care Physician offered the following guidelines:

*We must ask the patient what are they trying to buy time for?  
What amount of time are they trying to buy is going to be the  
question (Palliative Care Physician AUST).*

*With artificial nutritional support, the emotive issues aside, it has to be asked what clear goals are you trying to achieve? If there is no means of battering the cancer into submission then nutrition is not going to help...but...if there were some clear goals that the person had, like they couldn't eat and wanted to make it to his daughter's wedding in two weeks time, and could be put on TPN for two weeks, then I would be the person who would argue for it. Yeah, withdrawing it after the wedding and then allowing the normal process to take its course. A clear defined goal is probably a very important thing to have when initiating expensive treatments that way (Palliative Care Physician AUST).*

Two participants spoke of realistic goals when 'buying time' as being ultimately short term. These two interviews in particular were conducted in August 1999, and both participants explained that with their patients (at that time) they did not talk of reaching the new millennium. Short-term goals that were realistic were described as being:

*The family reunion in two weeks time, or other urgent short term goals like that are not out of the question, but we don't talk about making the 2000 celebrations (Oncologist USA).*

*I do not have a problem with buying time in certain cases, like it is fine to say yeah let's keep going with TPN for the next two weeks because the patient wants to make it to a child's birthday, but I not sure if you could justify it so they could see in the millennium. I mean, that wouldn't be feasible because the underlying disease would get them before that (Oncologist USA#2).*

It is interesting to note here that the time frame mentioned by these participants was exclusively two weeks. Such a definitive period of time appears to be a somewhat vague assumption of 'a fair thing' that is not based on any particular institutional policy or clinical guideline. The origin of the two-week period for 'buying time' is unclear. No reference to it was located in a subsequent review of the literature, which included several Intensive Care and Palliative Care texts (Marick 2001; Lynn and Schuster 2000; Doyle *et al* 1997; Oh 1990).

Other disclosures of the need for realistic goals, and when 'buying time' was unrealistic included the following comments from a Hospital Pharmacist:

*I am quite comfortable with the notion of buying time for very definite goals...identified goals...I mean if it is necessary for a patient to make up with an estranged son, or to get their life in order, well that's fine. I have no problem with assisting and participating in that process – for defined goals. But if it is a case that the patient is terminal, on death's door, morphined up to their eyeballs and about to die then I cannot support that process. But for the attainment of definite goals yes...buying quality time is perfectly OK as far as I am concerned. (Hospital Pharmacist AUST).*

Another participant shared a similar perspective in which 'buying time' for a terminally ill patient would be inappropriate:

*TPN is not going to change the outcome but might be good care for a limited time – I have no problem with that. But I do have a problem when somebody wants to buy time with nutrition in somebody who is actually in the active process of dying where I think it is quite wrong to provide it. That would be a cruel waste of everybody's time (Palliative Care Physician AUST).*

Most participants considered 'buying time' with artificial nutritional support as being worthwhile and reasonable. In the context of critical care, one participant described 'reasonable' as when a patient who did not have a large amount of time to live, would be maintained on all life supporting modalities for various reasons like:

*It is important that their existence is prolonged for a given period of time...like while family get here from England (Critical Care Physician AUST).*

And:

*It is not unreasonable to buy time in malignant disease. I have done that with TPN and the patient survived a bit longer and had some good quality time for unfinished business with her family*

*for which she and her family were very grateful. So yes, buying time is a reasonable thing to do (Critical Care Physician AUST).*

Another participant referred to Elizabeth Kubler Ross' work (one of only two that did in the entire research) with regard to 'buying time' in the case of advanced terminal illness and imminent death. This quote also mentions the importance of 'buying time' for family members:

*Kubler Ross talks of no longer having long term goals but short terms ones which are important and if you can get to those then buying time is worthwhile...it is certainly worthwhile for families (Oncologist USA).*

The most descriptive example of 'buying time' was shared by an Australian Nutrition Nurse Specialist. She explained a situation involving a young man with a terminal diagnosis of metastatic carcinoma of the liver who, secondary to catheter erosion, developed an iatrogenic small bowel syndrome, and due to a high output fistula, could only be maintained with TPN. Both surgery and further chemotherapy were considered as futile treatments in the face of a rapidly progressive disease:

*We talked quite frankly with him and his family of how we could provide TPN in the home and the potential hassles with CVC placement, care and the pump alarming etc. He really wanted to get home...to spend his last few weeks with his wife and young kids...it was heartbreaking, but we were doing the right thing. Most doctors would not have consented to such a costly treatment in the face of death, but TPN afforded him that incredibly precious time with his family in their own environment before he died. In the time before he died, I asked him whether or not he would have gone through it all (CVC etc) to have his home TPN and he said 'yes...most definitely he would'...and his wife...well the bereavement counsellor specifically followed up on it and she said that they would not have changed anything those last few weeks...they felt that his quality-of-life in the fact that he was home and enabled him to time to spend with his kids was precious (Nutrition Nurse Specialist AUST).*

Only two participants offered explanations of having problems with the concept of 'buying time'. The first, an Oncologist (USA), explained that he did not have a problem but the

people who would have a problem with 'buying time' for a patient were health insurance companies. The only participant who did not agree with the concept of 'buying time' was a Medical Social Worker who worked primarily with the advanced dementia patients. She explained that the majority of the patients in her care were artificially nourished via PEG tubes and enteral formula, and most were so severely demented and frail that they were bedfast, noncommunicative and nonresponsive. She expressed a degree of embarrassment during the interview when she awkwardly described some of her patients as being simple 'organisms' and 'stool machines' when commenting on their quality-of-life:

*Keeping them going with PEG feeding I think is wrong – like the patient has no quality-of-life. Many of my patients who are that far gone, I mean...[long awkward pause]...it seems like they are just this organism, they are totally nonresponsive, they are breathing on their own but they cannot talk, they do not respond to painful stimuli, or anything like that. All you are doing is keeping them clean, bathing them, tube feeding them and all they do is groan and poop...this sounds so bad but it is like they are just stool machines. It makes me wonder just what we are buying time for with these patients? (Medical Social Worker USA).*

The concluding question in her quote led on to what became the most controversial of all questions raised in the entire research project, that is, what are people 'buying time' for with the continued provision of artificial nutritional support in the advanced dementia patient? The question in the above case was explained by the participant as 'buying time for who?' when she shared a horrific patient care scenario suggesting abuse and financial gain. Again, the participant took a long time in carefully explaining what was obviously a very disturbing experience, yet one that she obviously felt very strongly about:

*This sounds real bad but I know it is true...that some people...some families or caregivers have ulterior motives. I have this real cynical theory that people continue with PEG tubes – some families want the PEG tube because in some cases it can prolong life...well most cases with our demented patients, and by prolonging someone's life who would receive a*

*welfare payment in a poor socioeconomic community, well that is their way of survival, you know. It is a really twisted thing, but I see it happening. And what is really bad is they are only concerned with the money because in terms of their overall care to the patient, well it is borderline abuse. They keep them alive to get the payment, and they don't care for them in any other way. It is appalling but it goes on...so it brings me back to the question of who exactly are we buying time for – the patient, or the family who benefits? (Medical Social Worker USA).*

This situation was the only description offered by the participants of what could be described as both fraud and neglect. It certainly raised an unexpected twist to the notion of 'buying time' via the provision of artificial nutritional support – one that was not mentioned by any of the other participants in the study nor featured in the literature reviewed for this research. The concept of treatment in such cases as being akin to abuse could possibly be paralleled with discussions on benefits versus burdens of aggressive therapies and their debilitating complications as mentioned in Chapter One 'Reviewing the Literature' (p. 28-29) yet in terms of questionable if not profoundly unethical financial gain, this situation is an isolated dilemma that demands further exploration and inquiry.

Another question arising from the data on 'buying time' has to do with how to withdraw treatment after the 'buying time' period has expired, or the clearly identified goal has passed? The problem here is to ask whether or not it is ethically sound, fair, or reasonable to withdraw life-sustaining nutrition the day after the goal has been reached, for example, the day after the birthday, the wedding, or the family reunion? The treatment has kept the patient alive until now, so is it not fair to assume that it will keep them alive for another two-week period? If so, is it ethically wrong to withdraw nutrition which would expedite the patient's death? This contested notion of justice renders such questions problematic. Only one participant commented on how one negotiates with patients after the goal has been achieved:

*Well then you have to provide more evidence. Usually a patient is pretty well aware of reality, but you can look for other short term goals but you may have to change your parameters – like,*

*well now the short term goal is just to be at home and be comfortable and spend a few more days with family or whatever (Oncologist USA).*

Despite this explanation, the fact that such treatment is dependent upon negotiation if not bargaining, raises questions regarding the act of withdrawing support in these patients. The use of an economic discourse here is interesting. Furthermore, the application of an economic construct of 'buying time' might need a discursive revision considering the finite contract that is being provided. A further exploration of this dilemma is examined in more detail in Chapter Twelve 'Reflections' (p. 284-285) of this thesis.

### **Demystifying Death and the Media**

This discussion point encompassed the experiences of participants who worked in close proximity to dying patients, primarily in palliative care and oncology settings. The concept that death is still granted a considerable amount of taboo and is hidden from view was a common perspective shared by these participants. Whereas 50 years ago when it was common practice for people to actually die at home, surrounded by family and friends, the reality today is that in many communities, death is confined to a clinical setting, and witnessed only by a discreet number of people who then possess a real perception of the process of dying. The misconception of what death might look like was blamed on the media, that is, film and television. This was mentioned by three participants: A Palliative Care Physician (AUST); an Oncologist (USA); and a Hospital Chaplain/Ethicist (USA). The following excerpts from their narratives explain the origins of this supposed taboo, plus the misinformation on the process of dying as provided by the popular media:

*I don't know how many people my age or younger have even seen people die in the home. Now, they just disappear in to the hospital and everybody else never really sees what it is like. Families of dying patients have absolutely no idea how to cope with it...it freaks them out to think that they aren't going to respond to treatment like they do in the movies (Oncologist USA).*



Lack of real information for people involved in end-of-life situations was coupled with comments on their decision-making capabilities being thwarted by unrealistic perceptions of what death might be like, or how it can be avoided, by how it is represented on major television shows:

*TV can be blamed for so much misinformation. The garbage that screenwriters churn out – like what we end up seeing and believing in terms of dying is just abysmal. What happens is that in real life, I have people, family members, making end-of-life decisions based on what they saw on 'Chicago Hope' or 'ER'...basing such decisions on major prime time TV dramas which are 20 years out of date when it comes to dying (Hospital Chaplain/Ethicist USA).*

This participant had an obvious professional commitment of exposing the shortcomings of such television dramas in terms of their misrepresentation of what a real death really is. His concern was compounded by the fact that shows like 'Chicago Hope' and 'ER' are televised all over the world thereby educating millions about what to expect from their health care system – that is, 'free', maximum treatment from which the majority of people recover:

*Let's not talk about nutrition and let's look at CPR rates, you know, like people actually surviving a code. Well the CPR success rates on "Chicago Hope" are about 96%. The truth is that in the United States anyway, surviving a code rates between 12% and 15%...and survival to discharge rates are less than three percent. So you have this incredible disparity about what the public is seeing on TV, thinking that they have to have their family member made a full code because they are going to make it through the code, rip themselves off the ventilator then peddle home on their bicycle a few days later (Hospital Chaplain/Ethicist USA).*

This quote also captures the high expectations on health care that are deceptively transmitted via the news media. Advances in medicine are often over-reported in the media, including the ever-expanding information available on the Internet, and hailed as major breakthroughs. The constant bombardment of the public with news of apparently

miraculous advances in the fight against disease subconsciously raises expectations of health. According to Buckman (1993) it becomes difficult for an individual to face the fact that he or she will not be cured despite the many miracles seen on television or in the papers.

The process of clarifying what death might actually be like, in terms of debunking the perceptions derived from film and/or television was considered a primary function in the role of palliative care. Making sure that both patients and families realise that what they might see on film or television dramas is very far removed from the truth, was a constant battle, especially for one Palliative Care Physician:

*It is a real down turn in the process of trying to do your job...when a family member expects miracle recoveries akin to a TV show, when in reality the patient is in the active stages of dying. I think they feel very cheated (Palliative Care Physician AUST).*

The feeling of being cheated could contribute to a growing amount of scepticism of what medicine can actually do. One Oncologist (USA) also explained that usually with patients and family there is an enormous faith in medicine, yet as more people (be they professionals, patients, their families and friends) see somebody die in hospital, it raises an awareness of what actually takes place. He too commented on film and television dramas contributing to confusion:

*TV doesn't help. I don't know how many times I have had to explain to people that people just don't take a big breath and then snuff it gracefully...it is very shocking for people to accept that in many circumstances there is nothing graceful about peripheral shutdown, cheyne stoking, and so on (Oncologist USA).*

Essentially the failing of film and television medical dramas is that they fail to represent how a person actually dies. A subsequent literature search after the data collection period did uncover several sources in support of these assumptions. Meyer (1998) explains that although the majority of people want their deaths to be quick, painless, at

home, and with family around, in reality 85% of deaths (in the USA) occur in medical settings with 15% of that 85% occurring in intensive care units. These deaths are seldom quick or painless and families and loved ones are kept at bay by unreasonable visiting hours. This belief is supported by Corr (1993) who claims that in many of these institutions, family members are excluded, or are only permitted to be present and participate in limited ways. Because dying is most likely to take place outside of the home (in modern societies), family members are often not present at the moment of death, and learn about a death by a telephone call from an institution. Cleaning, dressing, and preparation of the body – actions that once were regarded as final gestures of love and respect, are now likely to be performed by nurses and funeral directors – not family or loved ones, and not by doctors either.

This 'medicalization' of death featured strongly in the participants' stories and a subsequent reflection to a scene in a movie occurred for the researcher. The movie 'Places in the Heart' which was filmed in Waxahachie, Texas<sup>13</sup> in 1984, involved a moving, yet foreign scene (to the researcher) where a man's body was brought to the family home by male colleagues after being fatally wounded in a shooting. The man's corpse was laid down on the large kitchen table where the women then tended to him – bathing and dressing his bloodied body. The story took place in the post war depression period and typified how death would have been realistically dealt with by family and friends in the 1930's in a small Texas town. This confronting reality is in stark contrast to the aforementioned contemporary dramas.

## Conclusion

Many of the points made by the participants correspond with similar findings in the literature, including the so-called 'death myths' that permeate peoples' perceptions of death. The fact that death is often constituted as medical failure is significant. This is an important factor in the continuation of aggressive nutritional treatment for those patients entering their final stage of life.

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<sup>13</sup> Coincidentally, two of the research participants were from Waxahachie, Texas, and spoke 'off the record' of when the film was being shot in their hometown near a now deserted railway track, thus reminding the researcher of the particular scene.

This situation can be aligned with one of the death myths cited by Meyer (1997:30), namely, 'Death is evil. Death means failure'. Meyer holds that while the church is largely responsible for promoting this myth, the medical profession is responsible for its persistence. In examining the medicalization of death we learn from the participants' contributions that needless suffering may be alleviated by a thoughtful look at our assumptions and biases about proper end-of-life care.

Indeed acting to address misdirected intervention that does not foster a peaceful death demands research. Addressing the shortfall in appropriate death education for medical trainees only factored in the American interviews and literature. It was discovered that major steps were being taken to address this - namely by the Association of American Medical Colleges (AAMC). A 1997 review of medical education by Field and Cassel throughout the USA concluded that medical training failed to provide graduates with the knowledge, skills and attitudes required to care well for dying patients, and their families/carers. As a result the AAMC (1999) suggest that an increased emphasis on end-of-life education and clinical ethics education in the areas of medical futility and duty of care has resulted in 96% of USA medical schools now teach about death, dying and end-of-life care as part of an existing course. Further, one third of USA medical schools were in the process of improving the curriculum that address end-of-life care for the chronically, critically and terminally ill.

The lack of similar education programs in the UK and Australia suggests an interesting connection here considering their socialised and privatised tendencies respectively. Similarly, the connection between hi-tech deaths in critical care settings and the lack of acceptance of palliative care in such settings are surely compounded by this shortfall in the education process.

The most confrontational conclusion from the narratives explored in this chapter concerns the vexing concept of 'buying-time' in the specific case of tube feeding in a severely demented elderly patient for the carer's financial interest. One of the limitations of qualitative research is that we can never take from the one instance and automatically

claim a systemic problem. However, further inquiry is warranted into whether such practice is more extensive. Such inquiry however does not fit within the parameters of this thesis. It is important to note that other participants certainly raise the issue of revenue generation. Accordingly, it is most appropriate that this contentious issue is further examined in the next chapter entitled 'Money'.

## CHAPTER FIVE

### MONEY

#### Introduction

Whether health care is financed by the market or the government, whether providers are public employees or private entrepreneurs, according to Morreim (1995) no health care system has enough resources to meet every need or desire of every citizen. This assumption forms the basis of this chapter which has been aptly entitled 'Money' as it conveys in the simplest of terms, those issues raised when discussing utilisation of resources. The participants spoke in terms of 'generating revenue'; 'payment'; 'who pays?'; and, 'health system differences' which became the names given to the codes that were then merged to form this major theme. The provision of artificial nutritional support was discussed within the context of money mainly in terms of cost cutting, revenue generation, and wasted resources. However the actual provision of artificial feeding was not always a dominant point in these discussions. The participants overall tended to speak of wider reaching issues of which nutrition was only a small part of. The semi-structured nature of the interviewing allowed for this flexibility, and also made way for other discussion points that were not only unexpected, yet somewhat enlightening.

The four codes were discussed in various ways depending on the geographical location of the participant, or more simply, what model of health care delivery system the participant practiced within. This latter point shaped the participants' contributions more than any other factor, and it is useful here to explain the essential differences between health care delivery systems as experienced by the participants. Those participants from Australia and the UK defined their practice environments as being 'public health care systems', 'socialised health care', and/or 'universal health care'. These terms have been referred to as such in the literature (Parker 1999; Holm 1995; Himmelstein and Woolhandler 1986; Frenkel 1998; Schramm 1992). Both countries also employed a system of private health care whereby patients could choose to have private health care insurance which was optional.

The USA participants explained a health care delivery system as 'privatised', or as several participants stated 'capitalised', whereby health care delivery was not publicly funded via government imposed income tax (as in the UK and Australia), yet funded by health insurance companies via member contributions/premiums. These insurance companies were referred to as managed care<sup>14</sup> companies, health maintenance organisations, and health insurance companies. Publicly funded health care in the USA (which was confusingly referred to as Medicare – as it is in Australia, yet both having different meanings) provides health cover to people aged 65 and over, those who have permanent kidney failure, and certain people with disabilities. Additionally, Medicaid was also referred to, that is, the joint-funded (Federal and State) health insurance program for certain low income and needy people – a program which covers approximately 36 million Americans including children, the aged, blind and/or disabled (Official Health Financing Commission of America: [www.hcfa.gov](http://www.hcfa.gov)).

The following discussion points as contributed by the participants underpin this chapter: Resources; Power of Insurance Companies; Generating Revenue; and Apathy and Activism. They are discussed in order of relevance placed upon them by the participants. Interestingly, these discussions attracted more importance and contribution by those participants practising in the USA than from the UK or Australia.

## Resources

This discussion point was raised numerous times by the following 14 participants: A Gerontologist (USA); two General Surgeons (USA); a Critical Care Physician (UK); a Critical Care Physician (AUST); two Oncologists (USA); a Hospital Chaplain/Ethicist (USA); a Dietitian (USA); a Palliative Care Physician (AUST); a Nutrition Nurse Specialist (AUST); a Hospital Pharmacist (AUST); a Nutrition Nurse Specialist (UK); and a General Surgeon (AUST). The first point to be raised was the notion of wasting costly resources, that is, parenteral or enteral feeding on certain patients. This was discussed as occurring

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<sup>14</sup> 'Managed care' is medical care that is provided by a corporation established under State and Federal laws - a company that makes medical decisions for you in much the same way a financial adviser takes charge of your investment portfolio. Your managed care provider tells you which physicians to consult, monitors the medications and treatments they prescribe, and ensures that your costs remain as low as possible. For these services, you pay a set insurance premium each year.

in patients where the treatment could be considered futile, and also when the treatment could be considered as being superfluous. Firstly, in the case of futile treatment, one Gerontologist explained that a lot of TPN was wasted on critical care patients who were fast approaching death:

*I sometimes have patients in the ICU that stay for far too long. The ventilator costs a fortune, the dialysis costs a fortune, the TPN costs a fortune, and we just keep on going with it because no one wants to pull the plug...so we think about cutting costs, but it ends up costing a fortune. It ends up being a huge waste of resources for some patients, and yes – we do waste a lot of resources that way (Gerontologist USA).*

Cost cutting was mentioned numerous times in relation to both avoiding the wasting of resources and ways of saving money by the act of restricting or limiting the provision of artificial nutritional support. One participant explained that the 'managed care' environment in the USA had contributed a lot to this:

*I see certain environments where they are really into cost cutting and managed care is of real concern. Let's just say that if a person who really needed TPN (and it is not a matter of one or the other) – you know, like we could skimp on things and give them enteral...if they really needed it, then there may be situations where people might do that – might skimp on the TPN and give enteral. That is not that hard to comprehend because those managed care companies can really impact upon your practice (General Surgeon USA).*

All participants agreed that parenteral nutrition was far more costly than enteral nutrition, yet there were conflicting views between the participants with regard to nutritional support being an expensive treatment or not. The following participants explained it as being somewhat inexpensive when compared to other treatments:

*In the overall cost of health care, nutrition is a small amount of the big cost of the hospital stay (Gerontologist USA);*

*Sure TPN is expensive compared to enteral but when you compare it to some of the new generation antibiotics it is probably a walk in the park (Critical Care Physician UK);*



*There are many other things more expensive than TPN, and TPN has become cheaper by being able to buy it ready mixed, plus there are loads of suppliers now for premix in the UK (Nutrition Nurse Specialist UK);*

*Costs associated with nutritional support are not that great – I mean a hundred bucks a day for TPN is peanuts – I wouldn't view the costs as sort of overwhelmingly substantive...nutrition is a very small part of the overall cost involved in supportive treatment (Critical Care Physician AUST).*

This last participant did not consider the provision of artificial nutritional support as being pertinent to true cost cutting and resource allocation arguments. He explained his views in terms of managing the 'whole' patient in a critical care situation:

*The cost of nutrition, well it doesn't faze me. Even if we all know that the feeding isn't doing any good but we keep feeding to appease the relatives then so be it. I don't view that as being nearly as difficult as having a patient parked in the ICU on a ventilator, and I am cancelling surgery and sending people to Sydney or Melbourne from our emergency department – now that costs money, and I view that as a big thing. I don't view somebody getting a bag of milky white fluid costing \$100 a day, even if it is not strictly necessary, as a big thing. If giving them a bag of milky white fluid costing \$100 a day makes it easier for the doctors and family to come to terms with the disease, then I think that is money well spent...personally. I don't think that it is a big enough issue to get caught up about (Critical Care Physician AUST).*

Similarly, another participant referred to the potential of over-prescribing when in fact it might not be therapeutically beneficial due to the cost of TPN not being expensive when compared to other therapies:

*There is a lot of over-prescription of TPN because it is so readily available now to the point where you could consider it as being reasonably cheap, yet because of that it is often inappropriately over-prescribed (Oncologist USA).*

Conversely, several other participants challenged these assumptions by explaining that the treatment was expensive, to the extent that it could be withheld in an attempt to save

money. A Trauma Surgeon (USA) explained that the provision of TPN was very costly and prescribing it without considering the cheaper and more physiologically beneficial methods of enteral feeding would end up impacting upon the overall budget:

*TPN is costly, no doubt about it, and we got to make sure that we give it out to the people who really need it, otherwise it all comes back to the unit's budget, and the first thing to go will be the nurses' salaries...there won't be any money for nurses here if we don't look at cheaper alternatives...especially if those cheaper alternatives actually work a whole lot better (Trauma Surgeon USA).*

This participant was referring to enteral access and feeding as cheaper alternatives with improved physiological benefits. This is discussed in more detail in Chapter Nine 'Technology' (p. 246) where the parenteral versus enteral argument is explored in depth. It is interesting here to refer back to the literature where nutritional support is claimed to account for approximately one percent of total health care costs in the USA equated to approximately six billion dollars (Ofman and Koretz 1997), hardly an insignificant amount.

Artificial nutritional support in the form of complex home therapy was also explained as being very costly and impacting upon the health budget significantly. An Australian Nutrition Nurse Specialist offered a detailed description of how one home PN patient can 'blow out' the entire budget for a particular service:

*The North Shore Hospital has just closed a surgical bed because they now have four people on home PN and they cannot resource it without closing a bed. We too have four people on home PN and it is extraordinarily expensive - \$60 000 - \$70 000 each year for each patient – one of my patients is up to \$96 000 a year – and you sort of think Oh God how are we going to get the money? We get no money coming off the top of our budget, and we get no money from anywhere. In Victoria they have a scheme where they get \$50 000 per home PN patient which means that it is finite, and if you have cancer then you don't get home PN. So things are only going to get tighter (Nutrition Nurse Specialist AUST).*

This participant explained that home PN cost on average \$1600 per patient per week, which was an amount that was unwillingly funded by the various Australian private health insurance companies. Therefore, home PN was funded out of the public health area service which begrudgingly paid for such treatment. As the participant commented:

*We have to go through this bloody great palaver through the public hospital to pay for home TPN. It is thankless work...sure you might get a thanks from the patient and the family, but you don't have the hospital CEO saying 'congratulations...you have just spent \$40 000 on someone who has never contributed a cent to this hospital'...it really is like getting blood out of a stone (Nutrition Nurse Specialist AUST).*

The financial drain of costly nutritional therapies on the health budgets of either an institution or the wider community was also discussed by a Hospital Pharmacist. He explained the provision of artificial nutritional support as being either 'wise economy' or 'false economy' in terms of responsible allocation of health resources:

*We are the custodians of the money, and health gets so much money...we have to relate to the cost to the hospital, the cost to the community and we have to ask ourselves are we spending our money well, or wisely? So if someone chooses to place a person on costly TPN then there are significant implications...are we getting good value for money?...are we getting the best possible value from that money? And are we doing the best thing for our patient? (Hospital Pharmacist AUST).*

The economical impact on society is mentioned briefly in the literature on terminal care. Fischer (1992) argues that ethical evaluations have been raised by the desire of some individuals to prolong their lives at the high expense to society as such that other individuals are denied services because of limitation of available resources. Cost cutting was also discussed by a Critical Care Physician (UK) who embraced a certain degree of humour when explaining the severity of cost constraints in clinical reality. He explained a common situation in which he was told to make cuts to the ICU budget, then another five percent of cuts the following year, another five percent the year after, and yet another five percent the year after that. These cuts were to be made from a present baseline

budget which he described as being 'minimal'. In order to comprehend his budgetary situation he offered the following explanation which he had also conveyed at a meeting with hospital management:

*When I was thinking about how I could make these cuts to the ICU budget, the pharmacist said that we were spending too much money on TPN. I then suggested that instead of starving people by withholding costly nutrition support, the best way of saving money would be to bring in leather biting blocks so we wouldn't have to use opiates. The chief executive who was party to this discussion started laughing and said to me the he hoped that these bite blocks were going to be re-usable! So this is the sort of level we are working at (Critical Care Physician UK).*

Concerns regarding continual cost cutting as mentioned above does feature in the literature. Several authors argue that cost cutting devices result in one-time savings that temporarily diminish the baseline of medical expenditures without affecting the rate of growth. However, such devices like reducing length of stay can only be reduced so far, and once clinical routines of care have had their 'fat trimmed', further cuts will only compromise care (Ginsberg 1987; Schwarz 1987; Ginsberg 1983; Spivey 1984).

The ethical and efficient utilisation of costly artificial nutritional support was also discussed within the context of best practice based on good evidence. This was also tied in with discussions on wasted resources. For example, one participant explained that providing artificial nutritional support at the end-of-life was rarely dependent on good evidence that it was worth the expense. He referred to a study of cancer patients being artificially fed to the tune of \$100 000 per year of life, and that '*...obviously there are other situations in which such provision and cost has to better measured*' (Oncologist USA). At first, this comment read as being somewhat blunt in terms of placing a dollar figure measurement on somebody's life, yet after revisiting the interview transcript and comparing it to several other transcripts, similar blunt yet truthful confrontations of economic realities became apparent when discussing artificial nutritional support in vulnerable patients. This is only mentioned briefly in the related literature whereby Ofman and Koretz (1997:453) explain that there is insufficient evidence to support

nutritional therapeutic intervention in many patients, as its costs are not 'economically defensible'. They also claim that the widespread use of this modality cannot be justified in a cost-constrained health care system. One participant did offer a placating explanation:

*It is a question that comes up a lot – are we actually wasting resources on people when someone else could be benefiting from it...like artificially feeding a dying patient with TPN when a post op patient in ICU should really be getting it. Now all of this sounds really cruel to brand treatment as not economically viable but in reality that is what we sometimes do (Hospital Chaplain/Ethicist USA).*

The expression 'economically viable' was also suggested in terms of 'false economy'. Again, this term reads as being insensitive and unnecessarily abstract when considering that we are dealing with real people whose lives are dependant on the so-called 'milky white fluid'. However as another participant explained, the severity of cost constraints and the pressures placed upon service delivery by strict budget management created situations where such treatments were rationalised in order to either meet budget targets, and/or avoid other compensatory cost cutting mechanisms:

*We are always over budget...we always have too many patients per year to accommodate. Of course we don't send people away, but we are constantly reminded that we are going over budget, so that the economics of the provision of care has to come into it no matter how distasteful it is. To provide one patient with TPN or EN when that patient is actually dying – well in any other circumstance not be receiving it is quite wrong because it means that some other patient will then either not get a bed or will be denied some other treatment. Unfortunately such a basic thing as basic nutritional care comes down to money, and it very much impacts on the budget we have (Palliative Care Physician AUST).*

Operating within limited resources featured more prominently in the discussions offered by the UK and Australian participants. The impact of false economy on the community at large was only mentioned by one Australian participant. This Hospital Pharmacist described poor prescription (based on poor evidence) of both TPN and EN might not

necessarily impact upon the hospital budget *per se*, yet would have far reaching consequences on the wider community:

*I personally don't feel that I have a responsibility for buying into it...I like to stay out of those arguments. If some prima donna surgeon or physician demands TPN for every Tom, Dick and Harry then that is up to them. But it shouldn't be...that kind of practice ends up draining on the budget which ends up draining the community...like we will have to either cost cut in terms of closing beds or cancelling operating lists to come in on budget...and that is not fair to the people out there who really need those services (Hospital Pharmacist AUST).*

Cost cutting discussions were confined to those health care settings previously described as public, socialised or universal. Thus, these featured primarily in those discussions with participants working in either the Australian public hospital system, and the National Health Service (NHS) in the UK. It is useful to point out here that only those American participants who granted cost cutting with considerable importance were those practising within county hospitals which were funded by Medicare and Medicaid.<sup>15</sup> This however was more the exception than the rule, and conversely, those participants practising within privatised settings mentioned the potential of revenue generation.

### **Generating Revenue**

The concept of generating revenue via the provision of artificial nutritional support was described by some participants as the hospital being able to derive a 'fee for service' for the prescription and delivery of such treatments. Not all participants agreed that this occurred within their practice settings, yet most commented that it was not an unreasonable thing to assume. The denial of actually partaking in revenue generation not only protected the individual participants from admitting unethical behaviour, yet by virtue of believing that it 'probably did go on', and/or 'could see where that would happen', created an admission of sorts to the actual practice itself. Those practising

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<sup>15</sup> In the United States of America, Medicare is a health insurance program for people aged 65 years and older, some disabled people under 65, and people with end-stage renal disease. Medicaid is a jointly-funded, Federal/State health insurance program for certain low income and needy people. It covers approximately 36 million individuals including children, the aged, blind, and/or disabled, and people who are eligible to receive federally assisted income maintenance payments ([www.medicare.gov](http://www.medicare.gov), [www.hcfa.gov](http://www.hcfa.gov)). These definitions differ with the Australian version of Medicare which is Australia's universal health insurance scheme.

within public health care environments adamantly explained that reaping financial gain was impossible, as described in the following quotes:

*I doubt there is any way that we could make money out of providing TPN or EN...by providing it, well it actually costs us money in the NHS. Whether or not we wouldn't provide it because we couldn't afford it or had blown our budget, well that is possible but I doubt whether that would ever happen (Nutrition Nurse Specialist UK);*

*I don't think that goes on, well I hope it doesn't...no....that isn't quite true in the sense that in private hospitals TPN is expensive and we cut costs by skimping sometimes....we will use a half-baked TPN without lipids to cut down on cost instead of full TPN – that is somewhat of a little compromise to save on price (General Surgeon AUST);*

*On the NHS side of things, every single patient who is put on TPN – well we have our Rottweilers in the Pharmacy who will be trying busily to find any way possible to stop giving them TPN because it is a real drain on the budget (Critical Care Physician UK);*

*Here private hospitals rarely do their own TPN because of their lack in necessary infrastructure but I would bet my bottom dollar that if they could they would do so as a revenue generating exercise – that wouldn't surprise me (Critical Care Physician AUST).*

A Critical Care Physician (AUST) who worked exclusively in a public hospital setting provided a scathing attack on such practice when asked whether he thought that artificial nutritional support could be used as a source of revenue in a private setting. This colourful description embraced his personal description of ideal 'socialism' and 'free health care':

*The issue of fee for service medicine is something that I am fundamentally opposed to. I am basically very much left wing...I consider the collapse of communism to be the end of a rather noble social experiment actually. Um...so I am nailing my political colours to the mast here. I think that fee for service*

*medicine allows private hospitals and doctors to generate money on the basis of activity, and not on the basis of need. And it happens...you have people like me doing the right thing and then you have your chardonnay sipping money hungry bastards that charge the crap out of their patients for TPN whether they need it or not...probably finances their kids' school fees or their golf club membership (Critical Care Physician AUST).*

The sarcasm articulated in this last quote was not an exclusive feature on this subject from this sole participant. Other participants gave similar, yet far less provocative explanations of comparable practice. A Critical Care Physician (UK) described how he personally could not generate revenue from providing artificial nutritional support, namely TPN, in the public setting, yet could do so (if he wished) in the private setting:

*In the private system here in the UK you may well find abuse of nutrition for the usual income generation things that happen...yes, I know people who do that, but then in any system you are going to find the guys who abuse the system (Critical Care Physician UK).*

Similarly in the American privatised health care setting, a General Surgeon (USA) admitted that the practice of deriving income from fee for service medicine relating to prescription of artificial nutritional support did occur:

*Oh sure it is possible that some practitioners reap money from prescribing TPN and enteral support – I mean they are expensive treatments and the monitoring that goes along with it means for fees for the physician. I don't do that, and I would hate to think that it goes on, but it wouldn't surprise me (General Surgeon USA).*

Fidelity (or lack of, as implied by these last three participants) should fundamentally be a benign requirement, that is, that the doctor refrain from '...vulgar exploitation of vulnerable patients in order to line his pockets with a little extra gold...' (Morreim 1995:63). This leads to the related concern of conflicts of interest. An Oncologist (USA) offered a wider reaching explanation of the nature of generating revenue from within a



privatised setting that was not just confined to the questionable prescription of artificial nutritional support. As he spoke he mentioned that he was 'being a little cynical' yet 'frank and open' about what really occurs in practice when TPN might be used over EN because it would be more profitable for the provider:

*The efforts to use the gut and prescribe EN are certainly not taken on board by some...especially if they have shares in the company that makes TPN. It is exactly the same as renal physicians owning dialysis centres, and if you have interests in the company that makes the stuff well none of those companies ever talk about non-provision...they are all pro-provision (Oncologist USA).*

According to various sources gleaned from the health economics literature, doctors voluntarily incur conflicts of interest by becoming owners or investors in a variety of facilities, ranging from pharmaceutical or medical equipment companies, to free radiology or surgery centres, and to laboratory services both in and outside their own offices (Institute of Medicine 1986; Ginsberg 1986; Hillman *et al* 1990; Morreim 1989). The motivation behind providing aggressive nutritional support was discussed by another Oncologist (USA) who explained that '*...TPN companies are going to say that it is warranted this much because they want to sell more*'. He also added that some doctors might be overly aggressive in such provision because '*...they may want the charges, the reimbursement for administering a complicated treatment*' (Oncologist USA).

The concept of 'pro-provision' was also embraced by another participant describing the provision of medically futile feeding in the dying patient, and the somewhat sinister nature of such provision in terms of the potential for gaining financial reward via the privatised payment system for health care in the USA:

*Most doctors will agree when it is time to consider withdrawal of feeding in the dying patient but every now and then a patient will arrive back in the hospice setting after having a PEG tube placed by a surgeon, and we will be just amazed and ask why? Like why did someone do this instead of just letting them get on, but you know why...well all I can think of is that someone, some*

*doctor wanted the billing! Somebody wanted the money you know...it is ridiculous (Hospital Chaplain/Ethicist USA).*

Similarly, a Critical Care Nurse Specialist (USA) spoke of 'unethical people' with regard to billing for unnecessary nutritional treatments in patients who were suffering a catastrophic illness and rapidly approaching death:

*I think it happens a lot. I mean, there are a lot of unethical people out there. Now I can't prove that but we have had dying patients that we would recommend against placing a tube but the family goes and shops around the different hospitals, and in the past they have gotten what they have wanted somewhere...there is always somebody out there who is going to do what you want whether or not it is in the best interests for the patient. Nine out of ten people will easily agree that this is a bad thing to do, but the tenth person will go ahead and do it so, so you got to wonder what the tenth person's motivation is...and often times, in a situation such as that where you taking off a 95 year old's leg with end stage diabetes, or you are placing a feeding tube in them when they are clearly dying, then you think that this person just wanted the billing, just wanted the business. I think that goes on a whole lot more than what we would like to think. I think that there is always someone who will try to do it (Critical Care Nurse Specialist USA).*

Whether these responses are based on the participants' own cynical theories or clinical realities, the practice of revenue generation was not solely confined to the practice of doctors. A previously mentioned scenario in Chapter Four 'Death' (p. 129-130) involving a Medical Social Worker's (USA) confrontational perception of welfare fraud in terms of prolonged feeding for prolonged living in an advanced dementia patient, also deserves a certain synthesis in the revenue generation discussion. Despite being mentioned by only one participant, it does raise further questions as to the hidden practice of financial gains from the provision of artificial nutritional support – not from the doctor's perspective, but from the family's. She elucidated this in terms of prolonged feeding being demanded by the family because they realised that as long as the patient was being kept alive, an extra source of income in the form of welfare payments could be obtained. This explanation is repeated here to clarify this assumption:

*This sounds real bad but I know it is true...that some people...some families or caregivers have ulterior motives. I have this real cynical theory that people continue with PEG tubes – some families want the PEG tube because in some cases it can prolong life...well most cases with our demented patients, and by prolonging someone's life who would receive a welfare payment in a poor socioeconomic community, well that is their way of survival, you know. It is a really twisted thing, but I see it happening. And what is really bad is they are only concerned with the money because in terms of their overall care to the patient, well it is borderline abuse. They keep them alive to get the payment, and they don't care for them in any other way. It is appalling but it goes on...so it brings me back to question of who exactly are we buying time for – the patient, or the family who benefits? (Medical Social Worker USA).*

Only one participant commented on the financial impact revenue generating activities on behalf of doctors could potentially have on the patient and their family. She described the multifactorial nature of medical problems that many of her patients endured, and ultimately paid the price both financially and physically:

*These patients that require nutritional support have a whole gamut of problems. The fact that they can't eat is only one of a myriad of problems, and they usually have fifty people they have to go and see. They have to see the surgeon about their abdominal problems, they have to see the physician about their heart problem, they have to see the vascular surgeon about their ischaemic toe, they have to see the endocrinologist about their chronic osteomyelitis that we have probably given them from not enough calcium over the years and for their insulin for their diabetes....so they get pretty much 'specialtied out', but then they have to go see their respiratory physician because they have a pulmonary embolus from the thrombus that they've got from their long term central venous access, and it goes on and on...they are having to see a whole lot of people and they have a lot of bills coming in if they are privately insured...and I feel that if we generate another bill, well that is pretty terrible...they have to go to this office and that office to pay this and pay that, and these people have so much on their minds about what they have got to do with their lives (Nutrition Nurse Specialist AUST).*

In all of the participants' assumptions of questionable practice, they alluded to the fact that such practice would be extremely difficult to prove. One participant explained that proving such behaviour was a difficult subject to broach, and could be viewed as pure speculation (Medical Social Worker USA). Similarly, a Palliative Care Physician (AUST) mentioned the problem of not being able to prove certain unethical practices, and that such practices were made known via both urban legend and backroom discussions. This following quote does not refer to artificial nutritional support specifically, yet embraces the wider practice of fee for service medicine in oncology:

*I think that ordering TPN parallels many other things that happen in private practice, which I believe, are very much driven by the oncologist's pocket. And perhaps that is not even a conscious thing...perhaps it is just part of the way practice has gone, but I am sure that it is conscious. I am aware of an oncologist who is said to practice for at least ten days after the patient has died...and I think that is the kind of thing we are alluding to here – that yes, I am sure TPN is no different from some of the very expensive treatments that are actually thrown at patients when people perhaps, sitting in a different camp shake their heads and ask why is this being done...isn't it obvious that this person is at the end of their life? (Palliative Care Physician AUST).*

A similar scenario was given by an Oncologist (USA) who openly admitted that he had colleagues who were renowned for continuing to bill for service some weeks after the patient's funeral. This participant then shared a joke which essentially illuminated what he was insinuating, that is, '*why do they nail down the lids of coffins?*' The answer being '*to keep the oncologists out from administering the last doses of chemotherapy*'.

Humour, sarcasm, cynicism and scepticism were utilised by these participants to convey the unethical practices of generating revenue from the provision of such treatment.

Overall, this issue of generating revenue poses as one of the most controversial elements of the participants' discussions on the provision of artificial nutritional support.

Yet surprisingly this topic has warranted only scant attention in the related literature.

Whether this paucity of investigation signifies the diversity of practice differences between the public and private health care delivery systems rendering such discussions too complicated for intensive inquiry remains uncertain. One thing that is certain is that

the assumptions conveyed by the participants regardless of their practice settings warrant rigorous investigation. To some extent, this has recently occurred in the USA following the advent of managed care which leads to the next discussion point.

### **The Power of Insurance Companies**

It is necessary to point out here that this discussion point was fundamentally an issue for only those participants practising in the USA. Again, the actual provision of artificial nutritional support was spoken of as being only one small part of a much larger issue. The five participants contributing to this discussion included: A Health Service Administrator (USA); two Oncologists (USA); a Hospital Chaplain/Ethicist (USA); and a Law Professor (USA). The dominant proposition of these discussions focussed on the power health insurance companies could impose upon the actual practice of health care. The actual nature of reimbursement from insurance companies for services rendered by health care providers was viewed by some as changing the nature of practice and the quality of health care delivered. For example, one participant explained that since the advent of managed care, the quality of health care had deteriorated because the goal of the health insurance company was to fund a level of care that was considered adequate:

*Managed care companies now use the term 'adequate care'...not optimal care, but adequate, and they are very open about that in their policy statements...in their mission statements and stuff. That way, they will provide, they will fund for adequate care, whereas before, it was optimum care, you know, premium care, or whatever their best word was that they could think of for their mission statement...and now, they are very proud of 'adequate' (Health Service Administrator USA).*

Consequently, the level of health care that was funded by the insurance company was explained as being driven by cost constraints in order to save the provider money. Those who directly pay for health care, including government, businesses, and insurers, institute a broad variety of controls and incentives to ensure that physicians and patients consider the economic as well as the medical wisdom of their health plans (Morreim 1995). For example, one participant described the level of care that used to be provided in a neurosurgery setting:

*We used to be funded to keep the patient in for a few more days, get some good physical therapy going, some good rehab to make sure that they were safe in mobilising, get their swallowing under control so they wouldn't get aspiration problems...well now, they are pushed out the door in half the time. The problem here is that if we do provide more optimum treatment, and then we try to get reimbursed for it, well the insurance company will not approve it...so we end up writing off a lot of bills...we don't get paid for the care that we provide, the care that the patient really needs (Neurosurgeon USA).*

This participant went on to explain that the provision of purely adequate care would result in creating more expense because many patients would develop more complications from either expedited discharge, deficient care, and/or lack of appropriate follow up. He mentioned that between 1998 and 1999 he had witnessed the closure of numerous local home health care agencies that he used to refer to a lot for home physical therapy and skilled home nursing care for many of his post operative patients. These agencies had closed because they were not able to seek reimbursement for the many skilled visits that they provided, and consequently were no longer economically viable. Consequently, many of his postoperative patients were developing complications that would necessitate further hospitalisation:

*Unfortunately now it is common place for some of my patients to develop decubiti or footdrop – I mean, like it is accepted practice that following a complex laminectomy you get decubiti and, or footdrop. Now a couple of years ago that would be totally unacceptable, like bad practice. Now it is almost the norm (Neurosurgeon USA).*

The notion of health care providers being disempowered by strict reimbursement criteria from insurance companies was also mentioned in terms of only providing 'adequate' care. One participant described a common scenario in which the insurance company (or representative thereof) could dictate what treatment was necessary or not, without ever seeing the patient:

*Somebody at the insurance company will determine what medical procedures need to be done...and that person doesn't*

*necessarily need to be a physician that is determining this...so they have no idea of who the patient is and what that patient might really need...so whatever the doctor thinks is a fair thing, you know, like a necessary test or treatment, well that person in the insurance office can say 'no, they don't need that so we won't pay for it'. This goes on all the time (Health Service Administrator USA).*

In relation to artificial nutritional support, only the provision of TPN was problematic for these participants whereby the insurance company would query the necessity of parenteral feeding in certain clinical situations such as critical care. The participants did not experience problems with reimbursement for the provision of enteral feeding, however it was mentioned within the context of hospice care and the criteria for funding of such care:

*In a hospice situation you can find yourself arguing with insurance companies all the time...you see there is this theory that hospice care is for six months and that is it....well who is going to guarantee that it is going to be for six months. The biggest fear with a lot of patients in hospice is that they are going to live for seven months because then you have to justify the whole thing, and the insurance company can then turn around and try not to pay for any of the hospice care (Oncologist USA).*

In contrast to the provision of such hospice or palliative care in the UK or Australia, no such finite terms or restrictions to care exist. Despite the denial of certain treatments and 'optimal' care that could be considered as expensive, the value for money that patients were receiving from their costly insurance premiums was considered as being poor. After many years of paying insurance premiums to various companies, the quality of care that would be readily funded by the insurer was considered by some participants as far from adequate. One participant explained that paying substantial monthly insurance premiums for over 20 years could easily culminate in many thousands if not hundreds of thousands of dollars which would not determine the quality of care to be refunded if it was ever needed. When asked if whether or not all the money contributed to such companies over the years would make a difference in the quality and amount of care that would then be funded, she responded adamantly to the negative:

*It means that regardless of all the thousands of dollars you have paid into health insurance over the years, and if you then requested post op therapy thinking that it would be part of the costs covered, you then find out that it would not be part of your cover...you would only get what ever your insurance company would grant what is adequate (Health Service Administrator USA).*

The same participant added that the only party to benefit from the payment of premiums and denial of reimbursement was the insurance company. Embracing a certain tone of sarcasm, she explained that all the money contributed, and saved via denial of reimbursement, goes to the insurance company administration:

*The money all goes to insurance administration – who are like the people on the Fortune Magazine top ten CEO's...Fortune 500 people yeah! They are paying their salaries and buying their boats and buying their houses and giving them all the perks and the people that have their insurance aren't getting the care they need...it's horrible (Health Service Administrator USA).*

Similar dissatisfaction was conveyed with the processing time taken by insurance companies when claims for reimbursement were either denied or stalled when challenged by providers. One participant (Neurosurgeon USA) explained that he spent most of his weekends writing letters to such companies justifying to the point of 'begging' for consideration of further treatment for some of his patients. He explained that there was very little satisfaction in his work when he would be trying to do the right thing as a doctor and by his patients, when '...any old utilisation review nurse can go look through a claim and dictate to you and reject payment or stall it.' This dissatisfaction and/or disillusionment was also suggested by another participant who claimed that doctors were choosing to either leave medicine or not study medicine because of the power that insurance companies had over contemporary medical practice:

*I know a lot of doctors who have quit medicine because they cannot give their patients the care they need. I know one guy, a surgeon, well he now writes computer animation software for medical training. It is far more lucrative and he doesn't have to*



*fight with insurance companies the whole time (Oncologist USA).*

This disillusionment in practising medicine has been mentioned by Morreim (1995) who argues that doctors' positions have changed profoundly, as his/her obligations to each patient are now embedded in a network of competing obligations and conflicting interests. Another participant also commented on the frustration and disillusionment that could be experienced when dealing with 'far removed' representatives from insurance companies that could dictate denial of funding for treatments considered necessary by the provider:

*If you can talk to someone there at the insurance company who is experienced in what you are dealing with clinically then it is not usually a problem, but usually you are dealing with someone who is inexperienced in what you are dealing with, and they only have a written guideline and no real idea what even the disease process is – so you cannot talk to them about it (Hospital Chaplain/Ethicist USA).*

With regard to managed care in the USA, patients and providers are encountering significant changes in the way health care professionals provide crucial services (Rambur 1998). They discover that there are now incentives for providers to restrict or deny care, that tensions between the needs of the individual and the needs of the population exist and are growing, and that, perhaps most significantly, third party payers seem to have acquired more authority than health care providers in many matters that bear directly upon treatment (*ibid.*) The frustration that was conveyed by these participants in relation to the dominance and overriding influence that insurance companies had over the provision of health care was expressed from their perspectives as both providers and consumers of health care services. The 'activism' of the health care consumer in the privatised setting compared divergently with the 'apathy' referred to in the socialised setting. This is explored in more detail in the following discussion point.

### **Apathy and Activism**

This discussion point was not anticipated in the research proceedings which reflects its absence from the literature. Although only a few participants spoke of this concept, it is

worthy of a certain exploration within the context of health service differences. In many ways, the notion of consumer activism is closely related to previous discussions on autonomy in Chapter Three 'Principles' (p. 95). Consumer activism was expressed in terms of people taking on more responsibility for their health, and a heightened awareness of their health care, its consequences, and their rights as health care consumers within privatised settings. Conversely, apathy was expressed as being resultant from a socialised system of health care funding and provision that did not foster personal and/or financial responsibility, awareness and/or accountability. This was explained by one participant who had practiced in both the USA and Australia, as being secondary to the fact that people in socialised settings did not have to contribute financially for their health care and were therefore not as active in its delivery:

*I notice this a lot... that is, people take more responsibility over their health care, the health care of their family in the US, whereas in Australia we have been spoilt rotten by this system of Medicare, of socialised medicine that has been dished out – and that system does not foster the same responsibility and knowledge (Occupational Therapist AUST).*

This 'responsibility' for one's health care was explained by another participant as being diminished due to the paternalistic nature of socialised health care. That is, autonomy granted to the physician does not foster the same consumer awareness as experienced in a privatised setting:

*British law still grants autonomy to the physician and Australia's system is based on that model, whereas in America it is very much a user pays system where the patient has rights as a consumer, and the patient is usually very much aware of those rights (Hospital Chaplain/Ethicist USA).*

This view is a good example of presumed physician autonomy, which is well documented in the literature pertaining to the autonomy of doctors (BMA Ethics, Science and Information Division 1998). Responsibility for one's health and health care could be equated with the term 'public involvement', which has been explored and explained in depth throughout the primary health care literature. Yet pertaining to discussions on

acute tertiary health care, public involvement is often neglected (Calman 1994), therefore compounding the lack of recipient involvement and responsibility, and therefore reinforcing apathy. The opposite would mean patients and families being considered as part of the resource allocation process, thereby being aware of the range of possible treatment options, possible outcomes and success rates.

The concept of not contributing financially to one's health care as occurs in the UK (NHS) and Australia (Medicare) was considered by two participants in the USA as being more favourable than their current situation with managed care companies. One commented that she had heard of universal health care from a visiting nurse (from Australia), and remarked that it seemed to be '*...a lot fairer, and a lot less fuss...*' (Health Service Administrator USA):

*It sounds like...with universal health care coverage...that there is less 'treat em and street em' going on...like here, we ship them in and ship them out. I would not object at all to 10% being taken out of my pay check as long as everybody had the same and we were all insured, and we wouldn't have to write claims off all the time and having people burdened with medical expenses (Health Service Administrator USA).*

On the contrary, a participant from the UK explained that by financing one's own health care through private insurance schemes created a better system of consumer awareness, if not consumer demands:

*If you are paying for it then you see more of a user-pays mentality, like...well if I have been forking out a hundred bucks each pay for my private health cover, and I get sick, need a hospital bed and certain treatment, then I damn well want it (Nutrition Nurse Specialist UK).*

An Australian participant spoke of the apathy of people not taking out private health insurance, or those that do<sup>16</sup> could still opt for free public care. For example, she explained that:

*If something happened to me I can simply roll up at the nearest public hospital, even if I have private health insurance, because I won't have to pay for it...and anyway, if I did go to the private hospital, and if I needed more specialist care then I would be transferred to a public hospital so why bother paying for private health cover in the first place...and that is the attitude that a lot of Australians take (Nutrition Nurse Specialist AUST).*

Despite these suggestions of consumer apathy within socialised settings, one Australian participant did comment that from her experiences, the situation was beginning to change. She explained that many patients, especially the older population were apathetic, yet it was interesting to observe an increase in those people who did know their rights. As a means to overcome this apathy, she considered that regardless of one's insurance status, all patients admitted to public hospitals should contribute payment even if it was a token amount:

*It is my personal opinion that everyone who goes to hospital should be paying something on a daily rate towards their hospitalisation...even if it is only ten dollars a day because I think that many people...and this is just the frailty of human nature...they don't appreciate the things that they don't pay for. So therefore, they don't make an attempt to get themselves well, and there is no incentive to try and stay well, and for many people, finances are a real incentive to do this...in that if I have to go back to hospital, it is going to cost me money (Occupational Therapist AUST).*

This last comment alludes to the notion that money is essentially omnipotent and the driving force behind many treatment decisions, actual treatment provision, responsibility for one's own health status and health care, and the style in which health care delivery systems are modelled upon. The all-powerful dollar, regardless of its national currency,

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<sup>16</sup> Approximately 37% of Australians carried private health insurance at the of this interview, according to the Australian Health Insurance Association, reported on the Australian Broadcasting Corporation website: [www.abc.net.au/news/2000/07/item200007](http://www.abc.net.au/news/2000/07/item200007).

held far more predominance, influence and significance to the ethical questioning posed in this research than previously anticipated. Despite an extensive review of the international literature, discussions on health care delivery system differences and the way they may shape resource allocation decision-making were not located.

## **Conclusion**

The detail and emphasis afforded to money in regard to the provision of artificial nutritional support were greater for those participants practising within a privatised setting. Of these participants, those practising in the USA contributed more to these discussions than those from Australia and the UK. This surely reflects the important nature of health care and the difference between public and private models of service delivery. Although many of the participants' contributions to this major theme were directed at wider reaching aspects of acute health care provision, the breadth and depth of issues attested to reflected the participants' true perceptions of what was more than an issue of artificial nutrition.

Over-prescription of artificial nutritional support given its easier availability raises the possibility of the advantages of cost containment. There are indeed numerous ways in which the health care professional could reduce quantity of care without impairing quality. As demonstrated in this chapter there are many situations encompassing 'money' and artificial nutritional support – whether to save it or to make it. Regardless of service model or location, these complex situations of health care financing demand ethical analysis. However, what this means for providers and consumers in medicine's new economics remains unclear. While recognising that economics profoundly affects health care, it should be imperative that all providers can and should avoid compromising their patient's welfare in the name of generating revenue or even cutting costs. As Morreim (1995) reminds us, we can no longer speak of fidelity as a benign requirement that the health care provider refrain from exploitation of vulnerable patients in order to line his or her pocket with a little extra gold. The practice of treatment decisions based upon revenue generation demands critical evaluation although this is not possible within the parameters of this thesis.

In this chapter we have encountered the various cultural dimensions of money within various Western clinical arenas. The limitations of this study do not allow for an exploration of the non-Western monetary dimensions. In exploring monetary considerations, we inevitably need to understand the cultural milieu of artificial nutritional support, which is the subject of the following chapter.

## CHAPTER SIX

### CULTURE

#### Introduction

This chapter was created by the merging of the following codes: family; food and water; ordinary versus extraordinary care; sloganism of starvation; guilt; and multicultural differences. Essentially, this chapter explores the socio-cultural context of how artificial nutritional support is perceived by both provider and recipient. The 22 participants who contributed to discussions within this major theme included: A Gerontologist (USA); two General Surgeons (USA); a Critical Care Physician (UK); two Palliative Care Physicians (AUST); a Critical Care Physician (AUST); two Occupational Therapists (USA); two Oncologists (USA); a Hospital Chaplain/Ethicist (USA); a Gerontology Nurse Practitioner (USA); two Medical Social Workers (USA); two Clinical Dietitians (USA); a Nutrition Nurse Specialist (AUST); a Nutrition Nurse Specialist (UK); a Hospital Pharmacist (AUST); an Oncology Nurse Specialist (USA); and a Trauma Surgeon (USA). Two major discussion points are presented in order of relevance and contribution as emphasised by the participants in their various conversations. These have been termed 'Distortions' and 'Culture and Intervention'.

#### Distortions

'What is food to one man may be fierce poison to others' (Lucretius cited in Marino and Finnegan 1996:667) embraces the essence of this discussion point. It confronts the assumptions of artificial nutritional support being compared to food and water, or as the following participant explained as the fundamental requirement for living:

*There are lots of ethical issues I think, with nutritional support, and it sort of goes around the base that people see the provision of food and water as the basic requirement of life (Nutrition Nurse Specialist AUST).*

The comparison of artificial nutritional support with basic food and water has long been a controversial topic discussed frequently in the related literature under the common heading of 'ordinary versus extraordinary care' (Goldstein and Fuller 1994; Daly 1990;

Thomasma *et al* 1986; Watts and Cassel 1984). The participants however, gave numerous conflicting perspectives on this so-called confusion – some which were not anticipated by the researcher. For some participants, this confusion or distortion of complex nutritional therapies being akin to basic food and water was not an issue as evidenced in the following quotes:

*I have never had to deal with that...I have never had a problem with family when it comes to withdrawing TPN or tube feeding in an ICU patient. I guess for me it is not an issue, or that the feeding is just part of a whole array of treatments that we withdraw (Critical Care Physician UK);*

*I think that it is recognised as a medical treatment, but it is a medical treatment that maintains body weight, maintains hydration and not necessarily food. So, as a medical treatment, it is continued but not necessarily thought of as food I don't think (Oncologist USA);*

*I don't think that is the case, but I haven't really given it much thought...no, I think that TPN or enteral – well they are just part of the whole process just like the ventilator or the dialysis. So, no...I don't think that there is an issue with nutrition...it is just part of the whole treatment process (Hospital Pharmacist AUST).*

*I can understand how people, nonmedical people get them mixed up but clinical nutrition is only one part of the life-sustaining modalities that are rendered necessary for the survival of the patient...along with hydration, antibiotics, ventilation and so on (General Surgeon USA).*

These participants spoke of artificial nutritional support as fundamentally being a clinical intervention akin to a plethora of complex clinical modalities that are provided in an acute care setting, and one that is not equated in any way with eating food or drinking water. Essentially, they grouped clinical nutrition under the title of 'extraordinary care' or, as Studebaker (1988:306) explains, a 'medical treatment'. This raises a need to expose those treatments considered by the medical profession as being part of the technical



spectrum of life-sustaining clinical interventions, and those that for some are considered as basic care.

Those participants who did believe that there were issues around the distortions of 'food and water' and artificial nutritional support offered far more detailed explanations derived from their respective experiences. One participant offered this explanation of the confusion that can occur when artificial nutritional support is referred to as food in situations when people are dying:

*If artificial nutrition is called food, then the patient, the family thinks that if you don't provide it, you are starving them to death. So you have to be very careful about not referring to it as food and then explaining to them how people really die. People die basically dehydrated so we must talk about that death trajectory with people and how in fact that it is more comfortable to die that way than to die with nutrition and hydration where you can get stuff that happens...like diarrhoea, nausea, vomiting, aspiration, bloating, pain... (Hospital Chaplain/Ethicist USA).*

This quote raises an important issue of providing explanations to people of not only how they die, but also more to the point at hand, what artificial nutrition is and what it is not. This need for explanation, for communication and education in terms that people can understand was further elaborated on, revealing the problematic outcomes of what occurs when such information is not conveyed:

*Physicians, nurses, dietitians, nutritionists, still refer to artificial nutritional support as food and water, and it is not food and water. And to do that sets up a frame that the family then is almost obligated to continue...so when I educate families I talk about artificial nutrition and artificial hydration, medical treatments, all of which can be withdrawn...and talk to them about what happens if you withdraw it and what happens if you maintain it, because they do not know this stuff. I mean, how are they going to know?...they are not stupid, but they are not informed because nobody tells them this (Hospital Chaplain/Ethicist USA).*

Another participant similarly referred to other professionals referring to, or considering artificial nutrition as food and water, and the need for raised awareness of the outcomes of prolonged aggressive medical feeding:

*Many people don't see it as medical treatment...they see it as part of basic care, and throw statements at you like 'you have to feed them, you can't starve them to death'. Actually I have had that quoted at me just recently by a ward nurse who said to me that her patients are not going to thrash around the bed starving to death. We need to educate all our staff that when people are unconscious or very very sick there is a tendency for the gut to slow down, and you don't get that same feeling of hunger. But you get this blanket statement thrown at you – 'you will feed and that's that', regardless of whether you are probably going to do that patient more harm because there is a morbidity...mortality involved in nutrition support no matter what way you look at it – to some extent (Nutrition Nurse Specialist UK).*

The questioning of whether or not dying from the withdrawal of artificial nutritional support does appear in the affiliated literature frequently. In a 1996 response to an article regarding such withdrawal, a Registered Nurse remarked 'What hypocrisy! Does anyone actually think that dying of hunger and thirst is comfortable?' (Vause 1996:9). Such responses do well to compound the distortions apparent in differing discourses and knowledge systems between food and water, artificial nutritional support, hunger, thirst, and starvation. For those who cannot accept a negative answer to the question asked by Vause (1996), the contributing participants posed the question differently by embracing the aforementioned benefit versus burden argument. The complications referred to by the participants of burdensome feeding are well documented (Finucane *et al* 1999; Hull *et al* 1993; Kohli and Block 1995; Grant 1993; Finocchiaro *et al* 1997; Rabeneck *et al* 1996; Cowen *et al* 1997; Oyogoa *et al* 1999; Stuart *et al* 1993; Kutiyawala *et al* 1998; Wijdsicks and McMahon, 1999; Ciocon *et al* 1988; Keymling 1994; Patchell *et al* 1994; Abuksis *et al* 2000).

The literal description of starvation being similar to either withholding or withdrawing artificial nutritional support appeared in the literature in surprising dearth. One exceptional article however (Ahronheim and Gasner 1990) support the claims made by

the participants. They explain that the use of the word 'starvation' is especially provocative when it is applied to the clinical consequences of not providing artificial nutritional support. The picture it conjures up is a powerful one associated with the '...wasting, cracked skin, oedema, impaired wound healing, infections, swollen belly, and listlessness of protracted protein-calorie malnutrition in the third world so vividly portrayed on television' (Ahronheim and Gasner 1990:278). Understandably, such images disturb our well-fed society, yet as these participants suggest, may not be relevant to discussions about nourishing certain patients artificially. However, the symbolism of feeding as a basic caring task deserves a thorough appreciation and acknowledgement, thus necessitating appropriate communication between providers and recipients and their families/carers.

The inability of family to come to terms with 'food' not being provided was also experienced by one Medical Social Worker, who, when reflecting on her clinical experience also referred to the necessity for education and communication in understandable terms:

*When I worked the floors I often used to come across frequent conflict between the medical team and families...and the issues were normally around the termination of nutritional support. Family just could not come to terms with the notion that food was not going to be given and that their loved one would starve to death. Of course that is not how it happens, but to lay family that is how it seems. It takes hours of explanation and education and support (Medical Social Worker USA).*

Even though these participants accepted this distortion as being a painful reality in many ways, they all agreed that artificial nutritional support could not be equated to basic feeding, or the pleasures of eating. As one participant remarked when asked how he viewed a bag of TPN he replied:

*It is not a filet mignon by any stretch of the imagination (Palliative Care Physician AUST).*

Similarly, another participant who was adamant about artificial nutritional support being a medical treatment and not to be confused with food, water and eating, did agree that there was a certain confusion around the subject, yet not of major concern:

*I don't think that there is any symbolism of food and eating around nutritional support, but there is that disquiet, although not outspokenly (Critical Care Physician AUST).*

Interestingly, only one participant (Gerontologist USA) did convey similar thoughts on 'starvation' as perceived by many patients and families when the provision of artificial nutrition support is either withheld or withdrawn.

*This is how the family thinks...just think about it yourself, the thought of someone starving is kind of cruel, so I think that probably the family thinks the same way. If you withdraw or withhold tube feeding, or not put in the PEG for them to eat, well that would be starving them, and the family would think that they would be in agony from that, and I tend to agree, so I never withdraw feeds (Gerontologist USA).*

This was the only participant who shared the previously described distorted views on aligning withholding or withdrawing treatment with 'starving'. It is possible that this is because this participant (of Asian descent), was conveying both his professional and socio-cultural response to the issue of nutrition. It was later found in the related literature that this is a well-accepted perspective on both food and feeding in many Asian cultures. The importance of food itself in Asian cultures is well documented. Chang (1977) contends that few other cultures are as food oriented as the Asians. Cooking and food preparation has occupied a lofty position in Asian history, with one great Chinese philosopher claiming that 'governing a great nation is much like cooking a small fish' (cited in Chang 1977:32). The above participant was also the only participant who claimed that artificial nutritional support was different from other forms of medical treatment. He also conveyed his cultural beliefs regarding disclosure of a patient's diagnosis:

*It is common Asian cultural practice to keep certain diagnostic information from the patient according to the wishes of that patient's family, and we must abide by those wishes (Gerontologist USA).*

This participant did not consider that PN or EN should be classified in the same group of technological life-sustaining modalities such as ventilation and/or dialysis as described by the other participants contributing on the subject of ordinary versus extraordinary care. This sentiment is reflected in the literature by those proponents of continued treatment who explain why 'food and water' can never be denied (Derr 1986; Siegler and Wiesbard 1985; Anscombe 1981). Conversely, two participants gave explanations of why artificial nutritional support was not to be considered as basic or ordinary care by comparing the modes of nutritional delivery, that is, natural or artificial:

*If the patient can actually eat or drink normally then they are going to do that and that is natural. But if the patient is unable to do that for himself then it is not ordinary food and drink, and that of course renders feeding artificial (General Surgeon USA).*

The second participant gave a similar explanation yet also provided an interesting paradox of a certain inequity of providing simple oral feeding to dying patients and death row inmates:

*One thing we can do for patients and their families is educate them that food is fine as long as they can take it orally, I mean why not? As long as providing food orally is not going to cause them to cough and aspirate. But we are terrible at doing that...we are terrible at providing nice little morsels of delicious food as comfort at the end of life. We are kinder to death row inmates than we are to people trying to die! The guy on death row down at the State Prison...the day before he gets a lethal injection we feed him his last supper, and ask him what he wants – he can have anything he wants. Yet the guy in ICU who is really struggling, and wants a shot of Jack Daniel's, well we say 'no, it might kill you!' You know, how ironic (Hospital Chaplain/Ethicist USA).*

The primary component of the conversations on distortion was persuasively described by an Oncologist (USA) who emphasised the importance of communication and education in order to heighten awareness amongst patients and their families. This in reality, was often thwarted by virtue of the episodic consultative nature of hospital medicine:

*Normally the family comes around very quickly to the understanding that they are in a dying situation. It needs to be explained so carefully and clearly and more often than not, if they are frustrated with anything it is because their doctor has not come by and fully explained things to them. If he does come by it is for two minutes, and goes away and doesn't discuss all the issues that need to be discussed. I have never found it to be a problem because I always put in the time (Oncologist USA).*

This declaration is closely related to the same participant's comments in Chapter Three 'Principles' (p.110) where he explained that there would not be any ethical problems if doctors only communicated with their patients. This importance of communication and education regarding both the clinical and ethical realities of aggressive nutritional support in vulnerable patients is supported in the literature. McCamish and Crocker (1993) claim that communication is the operative word, explaining that difficult situations are facilitated by effective communication with the patient and family.

The cruelty and abandonment implied by the word 'starve' is not conveyed in the participants' stories. Indeed, as several participants suggest, the continuation of artificial nutritional support may in some cases be cruel, if not fatal. Essentially, these participants agreed that the non-provision of such treatment did not constitute starving, nor did it result in a gruesome, cruel, or violent death. The related topic of 'force feeding' dying patients was mentioned by several other participants within the context of 'needful intervention' which leads to the next discussion point that is still very much embedded within these discussions on the distortion of what actually constitutes food and artificial nutrition.

### Culture and Intervention

Feeding, unlike any other medical treatment, has a moral and emotional significance derived from culture (Ashby and Stoffell, 1995; Murcott 1984; Connelly 1989; Carson 1986), and is considered paramount to one's quality-of-life (McGrath 2002). As mentioned previously in this thesis, from breast-feeding to Thanksgiving and Christmas dinners, birthday cakes and potlucks, to food brought to families in mourning, feeding is central to the experience of passage. In the Judaic and Christian traditions, the shared meal is an important representation of the faith's life and moral significance. 'You are what you eat', 'Bread is the staff of life', 'An apple a day', 'Eat up, it's good for you' – such clichés and sayings highlight the commonplace symbolic representation of nutritional and social values (Murcott 1984). Feeding, according to Cox (1998) is an expression of nurturing and caring, unquestionably for infants and children, and in many cases for vulnerable adults as well. Once one enters the realm of complex, hi-tech medical care, it is difficult to shed the emotional symbolism of food. Yet the participants went beyond the literature in their narratives. By way of describing not only their own views but by sharing some descriptive accounts from practice, the participants revealed certain thought-provoking realities. The views conceded by the participants offered various insights on how nutrition was considered between certain socio-cultural groups. The emphasis afforded in our societies to 'food' was referred to by an Occupational Therapist working with elderly and demented patients explained that so much of her patients' lives revolved around food:

*From an occupational therapy and holistic perspective I think that food serves as a great function in our lives both in terms of visual stimulation, olfactory stimulation, the sensation of taste and also the social connotations that are concerned and that revolve around food...and I think that a lot of our elderly people who are not eating, well often that has a lot to do with lack of social environment – because we do tend to socialise a lot around food (Occupational Therapist USA).*

A Palliative Care Physician (AUST) offered the following confronting yet condensed quote revealing a certain 'taken for grantedness' of the importance (and incidence) of food in our lives:

*Food is a cultural process, and it is more pronounced in certain patients – like with Mediterranean families for example. To tell someone that you can't feed them, well you may as well shoot them. When we met today for this interview, I offered you a cup of coffee...it is a social thing. Offering and providing food is part of our way of saying to someone that we care, and in families it is sometimes the only way in which the love of the family has been expressed (Palliative Care Physician AUST).*

One participant directly referred to the social issue of food and feeding which, as he explained, was particularly prevalent in 'his' part of the country, that being the 'Deep South' of the USA. He described food as being of major importance to socialising in caring settings that were especially marked in the large Roman Catholic Hispanic communities. When commenting on how this particular culture would respond to the idea of either withholding or withdrawing artificial nutritional support from a patient, he specified that:

*You have a lot of tap dancing to do...with our Catholic Hispanic community, the cultural and religious impetus to feed and continue feeding, to do everything for as long as possible. So much importance is placed on food, on feasts with these people, that to then talk about removing it from a family member, a loved one, is just such a sensitive issue. You have to be so sensitive and careful (Hospital Chaplain/Ethicist USA).*

Another participant presented a somewhat controversial perspective on the issue of withholding or withdrawing tube feeding in African American patients. He explained in particularly sensitive terms that he had experienced strained dynamics when dealing with the families of dying African American patients with regard to their perceived inequality or discrimination concerning continued treatment:

*There is also a racial component – not all the time, but quite often – in dealing with the African American families, and you are an Anglo doctor...there is a very subtle 'white man is trying to do me in' aspect, and you have really got to watch it. And they sometimes imply that 'we are getting everything we deserve because we are African American'...and 'if I was white, you would put the PEG in'. I mean, it sounds really overstated*



*for me to say that here but there is that dynamic that I have experienced many times (Neurosurgeon USA).*

This notion of strained racial dynamics with regard to the provision of artificial nutritional support was not located in the related literature, however, several references to marked cultural dynamics concerning the withdrawal of life-sustaining treatment were subsequently retrieved in the literature on medical futility. Morrison and DeMichele (1997) discuss how culture, religion, and ethnicity affect perspectives on life, death, and the initiation and withdrawal of life supporting treatments. Their discussions include the American Caucasian culture, the African American Culture, the Hispanic/Mexican/Latino cultures, the Asian culture, and the Native American culture. Such 'strained' dynamics are referred to in brief terms by Morrison and DeMichele (1997) who explain that discrimination may be feared in hospital settings, increasing the wish to initiate or maintain life support in terminal illness.

A proposition closely related to the importance of food, or more specifically, the symbolism of food was the concept of intervention, or as several participants explained by coining the words of family members 'you have got to do something'. This notion that people 'must intervene' was mentioned by the majority of the contributing participants. By way of not intervening, or not providing nutrition (be it considered natural, artificial or otherwise) family members could feel deprived of the very essence of their role, or their cultural purpose, as carer:

*It is that cultural process of 'you've got to do something', and with people who are dying, with the spouse usually...if it is a female spouse (it may be sexist to say), but elderly females usually it has been their role to feed the family. The caring aspects are really the only things the family can do when medicine fails...and to have the feeding role taken away is a large chunk of their perceived ability to care (Palliative Care Physician AUST).*

McIntosh and Zey (1989:319) claim that society has decreed that '...a wife and mother's success rests as much on the socioemotional aspects of her food provision as on its healthfulness'. This statement reinforces the notion of food's symbolic meaning. Despite

this meaning, the above quote from this sole participant was the only mentioning of food provision and gender throughout the entire research. The same participant also described an innate need for family members to continue the active role of feeding (that is, providing food orally) in order to quell their own needs of knowing that they are providing care, yet often to the detriment of the patient's comfort. He offered a common experience in his dealings with families of Mediterranean ethnicity:

*I have experienced this many times with Mediterranean families where the husband, the father, the patriarch is ill, is dying...you often see, well they are almost unconscious and the family is around the patient literally stuffing food down their mouth because it is the only thing that the family knows what to do in order to make things better. Unfortunately it often either wakes the patient up so they realise how much pain they are in and the fact they are dying, or brings on a violent coughing fit (Palliative Care Physician AUST).*

The idea of not providing food was also explained in terms of guilt. The guilt that could be felt by family members by virtue of not providing the most basic act of nurturing to their dying relative was also related to the need to intervene. One participant explained that this could be relieved by explaining the realities of cancer cachexia in cancer related situations:

*People do feel guilty if they don't spoon feed the patient...yeah, actually I think that is very interesting...just the notion of natural feeding and understanding cancer cachexia. Mostly, we have a lot of families who come in and just ask about that...'he is just not eating – what should I do?' Well we can give them a multivitamin and so on, but we have to emphasise I think, that they should not feel guilty that they are not eating...that it is a part of the disease, part of comfort is not being force fed, and you will have waves and you just have to take advantage of it – their appetite – when they are ready to take a mouthful, but you can't force feed them to do that because it probably makes them more uncomfortable if you try to do that (Oncologist USA).*

Guilt was also referred to by a Gerontology Nurse Practitioner (USA), who explained that because food is a basic necessity for human survival, the idea of not providing it in its basic form could create highly emotive situations:

*People think like – let's give him food, and love, and warmth you know. They think that well we are here to take of Mamma or Daddy, I am taking care of them in their old age. There could be a lot of guilt involved. I see that a lot, and it is a very emotional issue for family (Gerontology Nurse Practitioner USA).*

This interpretation of feeding as nurturing, especially when embedded within the 'caring' discourse such as 'love' and 'warmth' was also alluded to as 'Mom's chicken soup'. This term, a well-known comfort food and therapeutic intervention in the North American society and popular culture (Canfield and Hansen 1993) was used by a Clinical Dietitian (USA) and an Oncology Nurse Specialist (USA) when describing their interactions with family members who were reluctant to refrain from 'force feeding' of their dying relatives:

*The patient is not going to starve, nor do they have an appetite...like when the patient is terminally ill then it is OK if they don't want to eat – that is part of their illness. It is the hardest thing for people, for their family to understand, like 'come on and have this, it will make you feel better'...trying to shovel in Mom's chicken soup which fixes everything. That is what people think but it isn't always the case, and for some that is really confusing and hard to accept (Clinical Dietitian USA);*

The second participant described a situation where the family members could not come to terms with not intervening with nutrition. In this situation, the family had insisted on the placement of a PEG tube in their dying mother who, by virtue of her disease process, had a very low platelet count. Shortly after the insertion procedure, she haemorrhaged, went into hypovolaemic shock and died within hours:

*The family really screwed up there and I believe that they wanted it so much because they felt as if they had to be doing something...like the most important thing was to keep her nourished, you know, like making someone chicken soup when they are sick. They could not handle the thought of just*

*standing by and watching her deny food or fluid... they felt that they had to do something, instead of feeling helpless and letting nature take its course (Oncology Nurse Specialist USA).*

This participant added that the initiation of artificial nutritional support was often a proactive stance by the family on behalf of a relative, and raised the issue of questioning whose benefit the feeding was for – the patient, or to quell the guilt and feelings of helplessness experienced by the family?

*Feeding is more a proactive stance on their behalf, the family...however family have to realise that it is not about them, it is about the person who is on the receiving end of the feeding tube. I have seen a lot of that. I think it is a parent-child relationship that is exacerbated by any past guilt that might be resurfacing (Oncology Nurse Specialist USA).*

This 'proactive stance' on behalf of the family, coupled with the question of 'who is actually being treated' when discussing the guilt experienced by family, was also referred to by another participant practising within the area of oncology. He commented on situations he had experienced in which the clinical team would often submit to the family's request for continued aggressive nutritional treatment to alleviate their guilt, yet to the potential detriment of the patient:

*Occasionally we would have family members that would insist on everything that can be done and jump up and down for the insertion of a central line so their dying relative can have TPN – people are a lot more knowledgeable than they used to be with the internet etc. I don't agree with central line insertion for those patients. In those cases it is an issue of treating the family members and not the patient...because often the underlying cause of the patient's deterioration has nothing to do with their nutritional status but it is because of their disease process taking over. Their underlying problem will not be fixed with nutrition. So it becomes a question of just who are we treating here? (Oncologist USA).*

Similarly, the difficulty for family to discontinue what they perceive as basic nurturing and loving care was described by another participant in terms of 'force feeding' and/or

'shovelling food down' when in fact it was clinically (and comfort-wise) inappropriate to do so. She explained the need for family to intervene and to feel as though they were 'doing something' as not being uncommon:

*I deal with this every day. Carer's are there trying to shovel food down them right up until the last minute. They find it very hard to stop that basic care I guess. I think that at the last minute we should not always feed the patient...I mean, the patient will stop taking food – that is a natural decline. Our patients die every day, and if they take food then we give them food – whatever they want, but if they don't, they don't want it, they don't need to have stuff rammed down their throats (Medical Social Worker USA).*

The same participant shared the following account from practice, which suggests both guilt and denial on behalf of family members who were desperate to intervene with nutrition:

*One patient that I have right now, that I saw just yesterday...well the family just keeps trying to shovel food into the patient's mouth at a much faster pace that the patient is at with her intake, and her ability to chew and to get it down...and I think that in some ways the family are forcing their own agenda...they have a hard time letting go. I think it is like denial...they can't let go of the person that the patient used to be. That is what I see, that the family doesn't want to let go (Medical Social Worker USA).*

The family's 'need' to intervene via the provision of nutrition was also explained by two Australian participants. Firstly, a Nutrition Nurse Specialist offered a similar explanation to the latter American participants regarding the difficulty in withholding a treatment that was considered basic nurturing:

*I asked the family if they had considered withdrawing the nutritional support, and they said that they just couldn't do it because they felt that it was just like turning and bathing and caring for him (Nutrition Nurse Specialist AUST).*

The next participant shared an account from her practice in a palliative care setting which involved a subtle conflict between the patient and the family over the need for nutritional intervention, and the reluctance of family to accept the outcome of the dying process:

*In the family's mind nutrition was his whole life-sustaining force as it were. The patient interestingly enough had been a cook, a chef, so he had been quite focused on food and the provision of food – that was his job, but as I said it wasn't so much his problem, but it was the problem of the people who loved him and their inability to just allow him to die. They thought that nutrition was his only hope of survival, and the ongoing means of keeping him alive and if we stopped it, then he would die. And there was a real sticking point in trying to help them understand that in fact he was dying from his disease – which was advanced gastric malignancy – and that he was not dying because he was not being provided nutrition (Palliative Care Physician AUST).*

The need for heightened awareness of the consequences of providing artificial nutritional support in those patients who are dying was also mentioned within this context of 'needful intervention'. One participant coined the terms 'curing and caring' when explaining the difficulties he had experienced when dealing with families who wanted to continue feeding their relatives despite the complications that ensued for the patient:

*Families get in these situations where they think that they have to treat always for cure instead of for comfort, and it is really clear that artificial nutrition in patients with a terminal condition is uncomfortable...it causes discomfort, it causes clinical sequelae that are uncomfortable and unmanageable and can cause intractable diarrhoea, can wake people up so that they fully appreciated their suffering and death. So we are simply unskilled at this, and by the nature of inexperience and not being educated about it, yes I think a lot of stuff happens that doesn't need to which is why some of us are so diligent about staying on top of it with people and reminding and educating physicians, educating families about it. They – families – don't know what their options are, and doing what we can to assuage guilt on the part of family members because they think they are killing somebody if they don't provide that support (Hospital Chaplain/Ethicist USA).*

The shortfall here it seems is that the 'pro-procedure/pro-intervention' characteristic of typical Western medicine in fact creates the same expectation for those on the receiving end of acute medical care. Families and their need to intervene with nutritional support is reinforced by the culture of Western medicine as we know it. The fact that medical practitioners throughout their previous academic and ongoing clinical education are bombarded with 'curing, intervention, procedure' therefore have limited appreciation of comfort care. There is therefore an overwhelming need to embrace palliative medicine as a specialty in order to heighten the awareness of appropriate symptom management, and to accept that withdrawing aggressive treatment is not akin to withdrawing care, rather, changing the focus of management. Surely this acceptance and appreciation of good death care needs to be embraced by all providers so to project a similar acceptance and appreciation on to patients and their families.

## **Conclusion**

The employment of burdensome treatment without real physiological justification coupled with the potential for clinical complication and subsequent discomfort raises the question: What powerful influence is operating that vindicates such intervention? The participants contributing to these discussions of culture, symbolism, distortion and needful intervention point to a primal nurturing within family frameworks as an important consideration. When this is applied to an acute clinical setting, it exposes such distortions of what constitutes food and feeding, curing and caring, and basic care or medical intervention. Socio-cultural ritual and the symbolism of the provision of food have fundamental roles in caring. Yet it is apparent that these fundamental roles also contribute to marked difficulties and vulnerabilities for both provider and recipient. As several of the participants suggested, the clarification of these distortions is dependent upon appropriate communication and education. As Dunlop *et al* (1995) claim, discussions with family should not be argued from a philosophical standpoint, yet it is important to present the facts carefully. However, as one participant suggested, the opportunities for extending appropriate communication and education were often not fostered by medical professionals (Oncologist USA). This again raises questions regarding the ability of health care providers to be effective communicators when

confronted with end-of-life scenarios. Whether this exposes inadequacies in their own educational preparation for caring for patients and families confronted by withdrawing or withholding artificial nutritional support (or life-sustaining treatment collectively) remains unclear. The literature generally does support the suggestions made by the participants contributing to this major theme of culture, yet with an overwhelming consensus that artificial nutritional support is not food and water, rather extraordinary medical treatment. However the main shortfall in the literature reviewed for this research was the reference to the socio-cultural equations of food to its artificial counterpart in which only a handful of excellent sources were located.

What is certain is that the rudimentary nurturing gesture of offering food and fluid transcends all cultures (Ashby and Stoffell 1995). Whatever the experience, this is affirmed by the wisdom of the participants in this study. This is not to say that patients who have difficulties in taking food and fluid are beyond care. It is rather an acknowledgement of the limits of usefulness of medical treatments and 'comfort food' in the care provided for dying persons. It could be argued from the collective view of the participants that symbolic meanings are not always sufficient for determining the rightness of actions. Such acknowledgements certainly raise conflicts regarding artificial nutritional support and what constitutes 'feeding'. These conflicts are discussed in the following chapter which has been aptly named 'Dilemmas'.



## **CHAPTER SEVEN**

### **DILEMMAS**

#### **Introduction**

The title of this chapter was chosen as it represented the perplexing and controversial nature of certain experiences associated with the questionable provision of artificial nutritional support as endured by the contributing participants. The merging of the following codes formed this major theme: conflict re feeding; overtreatment; legal issues; inappropriate treatment; ethical dilemmas; convenience; and abuse. The 27 participants contributing to discussions included: A Critical Care Physician (UK); a Critical Care Physician (AUST); a Hospital Chaplain/Ethicist (USA); a General Surgeon (UK); a Neurosurgeon (USA); two Critical Care Nurse Specialists (USA); three Clinical Dietitians (USA); a Palliative Care Physician (AUST); a Nutrition Nurse Specialist (UK); two Medical Social Workers (USA); two General Surgeons (USA); an Occupational Therapist (AUST); two Oncologists (USA); a Gerontology Nurse Practitioner (USA); a Law Professor (USA); a Nutrition Nurse Specialist (AUST); and Oncology Nurse Specialist (USA); a Health Service Administrator (USA); and a General Surgeon (AUST).

The main discussion points identified when reviewing all data pertaining to this major theme centred on the issues of abuse, conflict, and the law. However, a further in-depth analysis of these discussion points identified communication (or lack of) as the main area of concern for the participants. Abuse as a discussion point encompassed those controversial treatment issues of overtreatment, inappropriate treatment, and unexpectedly, convenient treatment. Legal issues, a discussion point which was contributed to exclusively by the USA participants, conveyed the practice realities of what one participant termed 'defensive medicine' and the unethical nature of health care litigation. Several other issues raised by the participants were also unanticipated, having not been commented on in the literature pertaining to ethics and nutrition. The following discussion points are considered in order of emphasis and content as granted by the participants.

## Abuse

It should be noted that the employment of the term 'abuse' was done so with a considerable degree of trepidation considering the controversial connotation it evokes. However, as several participants utilised this word freely in their narratives, as well as it appearing in the related literature, its employment was deemed appropriate. The literature however, does not contribute to the 'abuse' discussions in the same way as the participants. Only two articles were located that embraced the notion of abuse of artificial nutritional support (Archer *et al* 1996; Silberman 1991), referring to only the technical aspects of such therapy in strictly objective terms. Neither mentioned those subjective explanations as offered by the participants in this discussion point. The controversial nature of these discussions could be one reason why they are either overlooked or avoided in the related literature.

Discussions of the possible abuse of artificial nutrition as a treatment ranged from technical and clinical inappropriateness to burdensome and unethical practice, especially in those patients who were considered vulnerable. Only one participant believed that there was not the potential to abuse or exploit the readiness or improved availability of artificial nutritional support as a clinical modality. This participant (a General Surgeon AUST), referred to the technological aspect of his clinical responsibilities, and did not believe that such support could ever be abused. When asked whether or not he believed that there was a potential for such treatment to be over-used or under-used, he responded:

*I don't think that there is any ethical area really, I mean I get asked to place implanted ports for patients with cancer, who might need TPN, or a feeding tube...I get asked to perform a technical procedure, so I do it. I personally don't get involved thank God in all that ethical stuff...so for me it is not an issue whether they need the stuff or not. I just do my job. (General Surgeon AUST).*

Interestingly, this participant considered his technical role as being value neutral. Conversely, two other General Surgeons, both from the USA, had very conflicting opinions:

*TPN gets over-used all the time (General Surgeon USA);*

*There is a lot of over-use of TPN especially with people who are near death, and it always causes the patient more complications (General Surgeon USA);*

An interesting paradox was provided by another General Surgeon (UK) who explained that artificial nutrition was actually abused from all angles including the proponents for enteral and/or parenteral nutrition, and even those patients and carers who did not make enough effort to feed naturally:

*Is it abused?...well yes it is. It is abused by the evangelists for parenteral nutrition who feed people parenterally when perhaps they should be feeding enterally. It is abused by the much greater number of evangelists for enteral nutrition who believe that everybody can be enterally fed, and they slavishly pursue this without taking cognisance of inadequate nutritional support and don't use parenteral nutrition. And it abused by the whole job lot of them for patients who are able to eat and drink naturally (General Surgeon UK).*

The technical aspects of providing artificial nutrition when coupled with the scenario of 'overtreatment', 'inappropriate' treatment or 'abusive' treatment was similarly commented on by several other participants who suggested that too much emphasis was placed on its provision within an acute care setting. Overtreatment was mentioned by one Clinical Dietitian (USA) who explained that there should be a lot of concern for overprescribing of TPN when it is not clinically indicated, yet is prescribed without proper clinical guidelines:

*I see a lot of inappropriate TPN being written up...they will recommend TPN for a patient that came in completely well nourished and does not have any indication that they are a nutritional risk, like nil by mouth for a prolonged period of time...like they are going to have a routine coronary bypass and*

*graft surgery...and they get put on TPN...it is unbelievable. I feel that they do that because they can – like it is there so we may as well use the stuff. I think that it is a case of people throwing their weight around and overemphasise clinical nutrition without really getting a grip on the established clinical guidelines for its provision (Clinical Dietitian USA).*

The application of clinical guidelines for the provision of either parenteral or enteral nutrition is well documented (ASPEN 1993).<sup>17</sup> This view is also supported in the relatively recent clinical literature covering appropriate provision of both parenteral and enteral feeding (Archer *et al* 1996; Silberman 1991; Souba 1997; Nordenstrom and Thorne 1994; Wood 1998). Archer *et al* (1996) specifically claim that there are distinct indications as well as associated risks which mandate justification for its provision or non-provision. The same participant explained her reservations about the overtreatment of many surgical patients regarding TPN, and referred to the institutional guidelines based on best practice and evidenced based medicine, yet lamented on the apparent disregard for such guidelines by some clinicians:

*When someone comes in perfectly well nourished and is just going to have surgery that will make them nil by mouth for maybe seven days, then it is grossly inappropriate for them to be artificially nourished during that time. We have policies based on all the best research that shows that seven days will not be of any harm to the patient ...in fact you can be doing them more harm if you aggressively feed during that time. But unfortunately some of my colleagues don't like to be told, and they go ahead and feed and haven't thought it through that it is maybe too invasive for this person (Clinical Dietitian USA).*

This 'seven day rule' was also referred to by a Nutrition Nurse Specialist (UK) who explained that a maximum of seven days will pass before the Clinical Nutrition Team will commence feeding. She explained that malnutrition will not set in before this time, therefore feeding before the seven days had passed is inappropriate. Again, this participant referred to evidence based medicine as grounds for this clinical guideline:

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<sup>17</sup> According to the ASPEN website ([www.clinnutr.org](http://www.clinnutr.org)) these guidelines were being revised at time of data collection and are to be published in 2002.

*We are not great advocates of pre-surgical nutrition, nor do we 'feed' those previously well nourished patients for a maximum of seven days because there is absolutely no evidence out there to prove that there is any benefit to the patient (Nutrition Nurse Specialist UK).*

This clinical guideline is supported by both the ASPEN Guidelines for the Use of Parenteral and Enteral Nutrition in Adult and Pediatric Patients (1993), as well as several other leading researchers in the area of perioperative nutritional support (von Meyenfeldt *et al* 1992; The Veterans Affairs Total Parenteral Nutrition Cooperative Study Group 1991; Moore *et al* 1992; Archer *et al* 1996).

Another Clinical Dietitian (USA), who practiced between two surgical ICU's, a Neuro ICU, and a Trauma/Burns ICU in a major inner city county hospital, commented on the need for professional collaboration, and the recognition from all specialties that there were strict guidelines for the provision of artificial nutritional support, especially in the acute surgical patient, in order to avoid inappropriate treatment:

*Thankfully the surgical team sees us as knowing what we are talking about...we have a very good relationship with our doctors. It would be pretty unusual for us to do any bad feeding because most of them are like 'we trust you and you know what you are doing'....because our primary rule is the same as the doctor's – to do no harm, you know...that is what I tell my students, that is our primary purpose, not to hurt anybody. So here, we go for the best treatment option for the patient and nobody has any hidden agendas (Clinical Dietitian USA).*

The closing comment in the quote above raises an interesting question – 'what sort of hidden agendas could there be regarding the prescription of inappropriate artificial nutritional support?' Possibilities include those discussed in the chapter 'Money' whereby revenue could be generated by the prescribing physician, or cost savings made by the providing institution by withholding the treatment. When questioned regarding her comment, this participant explained that she sometimes interpreted over-prescription of TPN or EN as being 'convenient' for the prescriber. This view was also shared by

another intensive care clinician who believed that EN was prescribed by medical staff so they could avoid the monitoring and complications associated with TPN:

*I often think that it is too complicated for the doctors to arrange TPN, so they go ahead and order tube feeding without really understanding the plumbing [laughs], you know, the anatomy, and you will have enteral feeds spewing up all over the place...they don't want the responsibility of all the monitoring and extra responsibility of managing the TPN so they go for tube feeds when they should have gone with TPN but it was maybe too much of a deal for them to get their head around. I know that sounds pretty unprofessional but I think that is something that does go on (Critical Care Nurse Specialist USA).*

Similarly, a Clinical Dietitian (USA) argued that enteral feeding was more convenient for medical staff in terms of the lesser degree of clinical monitoring that it generated for medical staff when compared to the more complex parenteral feeding:

*I think that it is easier on the doctors ordering-wise to get tube feeds going because then they don't have to fill out a form every day as opposed to TPN where they do, and then they got to monitor their labs real close (Clinical Dietitian USA).*

Another participant (Neurosurgeon USA) agreed that TPN was often considered as being more inconvenient to the practitioner than EN, and offered several clinical practice explanations justifying his claim:

*I think TPN is often not prescribed when it should be because it involves having to monitor the patient rigorously when they are on TPN for metabolic complications from the parenteral solutions and associated problems from parenteral fat emulsions etc. Because here we have some pretty specific guidelines when you use TPN and how often you have to get electrolytes, and how often you have to monitor all of that, whereas you don't have to follow that if they are on enteral – you just want to get some kind of average calorie balance. But the doctors are not worried about convenience for the nursing staff (Neurosurgeon USA).*

The last comment pertaining to convenience for nursing staff raised a conflicting view with regard to the modality of feeding and to whom it is administered. These last two participants believed that enteral feeding was often prescribed as being the more convenient option for medical staff, yet the following participants suggested the contrary, that is, that TPN was more convenient due to its 'clean' nature. The fact that TPN avoids the instillation of nutritional formula into the gastrointestinal tract (thereby attaining complete bowel rest), creates the absence of digestive activity which in turn diminishes much residual bowel action (Stotland *et al* 1998). Consequently, a patient receiving TPN for any length of time will commonly not have a bowel action until the commencement of enteral or oral feeding. This outcome is favoured by many carers, primarily nurses, who enjoy the freedom from 'messy' beds. This notion of 'clean' convenience by virtue of TPN was raised by several participants from various specialties. A Nutrition Nurse Specialist (AUST) believed that TPN was considered as being very convenient for nursing staff (primarily in the ICU) who were almost obsessed with maintaining a 'faeces free' environment. She commented on the reaction of her ICU nursing colleagues when she wished to pursue enteral feeding as an alternative to TPN:

*TPN in the critical care setting is awfully convenient – it just gets hooked up to another pump and what's more, the patients don't open their bowels...which keeps everything nice and clean, and no messy bed to clean up. It is almost a joke when these nurses see me walking into the ICU obviously keen to pursue enteral access and they cringe and say 'here she comes, Sister Poop'. There really is an ICU nurse thing – about having complete control over the patient's physiological functions, complete order, almost military precision, and poop just throws that order all out of whack (Nutrition Nurse Specialist AUST).*

This supposed need for control, neatness and cleanliness was also referred to by a Hospital Chaplain/Ethicist (USA) who described a certain resentment when nursing staff were faced with the change in nutritional treatment from parenteral to enteral:

*The nursing staff love the convenient nature of TPN...to the point that they will complain to those wanting to initiate enteral feeding, that sure, you can go ahead and start enteral feeding if*

*you are prepared to hang around here and clean up the mess (Hospital Chaplain/Ethicist USA).*

Although this assumption is not commented on in so many words in the literature reviewed for this research, it is referred to in several clinical articles on enteral versus parenteral feeding in the critical care setting. Kudsk *et al* (1992:503) state that although clinicians agree that the gastrointestinal tract is the preferable route for nutrient administration, '...patients are often provided TPN because of ease and reliability of administration'. Moore *et al* (1992) support this claim by commenting that enteral nutrition may be cheaper and safer, but TPN is easier to administer.

The convenient nature of TPN was not limited to the absence of the body's elimination functions. Several participants spoke of many patients in whom artificial nutritional support would need to be provided often had pre-existing indwelling central venous access, for example, those oncology patients who had long-term implanted infusion ports, or tunnelled central venous catheters. Because these devices were already there, it was often easier for their nutritional needs to be met intravenously, instead of pursuing enteral access. This opinion is supported in the literature whereby Kudsk *et al* (1992) claim that it is easier to infuse parenteral nutrition through an indwelling central line than to deal with initiating enteral access and then caring for the consequences of nutrient administration via the gut, that is, bowel activity. An Oncologist (USA) explained this in terms of inappropriate provision of TPN which can predispose immuno-compromised patients to catheter sepsis:

*Enteral feeding could really be tried a lot more readily in oncology but it isn't because it is far more convenient to go for parenteral feeding because so many of these patients already have a CVC insitu. So most of them get TPN because people opt for convenience...until they get into trouble with sepsis. They don't understand that enteral is much easier, it is easier to do it in hospital, at home with the family – there are many many reasons why we should be doing it (Oncologist USA).*

Similarly, another participant commented on the convenient nature of pre-existing central venous access being abused for the purpose of parenteral feeding:



*It happens a lot with cancer patients because they have the catheter already there and it is easy so again that convenience thing raises its ugly head, but you have to ask yourself who is it easier for. It sure isn't easier for the family, and most importantly it isn't easier for the patient. I think a lot times with these patients, giving TPN is a real cop out because the clinicians can't be bothered going the extra mile and trialing enteral feeding (Clinical Dietitian USA).*

Likewise, the convenience of pre-existing central venous access was mentioned by a Gerontologist (USA) who referred to those patients in critical care settings who routinely had multiple lumen central venous access:

*I see a lot of that happening in the ICU where they have triple or quad lumen CVC's and it is real easy just to plug in another infusion without going through the motions of placing a feeding tube...or it is just convenient to leave the patient on TPN even though it is probably appropriate now to switch the patient to tube feeding, so I do see that happening (Gerontologist USA).*

One participant, a Gerontology Nurse Practitioner (USA) offered a literal description of 'abuse' in terms of the provision of artificial nutritional support – in this case enteral feeding via a PEG tube. He recounted an experience from practice whereby he became suspicious of a caregiver's noncompliance with not only the provision of tube feeding, but also the administration of medications as evidenced by the patient's abnormal serum levels. This account is grounded in the context of strained family dynamics as previously discussed in Chapter Six 'Culture' (p. 172-173) of this thesis.

*I see a lot of guilt, and then I see some stuff with people who might have had an overbearing parent, and now they are in control. In one particular family I remember that medications and feeding were given by the son as a ways of getting back at his dad. This patient did not have normal lab values for this one particular drug, and we were trying to figure it out, and it turned out that the son was doing some funny things with the medications in retaliation. That was weird, but he also did some pretty rough things with his PEG and feeds like run through a day's worth of feeds in an hour? It later turned out after talking with the sister that he was really getting back at his Dad....they'd*

*had a real bad relationship in past years (Gerontology Nurse Practitioner USA).*

This above scenario also represents a similar form of abuse as previously discussed with tube feeding elderly patients in Chapter Four 'Death (p. 129-130). However, the most confrontational and surprising contribution made by the participants with regard to 'abusive' feeding came from two participants in the USA who explained the somewhat bizarre occurrence of nursing homes or long term care facilities opting for feeding tube placement and enteral feeding, instead of maintaining normal oral feeding. The natural hand to mouth feeding of frail, elderly and often demented patients is in reality labour intensive. Both participants explained that often these facilities would not accept new patients if they did not have an indwelling feeding tube which would make 'meal times' much easier for staff:

*One thing that happens with nursing homes is that it is much more convenient if you can just PEG them and then feed them like that, and in fact, we can't send them to a nursing home...that is right...unless they have a PEG in place (Hospital Chaplain/Ethicist USA);*

*I know this sounds really bizarre. It is that simple, you cannot get them into a nursing home if the don't have a PEG insitu, I mean the nursing home will not take them, because they do not have the staff to manually feed them (Neurosurgeon USA).*

This scenario is not mentioned in the related literature yet is worthy of serious investigative inquiry along the lines of unnecessary medical and surgical intervention as it could well be equated with some degree of assault. On the contrary, the literature does make reference to the need for nurses to assess the functional status of geriatric patients and identify areas in which nutritional support is needed. Kenefick (1999:26) states that this includes '...providing preferred foods and ensuring nursing staff availability to provide physical assistance with eating'. This could well be the 'idealistic' feeding scenario and not the 'realistic' one as alluded to by the above participants. Despite such realistic explanations of convenience not being located in the associated literature does not preclude the absence of such practice, especially considering that we are witnessing a

marked increase in feeding tube insertion in vulnerable patients, especially the elderly (Oyogoa *et al* 1999). Anecdotal evidence provided by these participants practising within the area of gerontology as to the increased incidence of feeding tube placement is testament to this questionable practice. The benefits of this medical intervention are unclear, and the risks substantial. This is a fact well documented in the related clinical literature (Ashby and Stoffell 1995; Ciocon *et al* 1988; Finochiarro *et al* 1997; Finucane *et al* 1999; Mitchell and Lawson 1999).

This description of convenient practice so to accommodate (it could be argued) poor nursing care and cost cutting/staffing practices, were not exposed and discussed in the literature reviewed for this research. However, one closely related article authored by a consultant physician dying from cancer was subsequently located. Khadra (1998) claimed that perhaps modern health care cannot afford compassion and that it may not fit into the corporate model of patients as clients, nurses as managers, doctors as visitors and administrators as the pinnacle. The compassionate, yet time-consuming nature of hand to mouth feeding of the frail aged fits this claim well, and completely debunks the myth of quality care for senior citizens.

Only one participant offered an 'either/or' explanation regarding the convenience of artificial nutritional support comparing parenteral to enteral feeding. He argued that nursing staff were not concerned about the convenience of feeding in the same way that the surgeon or the physician would be:

*On one hand, the physician doesn't want to pursue enteral access if he or she can't be bothered or they might not have the knowledge or the skills to place a feeding tube intraoperatively, and then, on the other hand, if they do want to go for the gut, it can be convenient for them too because they don't want to be called when the central line clots off to go put a new central line in...you know, if it is an NG tube or a Dobhoff then the nursing staff can just go ahead and place another one down in most cases. But if the central line clots off then the doctor has to come and a put a central line back in (General Surgeon USA).*

These contrasting representations of how parenteral or enteral feeding are considered because of their convenience and not necessarily their physiological benefits to the person on the receiving end of treatment are clearly described by the participants. These descriptions of convenient care are also suggested in the literature, albeit not in the same depth and richness. Only one participant offered an opposing perspective on the notion of convenient feeding by arguing that any modality of artificial feeding was not at all convenient. She provided this descriptive account based on her past experiences of when patients were faced with leaving the artificial and protective environs of the acute care setting, to face long term artificial nutritional support in their own homes:

*I don't think that it is ever convenient...convenient for who? Maybe convenient for the doctor, but when you take this person home and the caregivers have to deal with this, it is not at all convenient – it is not convenient for the patient either in my opinion. It requires a lot of maintenance especially on the continuous feeding plans where the Dietitian has to set the pump. And a lot of people on our program are low income, and of low education, low literacy, and education of the families, the care providers is a huge issue. It is so tedious and time consuming and often there is a language barrier, and the supplies that take up an entire room in an often tiny dwelling – well it is not convenient at all. A lot of these people live in overcrowded unsanitary environments, roach infested, where it is just not conducive to good infection control. We are always going out there to fix a lot of them in the home – the tubes will be leaking or clogged. Our Nurse Practitioner will have to go out there and fix them – it is a big issue. The concept of the PEG is pretty basic plumbing but in reality they can be very problematic and you can't be there 24 hours a day to ensure they are working. Plus the carers sometimes, they are not compliant – this is a very difficult issue. It is not convenient for anybody (Medical Social Worker USA).*

Inappropriate provision of artificial nutritional support was also discussed at length by several participants who referred to improper feeding at the end-of-life, especially in those patients with a malignancy. Their comments were more angled at the potential complications arising from inappropriate aggressive feeding and not so much 'abuse' of the technology as suggested by the previous participants. A Palliative Care Physician

(AUST) explained an interesting clinical consequence of inappropriate nourishing of cancer patients which resulted in more rapid tumour growth:

*If there is no other aggressive anti-cancer treatment in place, not only is artificial feeding using up a lot of resources, but it is also kicking the cancer along without really benefiting the individual... you actually end up growing the cancer quicker (Palliative Care Physician AUST).*

Despite several supportive and also conflicting views subsequently located in the literature (Bozzetti *et al* 1999; Cozagglio and Bozzetti 1994), this participant offered the following explanation of how artificial nutritional support, primarily TPN, will actually increase the rate of tumour growth:

*There are a number of cancers where this can happen. The physiological model of the paired rat connection where researchers have stuck a couple of rat circulations together – one with cancer, one without cancer, and the rats feed normally, and both rats lose weight because of the circulating tumour factors going on. You artificially feed them and what happens is that both rats continue to lose weight, but the rat with the cancer grows a bigger cancer, and then you disconnect their circulations, and the one without the cancer gets back to a normal weight rate, and the one with the cancer just shrivels away and dies. So there is a biological process where the cancer actually changes the body's ability to handle the proteins and carbohydrates and is really left with basically just the glucose drive to go with. And to give an artificially rich nutrient solution to someone with a certain cancer really just promotes ill health rather than their health (Palliative Care Physician AUST).*

Another Palliative Care Physician (AUST) expressed similar sentiments regarding inappropriate aggressive nutritional treatment in those patients with an advanced malignancy that actually created more suffering:

*I know at times we prolong people's suffering quite inordinately through the wrongful provision of artificial nutritional support (Palliative Care Physician AUST).*

Similarly, another participant commented on inappropriate feeding at the end-of-life:

*Prolonged aggressive feeding of any sort can create a lingering death that is not the most humane way of managing someone's exit from this world (Oncology Nurse Specialist USA).*

The same participant also reflected back to her experiences as a nurse caring for the elderly who, by virtue of their age and/or their underlying disease processes, were considered incompetent, and treatment decisions were therefore made for them, not by them. She expressed concern regarding the inappropriate nature of these 'clinician imposed' treatment decisions that often lead to the demise of the patient:

*In the elderly, we seem to sweep them under the carpet and not give them the benefit of the doubt because the majority of them are incompetent. So we make their treatment decisions for them and subject them to prolonged deterioration or worse, kill them with the associated complications of tubes and tube feeding. I find this dilemma really difficult and sad (Oncology Nurse Specialist USA).*

Interestingly, the irony of 'nutrition specialists' not endorsing the provision of the very specialty that they upheld was explained by one participant as being a difficult paradox in her everyday work role:

*Everybody thinks that we, the nutrition team, who have jointly published heaps of papers and take our jobs very seriously, that we are there to always feed. People, patients, family, staff – they think we should feed everybody because that is what we are there to do, that is part of our job...we are there to highlight nutrition and that is it. Often, there is no understanding of perhaps the times when we shouldn't (Nutrition Nurse Specialist UK).*

This irony represents a certain misconception of other professionals, patients and family members on the role of feeding. Consequently, this leads to the following discussion point raised by the participants, that is, conflict.

## Conflict

Essentially, conflict was discussed in terms of what occurred when there was a breakdown in communication. Communication was implied by the participants as being the conveying of truthful information to colleagues, patients, and family members of the realities of artificial nutritional support, and the goals of such treatment. Not all participants believed that conflict was ever an issue when dealing with the provision of artificial nutritional support. These participants considered conflict to be between clinicians concerning the choice of either enteral or parenteral support of patients in a critical care setting. Two Critical Care Physicians (UK and AUST respectively) gave the following explanations:

*I cannot recall the last time I had any conflict in terms of feeding. What I says goes as far as feeding is concerned (Critical Care Physician UK);*

*I don't find that there is conflict about the area of nutrition management in this hospital as the surgeons by and large allow us to make those sorts of decisions (Critical Care Physician AUST).*

Another participant practising within a critical care environment also commented on the lack of conflict that he had experienced in terms of feeding which, he believed, was due to maintaining very close links with family members and providing a collaborative approach to care:

*I think we avoid a lot of conflict because we do a good job...we try to keep good contact with the families, with the doctors, and the nurses. We have a case management team with a social worker, and we have a lot of involvement from neurosurgery and good contact with the families. So I think that we know their wishes and we are straightforward with them, so in the time I have been here, I have never seen that conflict (Critical Care Nurse Specialist USA).*

However, for those participants practising in clinical environments elsewhere, the issue of conflict regarding feeding were abundant. For example, when a Palliative Care

Physician (AUST) was questioned whether or not conflict was an issue, the response was very different:

*Oh, about every week...three times a week it becomes an issue (Palliative Care Physician AUST).*

Despite his admission that conflict was common, he did explain that within the specialty of Palliative Care, there were 'theoretically' very few areas of conflict about the artificial nutritional support. However, issues did arise 'practically' when people wanted to have feeding continued when it was patently obvious that it was not going to be of benefit to the patient. Correspondingly, another participant commented on the incidence of conflict regarding feeding in vulnerable patients and how it sometimes reached 'crisis' level:

*Conflict occurs frequently. It happens every week. It is a major crisis we have now (General Surgeon UK).*

A Neurosurgeon (USA) explained conflict with family as a 'social decision' that resulted from an understanding of what constituted medical feeding and how it did not equate with cultural feeding:

*It is a social decision, because we know what to do medically, but the conflict that occurs with the family is just so amazing because it is what they understand. They don't understand the medicine, but they understand feeding – because it is part of their cultural background (Neurosurgeon USA).*

A multiform explanation of what constituted conflict(s) was also provided by the following participant in terms of religion, culture, race, finance and ultimately, the law:

*There are several conflicts when it comes to artificial nutrition...there are religious conflicts, there are cultural and racial conflicts, and there are financial conflicts. And I don't think that people outside the United States realise the legal implications – because I have a family that tells me that 'we need this PEG in there'...and 'my brother is lawyer and he would like to sit down and chat with you about this'...then you*



*are just going to put the tube in, so there are legal conflicts as well (Hospital Chaplain/Ethicist USA).*

A second Palliative Care Physician (AUST) recounted in detail two occasions from practice where conflict also reached a 'crisis' level due to a breakdown in communication between the referring medical team and receiving hospice team. This lapse in effective communication caused family members to 'fallout' with providers:

*On at least two occasions that I can remember, poor communication has really let us down. The patients were transferred to our unit with TPN still going and the dilemma was then left to us to discuss withdrawal of feeding with the patient, and patient's family...and the enormous fallout that comes from that has been destructive both in terms of our ongoing treatment of the patient and family, and also our continued relationship with the referring unit (Palliative Care Physician AUST).*

This same participant provided a thick, descriptive account from practice of a particular incident that obviously had considerable impact on her clinical experiences of conflict regarding feeding. This rich textual account has been presented in full in order to capture both the complexity and significance of such conflict:

*To give you an example, I remember very clearly a man who was probably in his late 50's, early 60's who had been diagnosed with a very advanced gastric carcinoma. He had a complication in that his daughter was a senior nurse in the referring oncology unit, and I don't know to what degree that influenced the treatment he was given, but he was a patient that had received TPN, when I believe perhaps in other patients it would never have been provided. However that was done, and when it became clear to the oncology unit in which he was being cared for, that the time had come where they could not do any further active treatment and they needed to consider placing him elsewhere, they asked if we would be prepared to take him into the hospice. Quite obviously it was a perfectly appropriate transfer except for the fact that he was on TPN. So, we went through the normal discussion with the doctor involved and the treating staff to discuss with this the patient and to get the 'all clear' that TPN be ceased and for him to come over to the hospice. In fact that was apparently never done, and so when the patient came into the unit and went through a routine*

*admission at which point it was discussed with the patient himself and his family including his wife that in the hospice situation we would not be continuing TPN as it was really quite opposed to the goals of hospice care to do that, and also because our budget didn't allow for it. All hell broke loose. We probably, I think, spent an enormous amount of energy with trying to come to some consensus, mainly with the patient's wife and family. My memory is that the patient himself was quite OK with the treatment being stopped, because I believe that he firmly understood that he was actively dying, and it was not achieving any great benefit. However, his wife and daughter saw things very differently and really felt that they had been conned into bringing him over to the hospice unit. Their view was that the oncology unit probably just wanted him out of there because his daughter worked there and it was very difficult for the staff to go on treating someone's parent and that these things had never really been explained to them. So that was just one instance in where it took really days of time and effort, and dealing with each individual member of the family as well as the patient, to encourage them to come to a point where they felt OK about our discontinuing that treatment. We did reach that point and his ongoing care I think was relatively satisfactory....but I think that there was always a discomfort in the minds of all of us that this should never have happened (Palliative Care Physician AUST).*

This account raises the fundamental flaw in patient-provider relations which are predisposed to conflict, that is, poor communication. It also highlights the need for truth-telling in terms of communicating poor prognosis, and treatment goals. The same participant exposed this flaw in her own descriptions of insufficient discussion of a medical nature that should take place between the treating team and the patient for what happens 'further down the track':

*I believe that far too often those conversations are left to somebody else, and often that somebody else is the palliative care specialist. So that reinforces that we are the deliverers of bad news (Palliative Care Physician AUST).*

This notion of providers who work within 'death care' environments such as palliative care or hospice settings being the harbingers of bad news is well documented in the literature (Poulson 1998; Ptacek and Ellison 2000). However, this raises certain

shortcomings in the abilities of other health care providers to fundamentally communicate effectively and truthfully. As the following participant explains, the power of truthful and effective communication is not only essential in medical care, but is essential in avoiding the unfortunate consequences of what Goldberg (2000:181) describes as a 'litigious society'. He offers this description of how patients and their families may not be equipped with the interpretative capabilities of complex medical jargon, yet are heightening their awareness due to receiving care in the information age:

*Ethical issues usually arise when the doctor doesn't talk to the patient. Ethics are the ethics of the patient. Those are the ethics that are most important. The ethics of the doctor are irrelevant and shouldn't take precedence. But most of all the ethical issues that make it to the legal front almost always are related to communication – Dr A or Nurse B said something that they shouldn't have or didn't say something that they should have. Patients, most of them, are not versed in medicine per se...they will probably attach to one or two or three statements out of a conversation with the doctor. If things get really complicated and frustrating for the patient, then instead of heading into the legal side of things it really is resolvable with more medical conversation other than legal conversation. But unfortunately that is not the reality in this country. A little knowledge is very dangerous, and unfortunately everyone has a little knowledge – doctors have a little knowledge, patients have a little knowledge, the Internet has a lot of knowledge – and you put all of that together and sometimes the decisions that are made are not academically defensible, but they be socially defensible, they be personally defensible, even ethically defensible, but legally, well that is another story (Oncologist USA).*

In the previously mentioned initiative of the American Medical Association's Institute for Ethics, The EPEC Project does contain teaching modules encompassing communications skills and discussing poor prognosis. These modules target an audience of practising physicians, nurses, medical students, and all allied health care providers. Their goal is to provide a framework to enhance communication between patients, families, and providers at all stages of the patient's relationship with his/her disease. The material actually encourages providers to spend time with their patients,

and to encourage patients to become active participants in their care. This initiative was launched in February 1999. It is indeed both a timely and pertinent initiative considering the certain shortcomings of health care providers' obvious inadequate preparation in these areas. No such education initiatives on end-of-life education were located in either the UK or Australian medical curricula which certainly represents a deficit. One of the many areas covered in the EPEC Project is that of working with the law with regard to decisions about life-sustaining treatment and end-of-life care. The contributing participants identified 'the law' as of major consequence in the way they provided care to those on the receiving end of artificial nutritional support, and are explored in the following discussion point.

### **Legal Issues**

The tendency to view artificial nutritional support as different to other forms of medical care is one that is sometimes shared by professional ethicists and courts (Mayo 1996). The related medico-legal literature concerning this modality conveys a near-unanimous consensus in the court decision of this subject (Meyers 1985; Nelson *et al* 1995). However, for the participants contributing to discussions on legal issues, the main ethical dilemma discussed was that of fear of litigation, or more simply, the practice of 'defensive medicine'. Several participants described certain treatment practices regarding artificial nutrition support provision that could be aligned with overtreatment in an attempt to avoid litigation proceedings. Despite the majority of contributing participants to this discussions being those who practiced within the USA health care delivery system, several other participants from the UK and Australia also shared similar views on defensive medical practice in order to avoid legal proceedings by families. The term 'defensive medicine' is typically understood to refer to instances where health care practice decisions are motivated primarily by the desire to protect him or herself from the risk of legal liability (Sharpe and Faden 1998). Studies have shown that medical practice patterns are indeed influenced by concerns about legal liability (Reynolds *et al* 1987). The following descriptions of overtreatment aligned with defensive medicine in a litigious society were offered by the following participants:

*There is the very real possibility of the defensive practice of medicine – in order to avoid being sued or avoid being sued successfully, you order a battery of tests that are not medically necessary, you continue or start aggressive treatments that are futile, or you keep the patient in the hospital longer than would be advisable just for that extra sentinel of safety (Law Professor USA);*

*You must understand that the United States is a litigious society, and frequently, not doing everything whether reasonable or not opens you up to a lawsuit. You get the 'why didn't you doctor?' question thrown at you, so there is a very real tendency to over-utilise treatments from that perspective (General Surgeon USA);*

*Not providing artificial feeding, even when it is clear that such treatment will put the patient at risk of more complications, well I think that is a very difficult decision for the doctor because I think in that sort of situation they would possibly be leaving themselves open for litigation (Occupational Therapist AUST);*

*Physicians are, for a whole bunch of reasons, they are scared of lawsuits and renegade family members wanting to sue for anything, and you know, they should be scared (Hospital Chaplain/Ethicist USA).*

This last comment discloses the notably litigious nature of the USA health care culture whereby malpractice insurance premiums for physicians now average a yearly contribution of ranging from \$6000 for an internist to over \$57 000 for an obstetrician/gynaecologist (Rice 1998). Recently, Albert (2001) predicted that these figures can be expected to rise between six percent and 50% over the next two years. This belief was also supported by another non-clinician participant who argued that medical liability premiums constituted approximately one percent of the cost of health care in the United States. He further explained the impact this had on the overall cost of health care:

*If you wiped out the need for liability insurance you would have a one percent effect on the cost of health care which might not seem much but you must remember that we are talking in billions of dollars when it comes to health (Law Professor USA).*

This above assumption is also maintained by Gray (1998). In line with the concept of defensive medicine, the previous participant further explained his comment of why physicians should be afraid of litigation:

*In the United States, it is, I don't know about other countries, we are so litigious that a lot of defensive medicine is practiced, and so you 'do the PEG' because you don't want to be deposed by an attorney six months later who tells you '...so let me see, the patient's nutritional requirements were not being met, and the standard of practice is to put in a PEG for that, and you didn't do it...therefore you are liable...you caused the death'. Now you can argue whether or not that is standard of practice in a terminal condition, but that is the fear that motivates a lot of end-of-life treatment...nobody wants to get sued for not doing everything that is possible (Hospital Chaplain/Ethicist USA).*

This described 'fear of litigation' was subsequently found in the medical ethics literature on withdrawing life-sustaining treatment. Weir and Gostin (1991) claim that the USA courts decide many such cases, usually because hospital attorneys have refused to allow their doctors to act in what they agree to be their patient's best interests, for fear of litigation. Jennett (1999) supports the assertions made by the participants regarding such conflicts not being worthy of legal deconstruction, but that doctors and families should be able to reach treatment decisions between themselves. This would demand the communication suggested by the participants with regard to avoiding conflict.

The way the fear of litigation shapes medical practice regarding artificial feeding was also commented on by another participant who explained the often times questionable motives of attorneys in order to 'win' a case:

*If I appear to the family that I am not doing everything possible, that I am taking care of this patient – like if I think that continuing feeding is killing the patient like with aspiration or infection, then I know that some smart ass attorney will encourage the family to say that I should have fed the patient because that patient might have got the immunity to fight and survive (Neurosurgeon USA).*

The supposed questionable motives of legal professionals was also discussed within the context of doing whatever one can in order to win the case, sue the physician successfully, and consequently make money. The same participant described his past experiences of litigation in which attorneys actually lied in order to argue their case because they were not under oath. This explanation was conveyed with notable angst and frustration on behalf of the participant:

*You know that the attorney standing there is lying, and everybody in the courtroom knows it. They know he is lying, but it is OK because it is legal. The attorney is not under oath to tell the truth so he can go and argue and call you everything he wants, and quote things that are totally irrelevant and that is perfectly legal. So we refer to it that we have a legal system – a legal system...not a justice system (Neurosurgeon USA).*

When this participant was questioned concerning the practices of these attorney's, he explained that '...they don't care...they only care if someone can get sued.' He also explained how disturbing it was for new medical graduates who were confronted with their first legal encounter as a physician:

*Regardless of what they might learn in med school and the content of those courses, new physicians are so naïve until they get their first law suit – it is so devastating so see such unethical behaviour (Neurosurgeon USA).*

An interesting contradiction between the definitions of law and ethics is exposed here. Several participants commented that law and ethics were not the same (as suggested by the previously explained 'unethical' practices of attorneys), however they explained that to attorneys, the definitions of the law and ethics were the same:

*Attorneys don't often understand the difference between law and ethics – they think that they are the same thing. It is their definition of ethics. To them, ethics equals law...if it is legal, it is ethical, and that is not true (Hospital Chaplain/Ethicist USA);*

*The definition of ethics for an attorney – for them to be ethical – they have to do everything that can to represent their client. So*

*if their client, you know, is lying, but they can give a legal argument that allows them to lie and they have done something unethical, and then the attorney doesn't do everything he can legally, then he is considered unethical. All of us here would call that fraud and totally unethical but for an attorney that is their definition of ethics. So if I (let's pretend I am an attorney), and I blame the physician for his supposed crime, then I have done my job, and that is ethical (General Surgeon USA).*

This notion that the law and ethics, or the law and morality were not the same was located in, as such, a precise explanation in a text providing translations from Greek philosophers. According to Socrates, the State may decide what is legally right and wrong, but the law and morality are not the same thing (cited in Robinson and Garratt 1996).

The practice of defensive medicine secondary to the fear of litigation was explained by a Gerontology Nurse Practitioner (USA) as the result of things having 'gone crazy'. He described a no-win situation in which a practitioner could in fact be sued for doing either/or in regard to the provision, or non-provision, of artificial nutritional support, yet provided some solace to this dilemma by stressing the importance of communication:

*I think a lot of treatment decisions are made because of the fact that health care in America has gone so crazy now...I mean you could just as easily be sued if you don't place a feeding tube, or you could be sued if you do put one in and the patient develops a complication. So in many ways we are screwed either way. I think that it really depends on the relationship that you have with the family and I think that as long as you have a good sort of relationship with the family, you don't have law suits. That is what we try to do. We don't have a choice but to do that because this is such a litigious society that we have created (Gerontology Nurse Practitioner USA).*

This sentiment regarding communication was similarly explained by a UK participant who also referred to the fact that health litigation was not a predominant feature in his practice:



*I think that what is very important in that situation is that people with an interest and understanding about why we might feed or not feed is to sit down with the relatives and take them through it. You must have open lines of communication with the family – that is imperative. The number of times doctors are going to do things that are diametrically opposed to the family's wishes is negligible, yet I think that is also because we don't tend to sue here in this country like they do in America (General Surgeon UK).*

An Australian participant expressed a similar view regarding the 'non-litigious' nature of health care in Australia, yet identified with the consequences of defensive medicine regarding artificial nutritional support. Her explanation also provided the interesting referral to the comparisons between the health care delivery systems as being akin to different planets:

*A lot of what I have read seems that it is a far greater problem in the United States than it is here in Australia, and I think that the underlying problem is the fear of litigation which I think that at this point in our history is not big for us...perhaps in maybe 10 years or so down the track, but I don't think we live in the same kind of fear of practice that the US doctors seem to. So I think often that is what drives inappropriate provision of nutrition...it seems to me a fear that if they don't do this, somebody, somewhere will sue them. And I think that we have much greater freedom to practice what I believe is true, more ethical medicine than in the States – that is just a very broad generalization, but most of the things that I have read really...well it is almost as if we are practising medicine on two different planets (Palliative Care Physician AUST).*

The consensus that the law and ethics were two different things, plus the explanation that communication and truth-telling were the keys to avoid both ethical dilemmas and legal consequence was poignantly summarised by one participant who emphatically explained that '*...ethics are the ethics of the patient....*' (Oncologist USA), and that these ethics are the ones that we should be concerned with. In explaining the common paradox between law and ethics he offered the following explanation with regard to end-of-life situations:

*The true ethical issue is something that the patient faces and the family faces...am I going to die? Am I going to spend \$100 000 of my children's inheritance and take good care of myself, or is it good care? That is your ethics. The patient could say that I am not going to do that or he could say yes I will spend my children's inheritance – it does not make him a worse or better individual, but you live according to you own ethics I think. As far as issues about if you bring this ethic to whether or not a treatment should be done I think that you are just legalising ethics and that is wrong. That is the basic fall down of medicine nowadays, that ethics is confused with the law, and that the doctor has been forced by the law to abdicate the responsibility of ethical patient care in order to be legal (Oncologist USA).*

This explanation evokes a powerful and confrontational reality also provided by another participant who cited a similar belief that medicine was losing its appeal as a profession due to this alleged 'abdication' and the constraints of defensive medicine:

*No-one wants to study, to practice medicine these days and I don't blame them...I am looking at getting out of it myself because you can't provide the care that patients deserve because you spend a career walking on eggshells waiting for the next deposition, or there is no money in it because some of us have to pay yearly premiums that equal up to 90% of our income. The law has become business and not justice (Neurosurgeon USA).*

The previous participant also acknowledged this sentiment:

*These sorts of decisions decreases the meaning of ethics because what it does is aligns it with legalities. Nowadays there is almost no such thing as ethics...there is only the legal aspects of ethics that we are concerned about. As long as you only concentrate on the medical, social, religious aspects of ethics and practice your medicine that way then you should not have to get to the legal aspects. That is a very frustrating way to do your job (Oncologist USA).*

Physician resentment of the legal system was located once in the medical ethics literature. Zussman (1992) claims that physicians are often vexed at what seems to be an overbearing legal system. He explains that physicians often resent the law deeply

and ascribe to it an influence unwarranted by court findings. Here we encounter the contested notion of justice, which is a recurrent theme in the bioethics literature. As the participants suggest, the law does not deliver unequivocal notions of justice.

## **Conclusion**

The lived experience of the participants shows that truth-telling and communication are ethical concepts which are, at times, honoured in the breach. The participants speak of institutional practices which discursively shape ethics. Those ethics are in sharp contrast with the ideals espoused by the literature. Despite the medical ethics texts reviewed for this research proclaiming that honesty between doctor and patient is the key element in the partnership (BMA 1998; BMA 1999), the narratives of the participants suggest that it is rather the exception than the rule. The discussions on 'convenience' feeding are similarly confronting considering their sharp contrast with the cultural symbolism of food and feeding. Such discussions are more confronting considering their absence in the related literature. In the case of the feeding tube, it could be concluded that these devices appear to have more rights than patients. Such a provocative speculation necessitates both extensive ethical and legal inquiry. Collectively, the dilemmas associated with the provision, or non-provision, of artificial nutritional support are certainly not limited to 'conflict'. Abuse, conflict, and the law, are problematic concepts that warrant a definite all-out analysis that would truly expose ethical dilemmas beyond both the scope of this research. Such confrontational inquiry would be challenging to say the least. The associated dilemma of 'futility' is equally as challenging, and provides the substance of the following chapter.

## CHAPTER EIGHT

### FUTILITY

#### Introduction

Few issues in health care are more complex and difficult than those addressed by patients, their relatives, and their health care professionals concerning the decision to withhold or withdraw life-prolonging treatment. This major interpretation chapter deals with the notion of *futility* within both the discrete concept of the provision of artificial nutritional support, and also within the broader context of the provision of life-sustaining treatments. This resulted in the merging of the following seven codes: futility; withdrawal of nutrition; advance directives; quality-of-life; curing and caring; complications from feeding; and benefits and burdens. These codes were discussed at length by the following 26 participants: A Nutrition Nurse Specialist (UK); a General Surgeon (AUST); an Oncology Nurse Specialist (USA); two General Surgeons (USA); a General Surgeon (UK); a Nutrition Nurse Specialist (AUST); a Clinical Pharmacist (AUST); a Hospital Chaplain/Ethicist (USA); a Gerontologist (USA); two Palliative Care Physicians (AUST); two Medical Social Workers (USA); a Gerontology Nurse Practitioner (USA); two Oncologists (USA); a Law Professor (USA); a Critical Care Physician (UK); three Critical Care Nurse Specialists (USA); a Clinical Dietitian (USA); a Medical Administrator (USA); and an Occupational Therapist (AUST). Significant overlapping of codes occurred throughout the interpretation process, primarily with withdrawal of nutrition and futility. The title of this chapter was chosen not just to embrace the most significant code name adopted by the participants, but also to reflect the timely nature of the concept of futility as represented in current medical and ethical/legal debate. Three major discussion points have been identified from what turned out to be both a vast and complex compilation of participant contributions. These are discussed in order of importance as afforded by the participants and have been termed futile feeding, honest communication, and advance care planning. Prior to the exploration of these discussion points, it is helpful firstly to examine the discourse of 'futility'.

### Discourse Analysis

Many aspects of modern medicine provoke spirited ethical argument, but few engender as much disagreement about what exactly is at issue as does the futility debate. The term 'futile' stems from the Latin word '*futilis*' meaning 'leaky', and is defined by the Australian Concise Oxford Dictionary as 'useless, ineffectual, vain, frivolous' (1987:428). In terms of medical futility, the concept is explained in terms of the simple recognition of the limits of medicine to cure and to extend life, and that health professionals should not be obliged to provide further curative treatment. The associated literature yields considerable acknowledgement of this concept and features frequently around discussions of futility judgements, futility and professional integrity, futility policies, death with dignity, and forgoing life support. However, such definitions are by no means clear-cut or without controversy. As Tomlinson and Czonka (1995) have argued, defining futility whether by setting quantitative standards or by identifying categories of patients who should not be treated, creates several risks. Defining medical futility creates the illusion of specificity where none is possible; it may lead to superficial medical evaluations, and it ties futility to narrow biomedical goals for the patient (*ibid.*).

Many different bodies of organised medicine (American Medical Association 1991; American Council of Physicians 1992; American Thoracic Society 1991; Society of Critical Care Medicine 1990), ethicists (Schneiderman *et al* 1990; The Hastings Center 1987), and legal commentators (Grant 1992; Darr 1995; Sadler and Mayo 1993), have offered markedly different definitions of futility that range from the lack of intended physiologic effect to low likelihood of survival to discharge, to low likelihood of surviving more than a few months, to poor quality-of-life or permanent dependence on intensive care. 'Futility' has quite different connotations. According to Jecker and Schneiderman (1992), 'futility' suggests that medical care is wasteful, that even the best efforts will be pointless, useless, if not hopeless. These discussions on futility however, are seldom able to stay within the narrow confines of medical usage.

One of the research participants offered what he considered to be a more appropriate and practical term (instead of the word 'futile'), that being 'irretrievable'. He explained this choice in reference to the Tony Bland<sup>18</sup> case in the UK:

*The Tony Bland case was interesting because they were actually allowed to withdraw nutritional support and other support, because he was considered to be irretrievable (Critical Care Physician UK).*

The same participant also provided an insight into whether or not the term 'withdrawal' was actually appropriate when discussing futility, as withdrawal of treatment did not necessarily occur, rather treatment was changed or modified:

*I often wonder whether the term 'withdrawal' is an inappropriate term because usually withdrawal is an active process only in terms of you turning things off. But what you are almost invariably doing is changing the focus or direction of treatment with a different end point...and I think that is a very different sort of thing...ethically (Critical Care Physician UK).*

The choice of language is therefore problematic considering that the identification of a palliative end point rather than an aggressive one could be compared to changing the focus of other therapies. The choice of language here is interesting in that it indicates the dominance of the acute care orientation of medical discourse. The same participant compared changing a patient's medication from gentamycin to vancomycin as a similar proposition, that is, not withdrawing antibiotic therapy, rather simply changing it:

*We have a patient upstairs now with septicaemia on gentamycin, and is not doing very well, and we got blood cultures back and it was MRSA, so we withdraw the gentamycin because it is not doing anything and we would use vancomycin – maybe that is different, I am not sure, but it is not that*

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<sup>18</sup> Tony Bland was left in PVS after the 1989 Hillsborough disaster. His parents fought a protracted legal battle for the right to allow him to die. The House of Lords Committee ruled that his artificial feeding was a medical treatment and was therefore withdrawn. This suggests a consequentialist ethic. According to Fisher (1994) the consequentialist view says that all that matters are consequences, meaning that if a person dies because we kill them or sit by and let them die, the result is the same. His case in particular is discussed in more detail in Chapter One 'Reviewing the Literature' (p. 10-12).

*different. It is a positive action in a different direction (Critical Care Physician UK).*

According to Schneiderman and colleagues (1996), no professional or societal consensus has been achieved about the definition of futility. Therefore, for the purpose of this discussion, the terms 'futility' and 'withdrawal' are employed, albeit with recognition of their precarious interpretation considering that discourses reflect differing conceptions of reality.

### **Futile Feeding**

This discussion point was imbued with overtones of the benefit versus burden argument, wasted utilisation of costly resources, and the principle of autonomy. The concept of futility in terms of the provision of artificial nutritional support was a common problem for the following participant who described his dealings with this problem as occurring 'all the time'. He offered what he explained was a common scenario in terms of futile feeding:

*There is a patient of mine with adenocarcinoma of unknown primary who is not responding to chemotherapy...he has intestinal obstruction, he has a line with IV morphine and a TPN line, and he got another round of chemotherapy in hope that something will 'open up' ...and now he has an NG tube for drainage...and he is a very young guy, it is a very difficult situation. Neither the chemo nor the TPN are doing him any good, in fact they are only dragging out more complications...but it is his choice to continue treatment even though it is not going to do him any good (Oncologist USA).*

Another issue of withdrawing nutritional treatment on the basis of futility as being problematic was discussed by one participant in terms of patient autonomy. He explained that questionable provision of artificial nutritional support is only a problem when the patient is not competent:

*When a patient is competent and requests the provision of nutritional support, then clinicians then have an ethical obligation to feed them. The dilemma only arises with withholding treatment because withholding and withdrawing from an ethical standpoint are just the same. The problem only*

*arises when you have an incompetent patient, that is, someone who is unconscious in an ICU, or has a stroke, or in a persistent vegetative state (General Surgeon UK).*

The same participant did not consider that there should be an issue about feeding in the terminally ill by explaining that if the patient who is terminally ill such that they are anticipated to die imminently, then it was not ethical to feed this patient, because there was no benefit:

*It is clearly unethical to feed those patients who are anticipated to die within ...let us say...7 to 14 days, because all you are doing is subjecting them to a potential discomfort and unpleasantness when there can be no tangible benefit...there is no benefit to feeding if death is imminent, and I regard death as imminent if it is within 10 days (General Surgeon UK).*

The consideration of artificial nutritional support as being futile was viewed by several participants as not being exclusively problematic, that is, that it was just one aspect of a myriad of aggressive treatments that collectively could be withdrawn, or considered futile. This was explained primarily within the context of costly critical care:

*If the patient has been in ICU for months and we know it is going to cost thousands of dollars for the ventilator, thousands of dollars for the TPN, plus all the sedation and inotropes...we roll that into one package when we discuss the overall care for these patients who are futile (Gerontologist USA);*

*The patients that have been in the surgical ICU for ages and their prognosis is like...you know...they are not going to make it, and nutrition is just part of everything that we withdraw. Nutrition is just part of that...like with long term patients I can't ever really remember a case where they specifically stopped the nutrition and just did that – they withdraw the ventilator support, stop antibiotics, and I guess stop nutrition as part of the big picture (Critical Care Nurse Specialist USA);*

*In a critical care situation, feeding is just part of that overall withdrawal of treatment, and in the care of the terminally ill it is pretty much the same...I have never really considered feeding*



*to be especially isolated from the rest of their management (General Surgeon USA);*

*In terms of withdrawal of nutrition, that is a decision that is made on the basis of a number of circumstances like when you commence life-sustaining therapy in the absence of a clear diagnosis, and then a clear diagnosis of an untreatable primary condition becomes apparent – like disseminated malignancy, in which expensive supportive therapy like nutrition and mechanical ventilation, dialysis etc are of no particular relevance or benefit so they are withdrawn (Critical Care Physician AUST).*

For the following two participants, the withdrawal of nutritional support was similarly part of the collective of aggressive life-sustaining treatment, and was an issue that had not been previously considered as exclusively significant:

*I have never really thought about it, I mean, the most frequent situation where we would stop the TPN or enteral feeds is when the patient has been offered the chance for a curative procedure, they have taken that chance and the wheels have fallen off, and the anastomosis has broken down, and they are septic, on the ventilator, dialysis, and the TPN is just part of that, and so the decision to withdraw the TPN is just part of the whole process and you don't decide to withdraw one aspect and not another – it is a case of well, do we have anything further to offer this patient? So the withdrawal of nutrition is part of the withdrawal of renal support and cardiovascular support and respiratory support (Clinical Pharmacist AUST);*

*Stopping the feeding happens within the context of withdrawal of all treatment, I mean, nutrition is part of a whole bunch of stuff that gets turned off and that's a fairly regular occurrence. I have never thought of it as being important on its own (General Surgeon AUST).*

This assertion is supported, albeit partially, throughout the related literature. Mayo (1996) contends that families and other surrogate decision-makers sometimes reach a different conclusion when the care consists of ventilation or other life support. This tendency to view artificial nutritional support as different is sometimes shared by

professional ethicists and courts (*ibid.*). This view is also shared by several participants who contributed to the previous discussion point 'Food and Water' in the previous chapter 'Culture' (p.163). There was a definite subset of patients that several participants did identify as being on 'the receiving end' of futile feeding, where the provision of artificial nutritional support was considered as both quantitatively and qualitatively inappropriate. These were essentially the frail aged dementia patients, and those terminal patients in the active process of dying. In particular, the frail aged warranted the following powerful yet controversial response from one General Surgeon (USA):

*A lot of geriatric patients get bed sores and sure, they need nutrition to heal those, and there is a huge ethical issue with those patients who are breaking down, they are not eating anymore, they do nothing, they have a feeding tube and they just become stool machines – that is all they do (General Surgeon USA).*

This participant's choice of description, that is, 'stool machines', conjures up an uncaring, inhumane attitude. This description however can also be literally and metaphorically interpreted as a simple machine that churns out a useless waste product. Such a blunt conveyance of perception was previously insinuated by a participant in Chapter Four 'Death' (p.129). A participant who also worked within the field of gerontology provided a similar negative view on the provision of aggressive nutritional support in the frail aged. This impassioned quote also highlights the consideration of quality-of-life in those patients who are incompetent:

*I used to think that it would be horrible to consider withdrawal of nutrition in a person because you would be starving that person to death and that would be a horrible way to die, but some of these patients that I see now, the lives that they are living aren't worth living...they are horrible, horrible lives...I mean, they are laid up in bed with Foley's and infected feeding tubes, decubiti, they cannot communicate with you at all, they are end stage dementia, and a lot of them have been in comas for years...that must be a horrible way to live (Gerontology Nurse Practitioner USA).*

Another participant gave his perspective on futile feeding in the neurosurgical ICU environment in terms of trying to continue a physiological process in a patient whose physiology was essentially defunct, and only partially restored by mechanical means:

*What we do with these patients is really stupid, I mean you have someone that is dying and you keep on filling their belly up with all this stuff that just sits there and doesn't do anything. I haven't seen a lot of that but it does happen and all you are doing is wasting your time and probably making things worse for the patient (Critical Care Nurse Specialist USA).*

Futile feeding was also discussed in terms of providing false hope for those patients with a terminal condition, and was equated with a 'life-line' (Palliative Care Physician AUST). This participant provided a concrete example of a patient with carcinoma of the oesophagus who, by virtue of an oesophageal obstruction, could only be nourished via a PEG:

*The problem that I have with feeding this patient is that at what point should it be ceased when it is clear that the patient is dying? Sometimes the answers are given to us, like if the tube becomes infected or there is some technical complication that means that it should be removed, and then after further discussion with the patient that another won't be reinserted. But there are times when people are not at all comfortable with the fact that they are dying and see that as their life-line and insist on feeds being given, when in any other situation they would in fact be allowed to die far more comfortably (Palliative Care Physician AUST).*

Making things worse for the patient via futile feeding was mentioned by another Palliative Care Physician (AUST) who explained that withdrawing nutritional support from a person who was dying often prolonged their life and made them less susceptible to complications and discomfort. Not feeding the patient was considered by this participant as a good thing, providing a kinder transition via dehydration (and the avoidance of annoying secretions), whilst maintaining the optimum in comfort:

*Someone who is in a coma and you are not providing artificial nutrition but you give good mouth care can last up to a fortnight or longer, cause they are still getting the natural processes – their natural fluids replaced in terms of sublingual absorption. So it is not hastening their death, it could even be prolonging their living, and it is a process of good care (Palliative Care Physician AUST).*

The same participant also explained the futile role of nutrition in those patients who did not need generous caloric supplementation. He provides the following explanation of how each patient should be carefully assessed on an individual holistic basis:

*There is no point giving someone 3000 calories a day if they are lying in bed and they need 600 – that is a waste of time and resources. Eventually nutrition should be wound down and then stopped because of their deteriorating clinical condition. So it is a process of looking where the person is, what they want, what they are trying to achieve, and what we have to offer. It is a very individualistic approach (Palliative Care Physician AUST).*

This above quote also highlights another theme mentioned frequently within the discussion of futility and that is the identification of goals – goals of treatment, and goals of the patient. The identification of goals and the realisation of the end point(s) of treatment are explored as part of communicating the purposes and limits of artificial nutritional support in the following discussion point.

### **Honest Communication**

Communicating not only the goals of treatment, but also the expectations of treatment considering the high probability of complications inherent in either parenteral or enteral feeding, featured throughout the discussions of futility and the withdrawal of treatment. The participants contributing to this discussion point essentially spoke of communication and identification of end points of treatment, and the difficulties that were often experienced when conveying the realities of treatment limitations and the likelihood of a patient's restoration and recovery. One participant working in the critical care environment explained that prior to any decision regarding the instigation of nutritional

therapy, the patient (if conscious) and the relatives were paramount to such discussion regarding treatment and its limitations:

*We always do that...when we talk to relatives about the purpose of intensive care is to fix people up and get them back to what they were like before, and if that isn't a viable likelihood or viable possibility, we have no right to subject them to the rigors of intensive care without any hope of actually achieving the end point that we are pretending that we are going for. So everyone gets told this when patients first arrive (Critical Care Physician UK).*

Honest communication of the expectations of treatment emerged as the important reason why the following participant did not experience any problems or difficulties regarding the withdrawal of nutritional support in the critical care setting when dealing with brain injured patients. By way of close interaction and communication with the patient's relatives in understandable terms, conflict regarding withdrawal or withholding of nutritional support could be avoided altogether:

*If the patient is, or is going to be pronounced brain dead, we will keep feeding until the family are together and then we tell them...'hey, it is looking this way'...and I believe we give them adequate time for the shock to kind of wear off a little bit or for it to have absorbed in, and the doctors are pretty straight forward with them, and we get support from the Transplant Team, and do our best to explain that really that person is no more, like a swing moving with nobody on it, so we have never had a problem – even though their relative's chest is still going up and down and their heart is still beating. We interact closely with the family and extend an understanding of what is really happening – one that they can understand (Critical Care Nurse Specialist USA).*

Conversely, another participant regularly experienced difficulties regarding communicating withdrawal and/or withholding of nutritional support due to the patient's and/or the family's inability to accept the limitation of treatment, or more simply to 'let go'. Families' attitudes are therefore shaped by the pro-provision nature of medicine as well

as medicine's lack of recognition of palliation. This was explained in terms of burdensome treatment within the frail aged:

*The patient who is in a nursing home often just stops eating, and the family just want some miracle cure or some button pushed to get them eating again and when that doesn't happen, well the family don't want to let go. And I understand that, and they want to put a tube in, so I explain that it is an option – we can put a tube in through their abdomen, do a PEG. But I think that when we don't deal with some of those issues then we wind up with a double-edged sword because we know that they are going to get decubiti and all those things, bed ridden problems. Often the family won't see those potential problems (General Surgeon USA).*

Communicating the potential complications and the reasonable expectations of such treatment was of paramount concern to the following participant who gave this simple yet descriptive explanation of why futile therapy of any sort had no place in the palliative care environment:

*Continuing on with an established feeding process is something that we would probably continue to do with the objective of trying to find out from the individual and the family – what are the real aims and goals, what are they trying to achieve with this? And what is going to be the outcome of a complication...it is all very well doing something, but if there is an expected outcome, an expected complication of a process, what are we going to do if that occurs? If sepsis is going to occur following TPN through a CVC, how are we going to treat it? Do we then go on a merry go round of keeping a process going because of commencing a treatment that we don't really agree with to a certain extent? Dealing with what people expect of palliative care as a service is part of taking on people as well, and also defining what we won't do, and what we shouldn't be doing in order to try to achieve things that are impossible (Palliative Care Physician AUST).*

Another participant working within the area of oncology also spoke of the importance of honest communication of treatment outcomes as well as establishing reasonable goals. He described an experience from practice that highlights the need for understanding the consequences of treatment provision and how autonomy impacts upon this:

*Patients have to make their choices, and live out the consequences of their choices. That is the pitfall of autonomy if there is a pitfall. I had a guy this past weekend with myeloma who said that early on in his disease that he would never hook himself up to a feeding tube, but now that he is farther along and his gut is starting to fail, he is going to change his mind. We don't have any policy that limits that kind of treatment, so patients often think and want and get what they think is the best thing without really understanding the consequences (Oncologist USA).*

This is an excellent example of the way in which circumstances mean that people do different things. A similar example could be the current euthanasia debate whereby people want euthanasia abstractly in various circumstances but when faced with those circumstances things change. This 'socio-temporal' space has been similarly mentioned by Zalcberg and Buchanan (1997:150).

Understanding the consequences of potentially burdensome treatment was also mentioned by a Nutrition Nurse Specialist (UK) with an emphasis placed on the associated complications of gaining access for both parenteral and enteral nutrition:

*We have had lots of patients who have aspirated post CVA with dysphagia and it has been enteral-related. We have had patients who have died post PEG insertion, and patients that have suffered pneumothorax post CVC insertion. Therefore it is so important that these risks have to be explained to the patient before you do any of this. The patient has to understand, and relatives have to understand that as well. But sometimes the relatives demand that the patient be fed regardless of the consequences and this can be disastrous for the patient (Nutrition Nurse Specialist UK).*

Another Nutrition Nurse Specialist (AUST) also commented on communication of realistic treatment outcomes and the benefits and burdens of such outcomes, as well as the importance of such communication being interpretable by the patient and family:

*You need to have confidence that the clinicians have explained the risks and benefits of treatment and that the patient knows exactly what is going on...and that they are informed at their*

*level of understanding, and not told a whole heap of medical jargon. You have to sit down and explain to them exactly what it involves, what the risks are, what the benefits are – if there are any benefits...there may not be any benefits (Nutrition Nurse Specialist AUST).*

The same participant also put forward the assumption that 'clinicians' (namely medical practitioners) were too optimistic of such treatment and not mindful of the detrimental consequences of futile treatment – both in terms of harming the patient as well as the unnecessary expenditure of costly resources:

*The doctors are always extremely optimistic that they only explain the benefits of feeding...they don't want to say to the patient 'well frankly my dear you are stuffed...here's a bullet...off you go'. They are more interested in pro-treatment regardless of the harm it can cause and the budget blow out it creates. They really need to be better informed of the downside (Nutrition Nurse Specialist AUST).*

Such ignorance of burdensome treatment was also suggested by another participant (General Surgeon USA), who explained, albeit briefly, that many of his colleagues were not mindful of the potential waste of time and money inherent in futile feeding:

*A lot of surgeons are not aware of how much all of this unnecessary treatment costs, and how wasteful it is considering it is only going to do harm...rarely have I seen any benefit in feeding a terminally ill patient. I mean...we should all know this because we are all under such constraints, yet I see it all the time...a lot of time expensive treatment like TPN is given out with very little if any true benefit (General Surgeon USA).*

Another participant shared similar thoughts on the problem of resource utilisation and expenditure of scarce resources for therapies that are not likely to restore health to the patient, and the financial risks inherent in such practices:

*One of the issues for me is how do I align the incentives for end-of-life care so that I don't expend resources for things that are not going to help. And whether you can do that without having the physicians who are actually responsible for writing the*



*prescriptions have some sort of financial risk involved...my personal feeling is that you can't (Oncologist USA).*

The dissemination of factual information about the consequences of treatment was explained by one participant in terms of the ongoing need for updated education regarding the benefits and burdens of artificial nutritional support, and the need to raise professional and lay awareness of medicine's limitations. He identified the shortfall in the skill base of end-of-life care as being responsible for improper communication to patients and their families:

*So we are simply unskilled at this, and by the nature of inexperience and not being educated about it, yes I think a lot of stuff happens that doesn't need to which is why some of us are so diligent about staying on top of it with people and reminding and educating physicians, educating families about it. They – families – don't know what their options are, and doing what we can to assuage guilt on the part of family members because they think they are killing somebody if they don't provide that treatment (Hospital Chaplain/Ethicist USA).*

Communicating honestly about the futility of aggressive treatment was identified by several participants as a difficulty that was unmatched in terms of their experience dealing with the vulnerable patient and/or family. The notion of 'can't you do something?' and the inability to 'let go' were discussed within the context of medicine's limitations and the so-called miracle cure. Despite the difficulties inherent in communicating bad news, the need to do so is imperative. The difficulty of stopping treatment once started was also mentioned:

*With feeding...um...usually it is not the individuals themselves who are saying 'feed me...I want to survive longer'...it is the relatives who are saying 'can't you do something?' But the argument is still there...there is still anguish, still hurt, and there is still suffering in that request of 'can't you do something'...it is the hardest thing I come up against (Palliative Care Physician AUST);*

*The real problem is the emotive issue of 'can't you do something?'...which tends not be a very good reason to do*

*something...but that obviously has to take a lot of time and effort to explain why you don't think it is a good idea to do (Palliative Care Physician AUST).*

Another Palliative Care Physician (AUST) explained in vehement terms not only the importance of honest communication regarding futility, but also how ethically questionable it was to do otherwise. She explained that those patients with a poor prognosis who have been commenced on what could be considered futile treatment, were given arguably false indications as to what their future held:

*The dilemma then becomes for us, ethically, to stop things that others have inappropriately started. I think that it is quite true to say that on many fronts, whether it be enteral nutrition or whether it be the straight provision of intravenous fluids, it is far easier to start some things and feel that you are doing something, than it ever is to stop it. And I think of the decisions about the appropriateness of commencing the therapy are not dealt with in nearly as greater depth as they ought to be at the time those decisions are taken (Palliative Care Physician AUST).*

The commencement of artificial nutritional support was therefore avoided where possible in questionable cases due to the difficulties of withdrawing support once it was already established. This featured frequently in the discussions regarding withholding and/or withdrawing treatment. One participant in particular gave the following explanation:

*We try not to start it because it is hard then after you start it because the family thinks that this is the magical bag of nutrition that is going to cure, and you don't have the heart to stop that. It is like giving the family false hope by starting nutrition in those situations. We have a lot of patients that have been like end stage organ failure, four systems down, and the family wants everything done and the doctor will try to put them on TPN but really, that is only going to make their organ failure worse and it is going to be of no benefit to them (Clinical Dietitian USA).*

Another participant spoke of the difficulties of ceasing aggressive treatment considering the distress not just for the patient and family, but also for staff:

*It is a huge distress for medical staff to have to go through the process of pulling back...it is much harder once it is started...it is much harder to withdraw something which is well established...it is more difficult once you are in an established thing to work out how to get out of it. (Palliative Care Physician AUST).*

This view is supported by Jett (1995) who maintains that it is often more difficult to withdraw technological interventions than it is to withhold them in the first place. One participant did however offer a succinct explanation of how he communicated the withdrawal of aggressive yet futile treatment in the critical care setting:

*Frequently when talking to a relative, one of the key things we use, and use in a very intentional way is that we say 'at this point in time, we have no real therapeutic options, in that we have nothing else to offer – the situation is desperate – nature will take its course inevitably in whatever we currently do – our focus has changed from trying to promote survival which we know we can't, to making sure that the patient is in comfort, and that there is no possibility of them suffering'....and that becomes our entire focus of our management, that is, our job is to ensure that during the next phase, they aren't in any discomfort as far as we can tell (Critical Care Physician UK).*

This explanation essentially describes a change in treatment focus from aggressive care to supportive care, and the implementation of a positive line of management with a completely different focus in terms of what medicine is trying to achieve. The primary objective is extending good death care, rather than embracing the burdens of so-called beneficial treatment. The same participant went on to provide an additional description of what he meant by not necessarily withdrawing care, but changing the focus of care:

*What you are actually doing is something very positive. You are making a positive decision that your role as a clinician is to look after that patient in an optimal way given the circumstances – which, if you were a family practitioner looking after someone who is terminally ill who has got severe pain in the middle of the night and is dying, then you would do a house call and give an opiate. If you have someone who is drowning on a ventilator with lousy lung disease then making sure they are not awake during that and suffering and feeling the intensity of asphyxia*

*while their lungs fall apart on them is actually what your primary job should be. If you look at it from that view point then the active administration of life saving treatments that aren't working, or are futile should not be hard to swap for those that are palliative. Therefore you never lose the battle because your primary objective has been achieved (Critical Care Physician UK).*

The importance of thorough communication is supported by McCamish and Crocker (1993) and Ravenscroft and Bell (2000) who maintain that difficult situations are resolved via effective communication involving the patient, family, surrogate and care givers. Several participants believed that much of the futility debate could be avoided altogether if the prior wishes of the patients were in fact known. By communicating one's wishes via the advance care planning afforded by advance directives and living wills, futile aggressive therapy could be ethically, and legally withheld in the name of patient autonomy. This issue is explored in the following discussion point.

### **Advance Care Planning**

This discussion point evolved from a general concept of advance care planning which included discussions on advance directives, living wills, durable power of attorney for health care, futility policies and quality-of-life. The term 'living will' was first used in the USA in 1969 by Kutner who argued that a competent adult should be able to have his or her wishes with regard to futile care recorded and respected. In 1991, legislation was taken further (in the USA) by the patient *Self-Determination Act* which compels all hospitals to inform patients of their rights in relation to advance directives (Murphy 1992). In the UK, the House of Lords Select Committee on Medical Ethics (1994) supported the development in advance directives on the basis that they enable expression of individual preferences and stimulate discussion between doctor and patient.

In Australia, no formal implementation of such advance care planning strategies were documented at the time of data collection. However, in a subsequent review of the literature, Bielger and colleagues (2000) explain that three Australian states and two territories now have legislation which provides for advance directives. Despite their prevalence in the USA, and the legislative developments in the UK and Australia,

advance directives in many instances have failed to guide clinical decision-making, and their utility has been questioned (Teno *et al* 1997).

Only five participants spoke exclusively of advance directives and withdrawing artificial nutritional support (a Gerontologist USA; a General Surgeon USA; a Law professor USA; an Oncology Nurse Specialist USA; and a Medical Social Worker USA), yet numerous others contributed to this discussion point in the broader terms of collective withdrawal of life-sustaining treatment. The one exception to the general assumptions put forward by the contributing participants was by a Gerontologist (USA) who did not associate the provision of artificial nutritional support as relevant to the discussion of advance care planning. Essentially, he did not consider such treatment to be ever associated with futile treatment, and as such, would provide it indefinitely:

*Directives address different things, you know, I always think of directives as addressing the ventilator, addressing the CPR, the inotropes, those kinds of things. When I think of directives I think about those things that acutely intervene to maintain their lives. I never think of directives of withdrawing or withholding nutritional support. I guess I just don't think of it that way, so, even though a lot a patients do have a living will, we just never attach the living will to nutritional support as one of the things they don't want continued (Gerontologist USA).*

This participant's stance on indefinite feeding was also consolidated in his following quote:

*Withdrawing nutrition – we never do that, even in patients who are chronically ill at the end of their lives, we would never withdraw nutrition, and that is something that we keep on giving. We withdraw medication, we withdraw other kinds of support, but nutrition is never something that we would consider withdrawing because we just think that, you know, you must keep on feeding them until something else will take their life (Gerontologist USA).*

Interestingly, the same participant exhibited a certain degree of contradiction when he subsequently explained that he often struggled with the idea of continuing aggressive measures to nourish patients at the end of their lives:

*We will continue to feed the patient until whatever, but, that comes to my mind a lot of times, you know...why do we need to put this in, you know, why do we put in a PEG for someone who is going to die very soon, and prolonging their life with nutrition which they, right now, to us are considered brain dead, they are just lying there comatose (Gerontologist USA).*

The other contributing participants did not exhibit any such predicament. All were reasonably clear in their explanations of continuing potentially futile treatment, or withdrawing the same, at the wishes of the patient as previously expressed in advance care planning. Interestingly, these discussions were offered by those participants working within the USA health care delivery system only. These participants gave the following explanations of the usefulness of such advance care planning, as well as expressing the difficulties that arise when such planning has not taken place:

*Living wills and advance directives are very very useful because then you know the patient's wishes and you can honour them. It is hard when you don't know what they want so then you put it to the family...and the family often say 'well I have no idea what Mother would want'...so I put it to them, what they would then want in this kind of situation...and sometimes they say that they would want everything possible so then I of course would be obligated to treat but at the same time negotiating again and discussing the futile nature of care, the detrimental effects of some of that care, you know, like aspiration pneumonia from the feed. So it is always easier and kinder to know what the patient wanted (General Surgeon USA).*

*I think it is tragic in so many ways to continue feeding in many of these patients because what we end up doing is supporting a slow progression of deterioration in situations where they have not been able to verbalise their thoughts, their wishes themselves – that is why I am a great believer in advance directives. I used to joke and say that when I am 75 or 80 or whatever, I am going to get a tattoo on my belly that reads 'No PEG, No G tube, No CPR' (Oncology Nurse Specialist USA).*

*We always discuss advance directives with everybody – patients, their families, their primary physicians, everybody. It seems to be a case of all or nothing – we don't have a lot of people who say that they are not quite sure of what they would do, so they either say no or pull out, or I want everything, but at least then you know what you are in for, and so do they – everybody goes in with their eyes open (Medical Social Worker USA);*

*Patients under my care, well we talk to them about what are their wishes, and they state whether or not they wish to remain fed and basically being kept alive through artificial means. It gives us all a very clear picture of the road ahead (General Surgeon USA).*

The difficulties that arise when advance care planning does not occur was discussed in terms of pressure on family members to make treatment decisions that could be swayed by feelings of duty and guilt. Such decision-making could be seen as bestowing an awkward, or fearful responsibility on to those who are then required to make decisions regarding the withdrawal and/or withholding of treatment. A second Medical Social Worker (USA) gave the following explanation:

*A lot of times I think that the family want to keep the patient alive out of a sense of duty or guilt. And that they think that this is what this person wanted. And other times I think that it is fear – that they feel by saying 'no' to something that is going to prolong life then they are taking responsibility for that person's life, and they don't want to be the ones to take responsibility for the end of that person's life. Like, you know, I keep trying to educate on do not resuscitate (DNR) and quality-of-life, and the family will say that yeah, the quality-of-life of that person is no good and she would feel a lot more peaceful, and logically you get right up to it, you know, you mention DNR and they are just like 'no – I can't be the one...I would have to pump on her chest...I just can't be the one to make that decision' (Medical Social Worker USA).*

This view is supported by Kaplan (1997) and Swigart et al (1996) who remind us that if physicians, patients, and families discuss the patient's values and beliefs about death and end-of-life care, there is a record, hopefully on paper, that provides valuable data to feed into the decision-making process. The importance of advance care planning was

subsequently explained by the same participant, in the situation where the patient is no longer autonomous or competent to make such treatment decisions:

*The patient is way gone, she can't tell you anymore, she never signed any directives and so there you go again continuing this kind of treatment so there is really all kinds of aggressive treatments still going on, and no one is willing to say stop, and I think that makes that decision so difficult, and often that decision is never made (Medical Social Worker USA).*

The continuation of futile treatment was also explained as occurring so to avoid bestowing a 'cruel punishment' on family members when faced with the massive responsibility of decision-making, when a miracle cure could be possible:

*I think what is driving physicians in keeping that treatment going even when they think it is futile but the family did not, is a sense that it would be cruel unusual punishment for the family to have a patient taken off life support and allowed to die when they are still praying for a miracle or they are still saying that the patient wanted every chance to live (Law Professor USA).*

The above quotes implies a vicious circle of continued aggressive treatment, not capable of restoring the patient back to a previous quality-of-life, and potentially exposing the patient to all the known complications of life-sustaining therapies. The prolongation of futile treatment in the wake of not knowing the patient's wishes, and the family's inability to make a decision regarding the withdrawal of such treatment, was similarly explained by the sole non-American participant commenting on this subject. He explained a situation in a critical care environment where a patient in PVS (in the ICU for 19 months) was continued on aggressive treatment due to the family's reluctance to permit a decision on withdrawal of treatment:

*...and so we had a patient who had nothing apart from roving eye movement, and it was like this for 19 months...I had a neurology colleague who kept bumping into me in the corridor and saying that 'you're mad, you're mad, just pull the tube, just sort it out, it is crazy, you are absolutely mad'...the family would not make the decision, and nobody knew what she would have*



*wanted...her husband was totally resistant to the idea of any type of withdrawal. So it took her 19 months to die. In cases like this we should really not have to keep on going (Critical Care Physician UK).*

This above quote leads to the subject of family demands of continued futile treatment as well as raising the critique as to whether those 19 months were worthwhile and according to whom? This quantitative and qualitative quandary as to who defines futility remains unclear. This was spoken of both in terms of evidence and quality-of-life. The question of who quantifies futile treatment was posed by one participant who explained that certain evidence was needed both clinically and financially to deal with the demands for continued futile treatment. This participant spoke from a background in oncology where certain chemotherapy and haematology treatments were exorbitantly expensive.

*Well, from my standpoint the biggest issue of end-of-life care is having good evidence that it is worth the expense. I am sure you know of the one study of cancer patients where you could do it (artificial feeding) but that it was about \$100 000 per year of life, but there are other situations in which it has to be better measured...we need better evidence of what is useful, or better policies about what actually is helpful care, and what is not helpful care (Oncologist USA).*

Policy regarding the provision of futile care was also mentioned by another participant who gave a detailed explanation derived from a recent practice experience that involved a family demanding the continuation of aggressive care for a patient in PVS. This rich textual excerpt also suggests the implementation of a futility policy via an institutional ethics committee:

*One of the mechanisms that is very useful is a very active, aggressive, assertive ethics committee at the hospital. And we meet at a moments notice and help pull the various parties together to talk about what really are the ethical options. The worst case scenario we had was a couple of years ago, [mentions patients name] in bed eight ICU, I'll never forget it...this woman, something happened in surgery which is why nobody, no doctor was going to say 'OK, lets just pull everything', because they knew that somebody was going to get*

*slammed over this. Something happened in surgery and this lady ended up in ICU for 11 and a half months. She had decubiti you could put your fist in, and the family were, kind of...fundamentalist religious type, and this family were impervious to intervention...I mean, nice people, well meaning people but it finally got to the point where they were showing up less and less. I think a number of things worked – the chaplains met with the pastor of their church. Unfortunately it was an African American family and there was that cultural dynamic again of 'what are you really trying to do here?'...so we got that, and then the nurses started inviting the family in at dressing changes, when it was time to do the wound the care of her decubitus ulcers which were huge, and all the debriding etc. So the nurses said to the family, 'come in here and watch this'...and a few times of doing that, I think they finally got it. This is 11 and a half months. She was in a vegetative state – she had been in a vegetative state the whole time since surgery – I think she was anoxic during surgery and there were major problems with her ventilation, I don't know, nobody quite figured out what happened. After that, the ethics committee developed a futile treatment policy that basically said that we think that this is futile treatment then we don't have to provide it. Interestingly enough, as of September 1<sup>st</sup> 1999 that is now a State law in Texas (Hospital Ethicist/Chaplain USA).*

This narrative demonstrates a consequentialist ethic on the behalf of the ICU clinicians in this given situation. By applying the 'shock tactic' (of what would have been a confronting wound care procedure) the clinicians achieved the desired result, that being the succumbing of the patient's relatives to the prevailing clinical consensus to withdraw treatment.

The process of determining futility was also offered by this participant. He explained that if the physician thinks that the treatment is nonbeneficial or 'medically futile', then the recommendation is made by the treating team to change the focus of treatment from aggressive to comfort. In those cases where the family still persisted with demanding futile care, the next step created what was essentially a formalised futility policy:

*Then the physician takes the decision to the facility ethics committee and if the ethics committee agrees that all continued treatment is futile, then now, as of September 1<sup>st</sup>, by State law,*

*the family has 10 days during which we have to continue full treatment, but they have 10 days to find another physician, and/or facility that will provide nonbeneficial, futile treatment, or we can withdraw treatment, or the family can go to court and try to get an extension of the time, but it is written in the law, the judge can't extend the time unless that in the judge's opinion there is some reasonable expectation that some facility will take this person, and if there is not, then that is it. But, I mean, it is too bad that you have to resort to legal manoeuvres (Hospital Ethicist/Chaplain USA).*

This above explanation exemplifies the recent policy development within the State of Texas. At the time of data collection, new laws were passed in the State of Texas regulating advance directives and end-of-life care. Three prior laws were combined and simplified into a single law and was entitled 'Directives to Physicians and Family or Surrogate'. The new advance directive allows patients to either request or reject treatment. The formulation of this law was considered straight forward by the working party, however a major area of difficulty (according to one of the research participants who was involved in the writing of the new law) was around 'futility'. The essence of this new law is that if an institution follows the prescribed process,<sup>19</sup> they achieve immunity from civil and criminal liability if they ultimately remove treatment over the objection of surrogate or living will.

The principle of justice can be seen here as a contested battleground. It has been championed by some as the basis for futility policies (Halevy and Brody 1996), and has been rejected by others such as Jecker and Schneiderman (1992) as confusing futility with rationing. The primary examples of futility policies featuring in the literature were the 'Houston Policy' (Halevy and Brody 1996), the Veterans' Administration Medical Center Policy – Buffalo, New York (Wear *et al* 1995), and the Parkland Memorial Hospital Policy – Dallas, Texas (Sadler and Mayo 1993). Other mentioning of such policies were also provided by Darr (1995), Pentz (1998), Rivin (1997) and Vawter (1996) and Fine (2001). There was no mentioning of futility policies by those participants from the UK or Australia.

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<sup>19</sup> See Appendices (p. 358) for a detailed explanation of the process (Appendix 4).

The only criticisms of advance care planning as it pertains to the question of futility was provided by one of the non-clinician participants in this research. A Law Professor (USA) explained that as an abstract principle, the futility scenario (that is, that doctors are under no obligation to provide futile care) was right both legally and ethically. However, proving what was futile was going to be problematic. His main criticism was that despite all things, the most probable outcome of such a dilemma was going to side with the wishes of the family of the patient:

*If doctors think that continuing artificial nutrition is futile they have the argument that they are under no professional obligation to provide futile care – which as an abstract principle is right both legally and ethically, but they are going to have a heck of a time proving what is futile, or what is futility. And the legal system has not had to deal with that very frequently. When it has, it has almost always sided with the patient and the patient's family demanding more care (Law Professor USA).*

This was the only legal commentary regarding advance care planning in the entire research. The same participant went on to explain that despite certain advance care planning measures being in place or absent, the end point was usually the same, that is, that the decision-makers' wishes were upheld, except in those cases where abuse might be suspected:

*The default system and legal system is set in favour of the surrogate decision maker and in favour of family decisions, except in those cases where it is absolutely clear that it is futile – or it is clear by preponderance of the evidence that it is doing significantly more harm than good to the patient in terms that might resonate with a judge thinking about patient abuse like more pain, more suffering. For example, the PVS patient...it would certainly appear that the patient is not in any real discomfort so that is a really hard argument to make for a PVS patient...but strangely enough, that is the patient a lot of doctors have in mind when they are thinking that there has to be a limit to care (Law Professor USA).*

A subsequent review of the literature supports this assertion (Hall 1994; Haddad 1996; Wear *et al* 1995; Council on Ethical and Judicial Affairs, American Medical Association

1999). Cowe (1996) argues that there is the possibility of abuse of living wills, and suggests that subtle persuasion from family members who stand to benefit from the patient's death could occur. Also, it may be possible that patients may choose to refuse treatment because they fear becoming a burden to their family as they become increasingly incapacitated (Cowe 1996). The same author suggests another form of abuse of living wills regarding resources, that being, an overburdened health service might promote the use of advance directives/living wills to reduce demand on scarce resources.

The second criticism of advance care planning was that it could be considered worthless considering that the outcomes were the same regardless of having directives in place or not. The same participant explained that in those countries, cities, institutions that did not espouse any formalised advance care planning, people were still dying the same 'hi-tech' deaths as those where such strategies did exist. His main criticism of advance directives *per se* went as such:

*The fact that you [Australian researcher] practice the same hi-tech and high quality care and the fact that people are dying pretty much the same way is actually my answer to your question because if you don't need advance directives to produce that result – if you don't need futility policies to produce the result then I think that is fine. I mean, I am not a believer in advance directives just for the sake of advance directives...they serve a function. Back in the days when doctors wouldn't respect family requests to stop care...what we are now seeing in the name of autonomy is an evolution by which advance directives are becoming a vehicle for demands as well as refusals (Law Professor USA).*

This participant explained that the advance directive was now turning into something other than what it was intended to, whereby certain medical decisions should not be of any real concern of the family and/or surrogate decision-maker. He gave as examples those extraneous matters that are extremely important to the clinician but not necessarily the family:

*...like should there be a rational limit on care, how much are we pouring into end-of-life treatments? (Law Professor USA).*

This comment highlights the need to revisit the principle of autonomy. As Daly (1994) explains, autonomy does not create requirements of services that we must provide. In such cases where family demands of continued costly treatment that is considered medically futile, some institutions have adopted policies regarding such requests which, essentially, limits patient autonomy. Limits on patient autonomy regarding futility is also examined by Jecker and Scheiderman (1992) who explain that autonomy has faced challenges that invoke medical futility and rationing of scarce health care resources. By and large, the related literature supports such challenges to autonomy. It is argued that physicians may withhold or refrain from offering specific futile therapy to burn patients in an acute care setting (Hammond and Ward 1989), low birth weight infants in a neonatal ICU (Lantos *et al* 1988), patients without a reasonable chance of discharge from an ICU (Taffet *et al* 1988), severely ill infants incapable of experiencing pain and whose prognosis is poor and survival questionable (Murphy 1988), and terminally ill incompetent patients whose families request aggressive therapies (Brennan 1981). We might ask then whether 'futility' diminishes respect for patient autonomy? Sulmasy (1998) ponders whether or not the whole futility movement is a backlash by physicians who have felt their power ebb over the past 30 years. He questions whether the increasing spirit of consumerism among patients made this state of affairs inevitable. This is also explained in terms of consumer activism, which is previously discussed in Chapter Five 'Money' (p. 156-157) of this thesis.

These varying discussions on futility all embody some predilection of the notion 'quality-of-life'. The majority of participants all agreed that the continuation of futile feeding (as well as all aggressive medical treatment collectively), could seriously affect the recipient's quality-of-life. Several participants gave concrete examples from practice, whilst others offered more general assumptions:

*There are things that can be done to prolong the process of living, provided that the person feels that the quality of their life*

*is appropriate. But irrespective of what we do, we can't sort of stop the actual process of death as an outcome of disease (Palliative Care Physician AUST);*

*It is hard, when quality-of-life is nothing and the family just keeps pushing the food down the tube – it is hard to cope with. To me, a lot of the time the patient appears comfortable, I mean a lot of times there is very good care that is given, they are turned, their skin, they put lotion on it, I mean, they are really being nurtured, and I guess that really nobody can say what is going on in their head when they are in this late stage of dementia – nobody knows subjectively what is in their minds. But it appears that they have no clue what is going on – like it is just this organism living here with no awareness of its surroundings. So what I do in those situation is that I talk about advance directives, about DNR orders and things like quality-of-life with the family...and a lot of times you get resistance you get 'no, we don't believe in that', and it may be a religious thing, or it maybe their values are different from the values that medicine holds (Medical Social Worker USA);*

*For me as a practitioner, if someone is, well if their quality-of-life is pretty much shot or they are they pretty much dying, I think my priority is making them comfortable than more their diet. I mean, that is where my focus would be as making them more comfortable...I mean if the tube feeding is interfering with the comfort then I think that is a good reason to discuss withdrawing (Critical Care Nurse Specialist USA).*

The difficulty in determining one's quality-of-life was also raised by one of the above participants. When explaining a situation whereby a patient who was deemed 'irretrievable' who then made a significant recovery, regaining consciousness from a dense stroke and began to feed himself again, this participant demonstrated how problematic it is to decipher someone else's quality-of-life:

*I think that in a lot of cases he would not have been fed and would have died. He would have been passed off as old, demented, stroked-out, and not worth the expense considering the poor quality-of-life that was assumed for him (Medical Social Worker USA).*

This above quote resonates with the literature regarding avoiding inappropriate prolongation of dying (Singer *et al* 1999; Ahronheim *et al* 1996; Capron 1997). The decision to limit nutritional therapy raises difficult questions about the 'standards' of life such as intelligence (Fletcher 1982), or potential for interaction (McCormick 1974). Neither is sufficient to conclude that the life of someone else is not worth living (Lynn and Childress 1983). The critical issue of quality-of-life was also raised within the context of futile treatment in the case of the frail aged patient. The following participant gave this example of how he regularly came across quality-of-life as an issue in the role as Hospital Ethicist, and provided an explanation of how he might deal with such issues:

*Quality-of-life is a big issue. My first question is whether the patient is in a condition that it is ultimately incompatible with life – they are to die from this, and then the second question is – is this the quality-of-life in which the patient wants to remain. We get this all the time. I swear I get a call once every two weeks from a family member who has an Alzheimer's patient in a nursing home with pneumonia asking 'what do I do?'...well, if you are a physician, you rightly say IV antibiotics will take care of the pneumonia, but if you are a family member you gotta ask that in curing pneumonia do we restore the patient to the previously acceptable quality-of-life for them...and if we don't, why are you treating them with antibiotics? Why aren't you treating them with morphine? (Hospital Ethicist/Chaplain USA).*

The overwhelming consensus in this discussion point, if not the entire major theme of futility, was that artificial nutritional support could not improve quality-of-life in a clinical sense. As one participant explained:

*It is not the patient's nutritional state that is going to save them or provide them with a better quality-of-life...ten days of living longer in pain are ten days of living longer in pain (Oncologist USA).*

These quotes raise the question of whether or not quality-of-life dilemmas could be avoided if 'quality-of-life' and 'futility' were broached via the consideration (and implementation) of advanced care planning? We might ask ourselves whether such



patients would ever get to the stage of suffering the complications of continued aggressive medical treatment if their prior wishes were known?

## **Conclusion**

The importance of understanding futility, despite its various definition(s), has far reaching implications for health care, and how health care professionals interact with patients and their loved ones. Despite the difficulties is assigning an absolute definition to the term futility (since it is inherently a value-laden determination), the participants favour a 'fair' process for determining and subsequently withholding or withdrawing what is thought to be futile care. Yet this is hardly straightforward. The biggest lesson derived from this chapter is that futility requires complex judgement. It cannot be decided quickly or easily. It requires considerable thought and 'honest communication' before families are approached with treatment discussions. This essentially provides the argument in favour for advance care planning strategies and the need for honest communication, thus debunking the so-called death myths. Whether such strategies are helpful in these circumstances remains unclear, inasmuch as not all of the participants' experiences of withdrawing care were based on the existence of advance directives, living wills, and/or durable power of attorney for health care.

Rationing and futility also remain contested discourses. Despite several participants alluding to the allocation of resources as a reason for the withholding or withdrawal of life-sustaining treatments, it was not an overwhelming consensus. This is consistent with broad ethical guidelines stating that such decisions should be based on the benefits and burdens of treatment for patients, not on social circumstances. Nevertheless, the literature suggests that society will respond to the rising cost of medical care by giving the appropriateness of aggressive artificial nutritional therapy (and life-sustaining technologies at large) increasing scrutiny (Englehardt and Rie 1986; Jecker and Scheiderman 1992; Menzel 1990; Frader and Watchko 1997; BMJ 1999).

Situations of futile feeding and medical futility collectively often constitute difficult dilemmas. According to the contributing participants, these dilemmas raise conflicting

emotions of both failure and frustration. It is essential that we are clear both in our own minds, and in our communications with others, about 'futility' and the extent of our obligations as health care providers. To do this we have a professional obligation to be well versed in the ethical debates regarding futility to contribute effectively (McCormack 1998; Erlen 1996). Such an assumption coincides with the previously explored issues of raising awareness of end-of-life education, good death care, and participation in ethics consultation activities. Encouraging such dialogue of advance care planning does seem to be easier said than done considering the certain taboo surrounding death as an acceptable outcome of health care. Surely this presents the most cumbersome challenge to the pro-aggressive treatment nature of health care with regard to the provision of aggressive nutritional support in vulnerable people. Discussions concerning medically futile treatments ultimately involve discussions on the technology used to provide them. The technology which constitutes artificial nutritional support forms the basis for the following chapter.

## CHAPTER NINE

### TECHNOLOGY

#### Introduction

The technical processes in which artificial nutritional support could be physically provided to patients inform the discussions that underpin this chapter. These discussions resulted from the merging the following codes: tube feeding; EN versus PN; using the gut; elderly; and critical care. Those 23 participants contributing to this major theme (who were predominantly practising within the USA) included: A Health Service Administrator (USA); two Oncologists (USA); a Palliative Care Physician (AUST); three Clinical Dietitians (USA); a Gerontology Nurse Practitioner (USA); a Nutrition Nurse Specialist (UK); two Medical Social Workers (USA); a Critical Care Physician (UK); two Critical Care Nurse Specialists (USA); a Nutrition Nurse Specialist (AUST); a Trauma Surgeon (USA); a Critical Care Physician (AUST); an Oncology Nurse Specialist (USA); two General Surgeons (USA); a Gerontologist (USA); a Hospital Chaplain/Ethicist (USA); and a General Surgeon (UK). The most significant merging of codes was seen between 'elderly' and 'tube feeding', and it is from the synthesis of this merger in which the major discussion point arose which has been entitled 'aggressive feeding'. The participants afforded a blatant emphasis on the role of tube feeding (which they defined as enteral nutrition via nasogastric or PEG tube) with a lesser emphasis on the use of parenteral nutrition. The second discussion point of this chapter provides mixed insights into the enteral versus parental nutrition debate and has been aptly named 'tubes or wires?'

#### Aggressive Feeding

The title of this discussion point was considered appropriate as being the essence of the arguments posed by the contributing participants. The origins of this term however deserves some inquiry. 'Aggressive' as a medical term denotes an acute sense of clinical rigor yet it is also implies a discourse of 'conflict'. This raises the question as to why we embrace the language of conflict with regard to medical treatment? We are therefore reminded of the interesting interactions of power and knowledge that shape our

language. This has recently been reiterated by Bjornsdottir (2001). The main concern of the participants centred on the aggressive if not inappropriate insertion of enteral feeding devices (and provision of EN thereafter) in those patients who could be considered as vulnerable - primarily the elderly and those patients with a terminal illness. The majority of the contributing participants raised their concerns in terms of the complications derived from such treatment, as well as the sustenance of ethical treatment considering quality-of-life. These concerns were primarily discussed within caring for the elderly. Despite plenty of anecdotal evidence existing to support the assumption that there was a certain increase in the placement of feeding tubes in those patients who could be considered as being vulnerable, only one reference was located despite an ongoing literature search to support this (Oyogoa *et al* 1999). The following participant shared his strong views on tube feeding in the elderly and the apparent increase in such practice:

*It seems as though they place an awful lot of PEG's here. I know that in our geriatric department that it is a big discussion with the families because often times when we have a PEG placed, the patient will actually start going downhill and they may not last much longer after the tube placement. I have seen a lot of illness associated with PEG's, and I think it is more sad just to be living a life with these tubes and no quality...just to be kept on going with no higher function whatsoever (Gerontology Nurse Practitioner USA).*

This quote includes reference to the increase in PEG placement in the elderly, clinical complications associated such placement, and questionable quality-of-life. The same participant goes on to clarify his viewpoints regarding the increase in morbidity (and mortality) associated with PEG insertion and feeding, as well as providing an uns subtle example from his practice regarding quality-of-life:

*There is definitely an increase in morbidity with these patients who get PEG's, and some of them die because of it. I would say that the majority of our patients who have PEG's are also demented...we talk to them and say that if they don't eat then we are going to have to talk about ways to feed you. Like I said, they are out of it, they can't communicate with you at all, their brain function...well they are just vegetables...they can't eat by themselves, can't do anything by themselves, let alone eat. But*

*if they did not have a PEG tube, they would have died a year or two ago, and you can easily argue that would have been a blessing, but as it turns out that has been a family decision – to keep things going via a PEG. It is hard to say whether or not that is inappropriate if not abuse...but I definitely think that it is inappropriate (Gerontology Nurse Practitioner USA).*

A similar view was offered by another participant practising in the area of gerontology:

*I have a negative view of artificial nutrition support...to me it always coincides with a general decline, lower quality-of-life – just in my experience that is what I have seen. To work out why these choices are made, why doctors do that – place PEG's all the time, I just don't know, I really don't know what they are trying to achieve (Medical Social Worker USA).*

Enteral (or what was commonly referred to as 'tube feeding') attracted the majority of ethical discussion by participants. For example, one of the UK participants (Nutrition Nurse Specialist) who regularly dealt with patients suffering from severe CVA's. She questioned her own practice regarding the commencement of nutritional treatment in these patients. Interestingly this participant also defined her patients in accordance with technology:

*The ethical dilemmas that we tend to come across are enteral patients, insofar as we get these patients with severe CVA's and strokes and the physicians start feeding within 48 hours of the CVA, but we (clinical nutrition team), we don't think that we should feed at all, because they probably aren't going to survive and we would use dysphagia as an indication of survival – if their swallowing hasn't returned in seven days we know that their outcome isn't good. But we get a lot of pressure from medical and nursing staff to feed these patients...you get a great furore of why you should tube feed these people when they are not going to survive, and their quality-of-life is going to be such that there is no quality-of-life, and certainly they end up in nursing homes, incompetent for the rest of their lives with a PEG insitu, and you wonder what we are trying to achieve with that? (Nutrition Nurse Specialist UK).*

Raising this question of 'what are we trying to achieve?' also occurred for a Clinical Dietitian (USA) who discussed the need for long term planning and honest communication with patient and family members regarding the placement of a permanent route for feeding. Her views on pre-treatment discussion and planning were often thwarted by the physicians' very own nonparticipation in such dialogue:

*Does the family want this person's life prolonged? Do they feel comfortable doing this, do they feel comfortable if they don't, and if they do take this person home and they are going to become very emaciated and dehydrated...how are they going to feel about that? What we need to do is to come to a sort of mutual agreement – and I support whatever they want. There needs to be that discussion. What is really annoying is when you have done all that, and the doctors don't take part in that discussion and then come along and figure that the patient is not eating so they schedule a PEG insertion...you know, all the good work has just been undone (Clinical Dietitian USA).*

The overall lack of planning, and lack of forethought regarding the appropriate provision of tube feeding was similarly communicated by the only Australian participant who contributed to this discussion point:

*I think it is a real issue for medical staff also. I think it is a real issue for those people who put these things in. I think perhaps at the time, the decision that is taken to use enteral feeding, it may be perfectly appropriate, and no one would deny that they haven't been inserted with the best intentions but I think not nearly sufficient thought is given to what happens further down the track, when other complications arise and without this being in, the patient would die perhaps in a much shorter time, so in fact I believe that in some cases they (feeding tubes) do prolong people's suffering far more than they ought. (Palliative Care Physician AUST).*

This comment also raises the issue of the primary treatment focus being on the acute phase rather than the chronic or terminal phase of illness. Inappropriate placement of feeding tubes was also resolutely commented on by an Oncology Nurse Practitioner (USA) who explained that she had experienced a lot of inappropriate PEG placements.

She shared the following experience from when she worked in an infectious diseases unit, caring mainly for people with AIDS:

*A young man had wasting syndrome and was very adamant that he wanted minimal intervention, but it was his family that wanted to proceed with tube feeding because he was no longer able to take anything by mouth. Ultimately they did place a PEG and he went home with hospice, but the PEG placement was traumatic and gave him much discomfort...the feeds also created a lot of gastric discomfort, diarrhoea, bloating and pain. It really complicated things for him and his family who ended up regretting the decision. PEG's in these circumstances can create a much higher onset of complications with these patients (Oncology Nurse Specialist USA).*

A similar complex example from practice in an oncology setting was also provided by a Palliative Care Physician who, reflecting on her practice, described a situation where a PEG tube had become infected:

*It was causing extraordinary pain, and it was very clear to everybody that the person was dying, but even the patient himself had become so attached to the PEG as his only lifeline and insisted on it being used against every bit of medical advice given to him. And then you are really caught, because there is this thing in there that is causing him pain and suffering to continue using it, but he is not giving permission not to use it. My thoughts are that it should have never been placed in the first place (Palliative Care Physician AUST).*

One participant in particular questioned her very own practice in terms of preventive care. She shared her thoughts of inappropriate feeding tube placement and usage in lieu of better nutritional preventive care within both elderly and end stage oncology/haematology patients:

*When I first started nursing in a medical unit, I found that there was a lot of aggressive feeding in elderly patients who were very debilitated, who were pretty much – gosh I can't believe that I am going to say this but there is a terrible phrase coined here in*

*this country called Gomer's<sup>20</sup> – you know...the unresponsive, curled up, contracted, cachectic elderly patient with a PEG or G-tube. That is really not right. I mean firstly, these patients should not end up like that anyway. There should be a lot more preventive care that occurs to ensure that these patients do not become contracted and cachectic. I often used to ask myself why are we sustaining life in these tragic individuals by placing feeding tubes (Oncology Nurse Specialist USA).*

This participant's impassioned discussion regarding the use of feeding tubes in the elderly did not stop there. She shared her view on the plight of the elderly regarding aggressive feeding tube placement and the clinical realities of associated complications:

*I find it really sad because the elderly population is really hidden from public view and debate. No one wants to deal with Gomer crumbles. All the money and research goes into cancer and AIDS and we debate continuously about whether or not to continue with aggressive treatment or to withdraw it. In the elderly we seem to sweep them under the carpet and not give them the benefit of the doubt because the majority of them are incompetent. So we make their treatment decisions for them and subject them to prolonged deterioration or worse, kill them with the associated complications of tubes and tube feeding. I find this really difficult and sad (Oncology Nurse Specialist USA).*

Nowhere else in this research was the prevention of this certain state of decline in vulnerable patients discussed with such ardour. However a considerable dialogue did take place regarding the recognition and responsibility of nutritional status as a basic medical and nursing care practice, and this is explored in detail in the next chapter.

The issue of quality-of-life associated with the placement and use of feeding tubes in vulnerable patients was also problematic for both Medical Social Workers (USA). The following participant explained that the placement of PEG's seemed to remove the 'life essence' in the patients under her care:

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<sup>20</sup> GOMER is an acronym for Get Out of My Emergency Room, a colloquial term popularised in the book 'The House of God', by Samuel Shern.



*Many of our patients have PEG tubes and their quality-of-life really seems to be impacted...they are not able to enjoy their food, chew, taste. I think feeding tubes really take away a lot of the humanness that I see in older people – it seems like they have lost part of their life essence (Medical Social Worker USA).*

This notion of 'humanness' is therefore explained as being erased by a technology, consequently raising questions of compromising the dignity of the human person. This same participant also commented on the aggressive nature of tube feeding in the elderly courtesy of 'pro-provision/pro-procedure' physicians. She shared the following experience from her practice in the area of gerontology:

*We recently had a frail aged patient, demented, who came to our unit with bed sores – nothing to do with her nutrition as such as she was eating fine...but upon discharge the doctor in charge of her care was just like cramming, forcing the family to PEG her...'you gotta put in a PEG tube, you gotta put in a PEG tube'...and in many other people's opinion this was premature and unnecessary. There are lots of times where they are inappropriately placed, like with this lady – she went down hill as soon as it went in (Medical Social Worker USA).*

The notion of aggressive placement of feeding tubes, or as the above participant described 'pro-procedure', has been referred to elsewhere in this thesis as the 'technological imperative'. This is not new to the associated literature, however there is a noticeable gap regarding discussion on pre-device insertion planning. From a technical perspective, the issues that surround feeding tube usage are purely that – technical. Yet the issues that face both patient and carer are hardly limited to the technological imperative. The clinical realities of aggressive tube feeding are well documented. The actual placement of a PEG itself can cause many complications including death (Finucane *et al* 1999). Mortality during PEG tube placement ranges from 0% to 2% (Hull *et al* 1993; Kohli and Block 1995). Perioperative mortality ranges from 6% to 24% (Grant *et al* 1998; Finocchiaro *et al* 1997; Rabeneck *et al* 1996). Complications associated with the placement of such a device include but are not limited to: colcutaneous fistula, gastro-oesophageal reflux, wound infection, granulation tissue formulation, tube leakage, tube blockage, insertion site bleeding (Kutiyanawala *et al* 1998); aspiration pneumonia,

accidental removal, gastrointestinal bleeding (Wijdicks and McMahon 1999). Aspiration probably contributes to a death rate of 40% in elderly patients (Ciocon *et al* 1988). Such complications were commented on by numerous participants. With reference to the previously shared narrative in Chapter Six 'Culture' (p. 174), an Oncology Nurse Specialist (USA) epitomised the above synopsis of feeding tube complications when she described the placement of a PEG tube in a dying woman. In this situation, the family had insisted on the placement of a PEG tube in their dying mother who, by virtue of her disease process, had a very low platelet count. Shortly after the insertion procedure, she haemorrhaged, went into hypovolaemic shock and died within hours.

The above offerings from the literature were subsequently supported by the participants' very own experiences from practice. However, one profound issue that two participants raised that was not located in the reviewed literature was that of the natural process of dying via the cessation of eating. A Medical Social Worker (USA) explained in that (in gerontology) it was not only swallowing difficulties that gave rise to tube feeding, yet more so dementia and the process of life's natural decline:

*They forget to eat, they don't remember how to eat, food just isn't a priority, they can't take the feed that others are offering and swallow safely. I have a lot of issues about people wanting to place feeding tubes in people with end stage dementia, or at the end of their lives. There are many people who do that and see it as a viable option. That is something that I do not push professionally from an ethical stance because I see it as gross interference with life's natural process of wrapping things up (Medical Social Worker USA).*

This quote resonates with another participant's views on the provision of artificial nutritional support in vulnerable patients when he simply explained that '*...they aren't supposed to be eating anything because that is the way people die*' (Hospital Chaplain/Ethicist USA). Not recognising the natural process of death and continuing to treat aggressively has been discussed by Nuland (1995) and Meyer (1998). Both these sources stand alone as deliberately exposing the ethos of medicine to prolong life (and death essentially) as long as clinically and/or technically possible.

The lack of participation by physicians in what is essentially an end-of-life/withdrawal of treatment issue, could in fact represent the overall unwillingness and discomfort displayed by medical practitioners regarding such issues. This could also be represented by the seemingly minimal emphasis placed on such issues within medical curricula. Such an assertion has been mentioned, in part, in the literature albeit insufficiently. A recent publication by the Association of American Medical Colleges (1999) discusses the importance of education and evaluation in this general area of end-of-life care, and claims that one third of medical schools in the USA are in the process of improving the curriculum that addresses palliative care for the chronically and terminally ill. The other major contributor throughout the literature pertains to the previously mentioned EPEC Project which is designed to educate all USA physicians on the essential clinical competencies required to provide quality end-of-life care (AMA 1999). No such resources, or mention of similar projects/strategies in the UK or Australia were located.

### **Tubes or Wires?**

This discussion point encompasses those exchanges concerning the choice of providing either enteral (*tubes*) or parenteral (*wires*) nutrition. Whereas previous discussion has centred on the issue of nutrition in the elderly and those with a terminal illness, this discussion point considered mainly those medical/surgical patients who were acutely ill and being cared for in a critical care environment. The majority of participants did not consider the debate between EN or PN as having any particular ethical relevance. However several did see a connection regarding the professional issues of convenience, resources, and a reluctance to change practice. One participant in particular vehemently expressed his belief that there was in fact an ethical argument at stake:

*Absolutely!...One of the fundamental precepts of ethics is that you give the patient the choice and then having given the patient the choice you do maximum benefit for minimum harm. And harm and benefit are not the same – they are different. And there is a colossal naivete about nutritional support against these evangelists for enteral and parenteral nutrition. So the enteral pharisees have swallowed the line that everybody can be fed enterally (General Surgeon UK).*

Conversely, another participant did not consider any ethical dimension to the EN versus PN debate(s) and based such treatment decisions on a clinical basis which was influenced by outcome and cost:

*There are very few, if any, ethical dimensions to that. That decision is a decision based on a clinical decision with a preference to use enteral nutrition because it is better, cheaper – so the dimensions of that decision are dictated by clinical circumstances rather than by any sort of specific ethical decision (Critical Care Physician AUST).*

Interestingly here the nature of ethics is contested. Both participants essentially explain that decisions regarding treatment are 'medical procedure', and by mentioning medical judgement, thereby removes ethical judgement. However, the first participant is quick to denote autonomy and the 'ethical trump card'. Nevertheless, ethics does not end there in a clinical sense. For the most part, participants contributing to this discussion point considered that more effort should be made in providing EN. Examples of such 'pro-enteral' discussion included the following:

*I am really sold on the concept of enteral alimentation...I hardly ever use TPN. As a surgeon, I just don't have much use for it. In my particular practice I have always leaned more toward enteral alimentation even for my ICU patients because it is better (General Surgeon USA);*

*There has really been a big swing to enteral feeding – more people are more receptive to it...most people don't realise that the gut needs something in there, plus it is easier, cheaper, you have less complications – no pneumothorax or catheter sepsis, less metabolic fluctuations, so I am very pro-enteral (General Surgeon USA);*

*Using the gut really does affect length of stay, I mean there are formulas that enhance the immune response and slow down the inflammatory process...there is good clinical evidence that you can get ICU patients off ventilators earlier with this stuff (Clinical Dietitian USA);*

On the contrary, several participants spoke negatively of EN in acute care situations:

*Shoving litres of enteral formula into their stomachs so they can aspirate it all, when nothing is actually happening and they are not absorbing anything seems to be moronic in the extreme. I will not fill up someone's gut with nice sugary materials because invariably they get into trouble, so it is best to give them TPN (General Surgeon UK);*

*I have to revere the benefits of TPN and must admit that I am pretty slow to take up with the enteral side of things...you know, in principle is sounds wonderful but practically getting these tubes past the ligament of Treitz is very difficult and then the gut won't accept the feeds. I am happier to leave things be and push on with TPN – especially in the ICU (General Surgeon USA);*

*There is a great enthusiasm for PEG's and jejunostomies, but what happens if the PEG goes wrong? Well the consequences can be disastrous for the patient, and there is now a recognised mortality related to tube insertion. I mean it is not common but I think that is unacceptable. How would people feel if we were killing people with parenteral nutrition...they would feel quite rightly very strongly about it. So that is the down side of enteral (General Surgeon UK);*

*Pro-enteral ICU doctors say 'use the gut', and I just know that there is no way that it is going to work, and then they have their bellies all blown up, and they say it doesn't matter if they have an ileus, arguing that all the literature shows that you can absorb it ...and sure enough, two days later, they have a bit of a vomit and aspirate, and I say, yeah well all right so lets go back to TPN, so I don't have much time for enteral feeding (General Surgeon AUST).*

One participant however did offer a conclusive albeit analytical explanation of the profound benefits of enteral nutritional support in the critical category of patients when he reflected on his experiences of caring for burns patients over a period of some twenty years:

*I have a patient in the Burns ICU right now on TPN – like he is the first TPN in six months, and we are running a big unit, 200 patients a year through the Burns ICU, and a total of 600 in the Burns Unit a year so we are not talking about small numbers, we are talking about big numbers, and I think that it is really is a*

*question of never letting them get an ileus cause you start feeding them across the board. I think that in the United States everybody believes, at least all the surgeons believe that the gut is better, and a lot has come from Wesley Alexander's work in burns, and even Dudrick<sup>21</sup> the founder of TPN is a surgeon still, I mean he will still primarily gut feed patients...and the thought is, that is what God made us to do to begin with, he gave us a gut so it ought to be a good idea to use it because we are designed that way. But I guess that, well, we haven't seen a lot of changes with burns care in the last 20 years – except feeding. And we do much better than we did 20 years ago so, I say we blame that on feeding – like less time in ICU, less time in hospital which is complex, multifactorial, and better survival...and is it all the gut? Well no, but we aren't giving any different antibiotics, same antibiotics were here 20 years ago, same theory of getting the patient to the operating room quickly was here 20 years ago. So you might ask what wasn't here 20 years ago – well feeding, post pyloric enteral feeding wasn't so we at least attribute most of our success to feeding (Trauma Surgeon USA).*

Issues of convenience (as previously discussed in Chapter Seven 'Dilemmas' p. 185-186) were raised by several participants in terms of the ongoing debate of EN versus PN. Conflict arising from this debate was experienced regularly in most practice settings. A Gerontologist (USA) offered the following scenario as a common occurrence when dealing with treatment decisions regarding artificial nutritional support in a general medical setting:

*Let's say between TPN and tube feeding, a lot of the time, a lot of the nutritionists, the GI doctors suggest that we need to give tube feeding as much as possible versus PN. But a lot of doctors don't think that way. I see a lot of them write the patients up for TPN when it might be better to give them tube feeding. Maybe they do that because it is convenient for them just to leave the patient on TPN even though it is probably appropriate now to switch them to tube feeding because that is better for the patient – so, yeah, I do see that happening a lot (Gerontologist USA).*

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<sup>21</sup> Although many researchers contributed to the development of TPN, Stanely Dudrick is usually given preeminence. It was his report in 1968 that provided the impetus for the rapid development of clinical TPN. See Dudrick *et al*, Long-term parenteral nutrition with growth, development and positive nitrogen balance. *Surgery*. 1968; 64: 134-142.

Observing current research and best practice with reference to which modality one would choose to provide was commented by a Nutrition Nurse Specialist (AUST):

*You have to go with the literature and at the moment the literature is suggesting that enteral feeding is the way to go. So until then when the literature to the contrary turns up then we have to go with the flow and because that is what is best for the patient...and the reason we are all here is to look after these patients and to provide the best care possible (Nutrition Nurse Specialist AUST).*

In their dealings with the sick and vulnerable, clinicians are bestowed with a considerable degree of trust. Patients and their proxies must have confidence that decisions concerning the provision of enteral or parenteral nutrition are based on sound clinical and ethical judgement. Either modality can predispose the recipient to a myriad of complications – not all of which are purely technical. The resounding consensus drawn from this discussion point is to be aware of current best practice and identifying one's reluctance to accept progressive practice. What defines best practice however, is forever debatable. However such 'ethical' debate is absent from the vast literature available on EN versus PN in the clinical literature. As the interpretive chapters show, this debate is worth having because it teaches us a lot especially in those areas that remain unchallenged.

## **Conclusion**

Considering the arguable increase of enteral tube feeding in vulnerable patient populations, and the absence of necessary dialogue concerning such aggressive nutritional treatment, raises an interesting parallel with the previously mentioned discussion points 'Advance Care Planning' and 'Honest Communication'. We are reminded by Scofield (1991) that we should be as concerned about inappropriate, unwarranted use of feeding apparatuses as we are about the improper use of restraints and urinary catheters – especially in the elderly. Sadly, this aspect of the ethics of the feeding tube has attracted little attention. The essential questions raised in this chapter are 'what are we trying to achieve?' and 'how do we avoid bad decisions?', ultimately raise the need for better planning and communication – not only of the ethical issues

inherent in such practice, but also the clinical realities that are not confined to the acute hospital environs.

One interesting omission in the narratives of the participants is the failure to discuss the provision of either enteral or parenteral feeding of children and adolescents. All discussions consider the patient as an adult. The literature also affords an overwhelming emphasis to the patient as 'adult' with some exceptions, albeit these are essentially clinical papers on (but not limited to): Crohns disease in childhood and adolescence; treatment of severe anorexia nervosa; intragastric feeding following traumatic brain injury; and management of dysphagia in stroke patients. The consequences of aggressive tube feeding should be made visible to all concerned and not be covertly sanctioned within the confines of long term care settings, be they institutions or one's own home.

So how do we improve such decision-making and improve the channels for appropriate communication? How do we remind clinicians of the role of nutrition in vulnerable people, be they frail aged, terminally ill, or critically ill? Raising such awareness certainly coincides with the need appreciate to end-of-life education. The provision of appropriate nutritional support in patients regardless of their clinical setting is another concern. This is explored in the final interpretive chapter of this thesis which has been entitled 'Responsibility'.



## **CHAPTER TEN**

### **RESPONSIBILITY**

#### **Introduction**

This final empirical chapter represents a marked departure from the previous chapters which discussed the many and varied ethical issues inherent in the provision of 'artificial' nutritional support. The following discussion offers those fundamental views of the basic necessity of 'natural' nutrition in acute care settings, and the shortfalls experienced by the participants under the heading of 'Responsibility'. This title was chosen as it was stated by the participants of what is often lacking or poorly defined in a clinical sense when it comes to the provision of adequate nourishment of hospitalised patients. The seven codes that contrived this major theme were: responsibility for nutrition; malnutrition in hospital; nutrition not sexy enough; basic care; education issues; reluctance to change practice; and research in nutrition. The 24 contributing participants comprised of: A Gerontologist (USA); two General Surgeons (USA); a General Surgeon (UK); a Critical Care Physician (UK); two Occupational Therapists (USA); an Occupational Therapist (AUST); two Oncologists (USA); three Critical Care Nurse Specialists (USA); an Oncology Nurse Specialist (USA); a Nutrition Nurse Specialist (UK); a Nutrition Nurse Specialist (AUST); three Clinical Dietitians (USA); a Hospital Pharmacist (AUST); a Neurosurgeon (USA); a Hospital Chaplain/Ethicist (USA); and a Trauma Surgeon (USA).

Three main discussion points arose from the merging of codes, and these have been entitled and ordered according to their subject matter and importance as expressed by the participants. These discussion points deal with the apparent lack of emphasis placed on the basic necessity of nutrition and the consequence of malnutrition evident in acute care settings, and pose the question as to whether patients fall in the gaps of responsibility. Other shortfalls are also discussed and these include the lack of education regarding nutrition support, the need to raise awareness of such deficits, as well as several criticisms of inadequate basic patient care. Essentially, it is the lack of

recognition and the discharging of responsibility for nutrition that provides the basis of this chapter.

### **Not Enough Emphasis on Nutrition**

Essentially this discussion point deals with those concerns of the simple fact that nutrition, be it artificial or simple oral intake, is considered with the importance (or emphasis) that it rightly deserves. The majority of participants agreed that not only complex clinical nutrition failed to attract the appropriate attention it deserved, yet more troubling was the assertion that simple oral intake was often ignored. Several reasons for the lack of importance afforded to the monitoring of simple oral intake were offered by the following participants:

*I think that unfortunately the physicians have less involvement and less understanding of the complexity of oral intake and it seems that they, and the majority of nurses are more concerned with the patient's bowel and bladder habits rather than what goes in the other end (Occupational Therapist USA);*

*The doctors don't think about nutrition because they are so busy, and nutrition to them is just too basic to warrant any immediate clinical concern (Critical Care Nurse Specialist USA);*

*I think one of the biggest issues with the lack of nutrition support is the delay that seems to happen so often. We see people who should have been started five to seven days ago and this really puts them behind the eight-ball, and why does this happen....well I think it is because the medical team has been too busy doing everything else that they forget the basics. That is troubling for me (Oncologist USA);*

*Medical schools all over the world get very little, if anything on nutrition. In that context, I believe that not enough emphasis is put on nutrition – it is probably seen as being too basic, too boring. It is not high-powered hi-tech stuff you know (Clinical Dietitian USA).*

The concept that 'food' is not considered as being 'clinically rigorous' was a common concern for the majority of participants. This concept of technological determinism is well

documented, especially in the nursing literature on the critique of science (Nyatanga 1991; Parker 1987; Lumby 1992; Johnson 2000). Several participants also discussed this concern in tandem with an overarching concern that there was in fact, a notable incidence of malnutrition among hospitalised patients. The following participant offered this sarcastic explanation, yet one that resonated with the other contributing participants:

*If you wanted to find a group of people in the UK who are malnourished, all you have to do is go to your nearest NHS hospital and malnutrition is there – institutionalised! (Critical Care Physician UK).*

This sweeping statement is supported in part by one particular offering in the related literature pertaining to malnutrition in British hospitals (McWhirter and Pennington 1994), and is further elucidated by this interesting explanation of how malnutrition can occur in a hospitalised patient:

*When a patient hits the place, they get put on nil by mouth for investigations, they get put on nil by mouth for operations, everything gets delayed, cancelled, postponed, and they are left nil by mouth for ages. And the biggest single sin that a junior resident can commit is to actually feed a patient when they are booked to have something done, because they have a window of opportunity to get an investigation done, or the surgery done, and they miss it because the patient has been fed – had his or her hunger alleviated, then that is almost a sackable offence. So everything that we do is geared either to diagnosis of something other than malnutrition, or to providing malnutrition for those who haven't got it simply because feeding is way down on the list of priorities (Critical Care Physician UK).*

Despite an extensive Medline search, no articles pertaining to the above suggestion were located. However, two articles specifically dealing with a review of excessive fasting in paediatric patients prior to elective surgery were found (Veall et al 1995; Maclean and Renwick 1993). The above explanation also suggests an element of 'bad planning'. Bad planning leading to the overlooking of a patient's need for, and lack of nutritional sustenance, was also suggested by several participants when they explained their dismay at the way hospital wards were managed from a human resource perspective.

This raises the question as to for whom is the ward managed? Does the institution need to operate in a particular manner despite the needs of the patient? For example, the occurrence of patients not being fed due to staff shortages, or the lack of recognition of a patient's cognitive inability to feed oneself was explained:

*We see a lot of older and weak patients who are unable to feed themselves very well, and the people who bring in the meals are not nurses, and they bring in the meals and then when the time comes, they take away the meals whether the patient has eaten or not. They do not notice how much the patient has eaten and if no one notices, then it is taken for granted that they have eaten when in fact they have gone hungry (Gerontologist USA);*

The same participant goes on further to explain his frustration with what he considered should be fundamental patient care:

*Periodically, I will come on to the ward and see that their meal trays are still full and they are just on the side because the patient is unable to feed themselves. Unfortunately, if someone would feed them they would eat it, but I have to write orders, I actually have to write a doctor's order to 'please assist patient with meals', and then the nurses will do it, but otherwise they will not (Gerontologist USA).*

This raises the alarming concern that the basic provision of food and water to a needy patient is dismissed as either irrelevant, too basic, or possibly too inconvenient in the midst of other more rigorous clinical responsibilities, therefore necessitating a special written order. Feeding a patient is essentially a natural extension of good nursing care that should be integrated automatically into the care plan of the patient. Similarly, another participant practising in the area of gerontology explained 'bad planning' of the coordination of meal times and human resources:

*A lot of PCA's [patient care assistants], well their job is just to bring out all the trays and collect the trays at the right time. So at 5.30pm they disperse the trays, and then at 6.30pm it is time for them to collect the trays. That is their job. They do not have to be concerned about the clinical aspects of the patient's nutritional status. They just gotta take care of the trays. They*

*just work there to earn a wage, and are not into the health care mentality (Gerontology Nurse Practitioner USA).*

The cognitive abilities of patients in terms of self care and the simple activities of daily living such as feeding (and associated inability to feed), was of primary importance to a subset of participants, namely the three Occupational Therapists that contributed to this research. The fundamental ability to actually eat, and to then enjoy eating, could be subsequently challenged by hospitalisation and medical care itself. These participants explained how hospitalisation and medical care provide certain hurdles to the process of eating and nutrition, and describe the simple barriers these patients contend with in order to eat:

*If a patient is cognitively able enough to not only understand that there is food in front of them and physically be able to feed themselves then their nutritional intake is often somewhat adequate. A lot of them have anorectic tendencies and lack of appetite and loss of taste buds due to old age and heaps of medications. They may also be on a restrictive diet like a renal diet (or no taste diet) or one for dysphagia, like pureed, thickened fluids, and the likelihood of them getting adequate nutrition is unlikely (Occupational Therapist USA).*

Staffing of hospital wards and the associated poor management of meal times was also raised:

*I think that the staff levels are inadequate to meet the patients' needs and that the people who are often providing the front line care to the patients are inadequately informed of either cognitive, physical status or swallowing status. For example, it is very likely that a certified nursing assistant will place a tray in front of a patient and not be aware of either the diet or the patient's physical or cognitive limitations. The tray will be there in an inappropriate position, the patient is unable to reach it, either the utensils or the food, or sometimes there is an error in their dietary tray and the patient is unable to eat the food that is provided (Occupational Therapist USA).*

Several other examples were provided of how and why some patients did not receive adequate oral intake whilst hospitalised. Funding also featured, in that certain payer

issues (in the USA health care environment) and subsequent staffing levels that are affordable within reimbursement situations led to situations of not enough staff being present to assist with meals:

*We would see a much better rate of oral intake if there were more staff present to encourage patients to feed themselves, rather than shoving food in their mouth at an inappropriate rate...and I think that if the nursing staff had more time to present food to people in a way that made food appetising rather than off-putting or over stimulating (Occupational Therapist USA).*

The Australian Occupational Therapist participant shared similar views with her American counterparts:

*My experience is a frequent experience where people who are not physically capable of feeding themselves are left often unfed. I have known of relatives who had to visit the patient everyday and assist them with their meals because of their fear that their relative would not be fed by the ward staff (Occupational Therapist AUST).*

Her main concerns centred on the lack of 'basic care', if not a criticism of a shortfall in what should be fundamental quality nursing care:

*I think that basic care like nutrition is so basic, and good basic nursing skills that should be observed and so often these basic things are ignored. Hygiene comes into it as well because to have an appetite, good mouth care is important, yet so often these patients have foul mouths, and one example I can remember where a patient had been in hospital for 11 days with no toothbrush, no mouth toilet. The nurses are either too busy or don't care that having a mouth like sandpaper or the bottom of a parrot's cage does not lend itself to a healthy appetite let alone sense of well being (Occupational Therapist AUST).*

*I think that basic care is being ignored. I think without a doubt that it is the nurse's responsibility in the first instance. I think that if there is something physically preventing the patient getting*

*their hand to their mouth then they should be referred to the appropriate therapy for intervention (Occupational Therapist AUST).*

Bad management associated with staffing levels and coordination of meal times was of similar concern for the same participant:

*The meals are plonked down in front of the patient often where they can't reach them, by the kitchen ladies who hand out the meals, and of course, one of the biggest problems is when lunch or dinner time comes, half the nurses are off the ward at their own meal break, so that if their patient requires feeding, unless one of the other nurses is prepared to help out and is aware of the problem in need, the patient does not get to eat – unless they have a relative there to assist (Occupational Therapist AUST).*

This last quote outlines a fundamental flaw in the recognition of basic patient needs, as well as revealing the questionable ethic of the institution. It also highlights an obvious need for better coordination of staffing to ensure that well-informed staff are present at meal times to ensure that patients receive the therapeutic intervention necessary to ensure that their most fundamental requirements for improved functioning and recovery, if not human existence, are being met. However, better coordination of staffing is hardly the sole solution. Simple awareness of the importance of nutrition also appears to be seriously lacking. Several participants mentioned this as being partially resolved by hospitals having designated nutrition teams that afford a sense of 'professional seriousness' to a subject that was otherwise dismissed as being boring or too basic:

*We have a nutrition team that is very visible and people do take note (Clinical Dietitian USA);*

*We follow the recommendations from the nutrition team in terms of what and how we should be feeding our patients because they know what they are doing, they are the experts (Gerontologist USA);*

*Malnutrition is not high on the list here because it is being addressed by the Nutritional Support Team who do all the assessing and intervention (General Surgeon USA);*

*All our patients get a Dietitian who reviews them regularly, and we follow their recommendations (Critical Care Nurse Specialist USA);*

*In this hospital, yes...I feel that the Dietitians are very active and really get in there and appropriately recommend when a patient should be put on nutrition support, and always assess the diet to make sure that it is appropriate. This hospital really recognises the importance and the contribution of the nutrition department (Clinical Dietitian USA).*

The emphasis and importance afforded to simple or complex nutritional intake is obviously enhanced by the presence of a nutrition team. This assertion is also supported by the recent literature on the emergence of Clinical Nutrition Teams (Hebuterne and Schneider 2000; Suchner *et al* 2000), as well as the literature, albeit minimal, associated with the concept of malnutrition in hospitals. Only three major articles (McWhirter and Pennington 1994; Allison 1998; Plester 1996) were located on this somewhat hard to believe occurrence which formed the next discussion point.

### **Malnutrition in Hospital**

The notion of malnutrition was not defined within the discourse of ethics in the dominant ethics literature. The literature which documents malnutrition tends to do so within the discourse of 'quality' as opposed to 'ethics' as demonstrated by Elia and Stratton (2000) and McWhirter and Pennington (1994). The concept of malnutrition in hospital was essentially explained as being tacit, taken for granted, hidden or as one participant explained '*not allowed to happen*' thus being '*swept under the carpet*' (Critical Care Physician UK). The fact that many professionals were not attuned to the incidence of malnutrition amongst hospitalised patients was also raised, as well as the misconception that malnutrition was not associated with people living in industrialised countries – hence only being considered as a phenomenon akin to third world and famine-stricken nations. This supposed ignorance of malnutrition amongst hospitalised patients (if not a consequence of hospitalisation) was explained in extraordinary detail by one of the UK



participants. His explanations range from deficits in the education of health professionals to unfortunate shortcomings of hospital catering:

*We are not attuned to malnutrition in hospital. From the medical students who are trained to look at skinny people from the perspective of what underlying disease is making them skinny, and not from the perspective that they are malnourished. Malnutrition is not considered to be a significant entity...in the UK anyway...because that is what health care systems tell us – that basically that is not really allowable so it does not happen (Critical Care Physician UK);*

*The focus on the wards has to do with illness, and not necessarily recovery...so we see the nurses all hell bent on getting all the drugs administered and attending to the machines that go 'beep' rather than attending to the basic needs of the patients such as nourishing (Critical Care Physician UK);*

*One of the great wonders of the world is that the NHS buys the best produce available cause they are the biggest purchaser in the UK of food products. The kitchens here have actually special legislation – they are not just ordinary kitchens, they have got to be up to a certain standard in meal provision. The cooks here (I find this amazing) are actually specialty trained. The foods they prepare have to be dietetically and nutritionally sound and planned. And given that, how come they produce what they produce, that is, the crappiest off-putting food out! That is the great wonder of the world. The food smells awful, looks awful, gets slopped out to them and the nurses then go off and do whatever nurses do and then come back and collect it all up (Critical Care Physician UK).*

The problem of hospital food was located in the clinical nutrition literature. Allison (1998) discusses the role of hospital catering and contests that it is not well designed to care adequately for the nutritional needs of the sick and is in need of reform. He maintains that malnutrition among hospital inpatients is common, occurring in up to 40% of admissions, and that problems with hospital catering play a large part in causing the problem. The above participant also offered an excellent explanation (albeit somewhat sarcastic reflecting the frustration experienced) of how bad planning and the reality of hospital management could interfere with the adequate nourishment of patients. His

contribution also mirrors those comments made by the three Occupational Therapist participants in the previous discussion point with particular reference to criticisms of nursing patterns:

*This is how frustrating it is to find out how your patients are going...you go on to the ward and first find the nurse, now that might take a while, and then you find a nurse who knows anything about the ward – that may take several weeks considering all the agency and PRN nurses...and then find a nurse who knows the ward and even knows the patients, and then you can ask what their nutritional intake has been, and they won't have any idea. I guess I am being a bit sarcastic but it does represent the actual pattern of nursing behaviours in our wards. And if you ask nurses to put patients on diet sheets so we know what they have eaten, it never happens...they lose interest in that between coffee breaks (Critical Care Physician UK).*

Another UK participant also commented on what seemed for her to be a recent 'loss' in the art of nursing, that is, the disregard for basic patient care that essentially formed the foundation of the profession's original existence. She also alluded to the previously discussed issue of staffing patterns and bad planning:

*Nurses have seemed to have forgotten about the general day to day importance of nutrition. I have just completed a meal audit here and I know that nursing staff do not take responsibility for nutrition at all, from the point of giving someone their dinner and sitting them up, and making sure that they can reach the table and their food, and we wonder why patients are becoming malnourished in hospital. Those things seem so minor but the art of nursing, of simple caring, is really one of those things that has disappeared...and it has been handed over to people who are not qualified. Nurses are very good at the technical side of things and quick to hang up a flask of TPN, but shocking when it comes to simple feeding. Consequently patients often go hungry (Nutrition Nurse Specialist UK).*

This last comment also raises another criticism of nursing's shortfall in the provision of basic care, and that is the apparent seductive power of the technological imperative. The seduction of 'science' in nursing is not a new phenomenon and is well addressed in the

nursing literature refuting science in nursing (Nyatanga 1991; Lumby 1991; Parker 1991; Parker 1987). The notion that nutrition is not 'sexy' enough was explained by the same participant in terms of the seduction of science. She also reiterates previous comments made regarding the management of meal times in hospital:

*Nursing has really been seduced by science and feeding someone naturally isn't that sexy. Also we aren't very good at the simple organisation like when the meals come and half the nurses are off the floor having their own breaks. Or they are too busy doing a drug round or are called to do a round with a busy surgeon and so on...those things take precedence over getting to the patients' meals. Our priorities seem to have shifted (Nutrition Nurse Specialist UK).*

Similarly, an Australian Critical Care Physician commented on an apparent shift of priorities and referred to the lack of basic nursing measures regarding nutrition and hydration of patients:

*You can do the simple nursing things that we sort of lost track of...I mean, you can get out a small spoon and offer them a little bit of fluid and keep their mouth moist and clean, and if they are able to take a little bit of food it can be ladled in with a little spoon. Those things are good nursing care and are qualitatively very different - although probably not as clinically challenging - as putting a tube down someone's nose into their stomach and drip feeding them (Critical Care Physician AUST).*

The 'clinically unchallenging' nature of the simple oral provision of nutrition fits well within the previous descriptions of nutrition not being 'sexy' or scientifically seductive enough to warrant due consideration and nursing attention. Yet these criticisms should not rest with the discipline of nursing alone. Medicine too, sports a certain shortfall regarding the awareness of malnutrition among hospitalised patients, and the importance of nutritional assessment, teaching and research. Other shortfalls include the role of nutrition in end-of-life care, as well the paradoxical occurrence of 'over-nourishing' patients. These issues inform the final discussion point of this chapter.

### Other Shortfalls

The fact that 'nutrition' *per se* does not rate highly in medical or nursing curricula is mentioned in the literature, albeit briefly, regarding malnutrition in hospital (McWhirter and Pennington 1994). Despite this shortfall, one participant did mention a recent improvement in this shortfall:

*A survey done by BAPEN<sup>22</sup> last year showed that only 30% of hospitals had nutrition teams, so clearly there is not sufficient awareness in this country or in most European countries, and so there is still a relatively little amount of nutrition taught in undergraduate medical school curricula. Although, I am pleased to say that there is an increasing acceptance of most of the colleges of the need to have some modules of nutrition for specialist registrar training in gastroenterology, so it is moving, but not enough as yet (General Surgeon UK).*

Another perspective of the shortfall in clinician education was provided by another UK participant. He also referred to the 'technological imperative' as distorting the simplicity of what is a very basic concept, that is, if you do not eat, you become malnourished:

*It is all clinically...unnecessarily so. The biochemistry side is well researched, particularly in Australia, and it is an expensive way of doing what a taxi driver can tell you. So here, we use the 'taxi driver' sign a lot [grins]. If a taxi driver can tell you that it looks as if someone has lost a lot of weight, then you don't need all that biochemistry. A lot of that science – biochemical markers and anthropometric measurements are only confirming what a taxi driver can tell you...that the patient has lost a lot of weight and looks malnourished (Critical Care Physician UK).*

This above quote supports the previously made proposition that basic nutritional assessment, education and care have been lost to what appears to be a disinterest in basic supportive care that need not be attached to the clinical rigors of scientific analysis. This assumption also supports the theory that nutrition rates low down on the list of medical and nursing priorities as determined by the technological imperative. Another factor possibly contributing to this low rating is the fact that it is very difficult ethically to

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<sup>22</sup> BAPEN – British Association of Parenteral and Enteral Nutrition

justify scientific research on nutrition due to the reality that ethics clearance would never be granted with regard to 'starving' a control group. This was explained by the same participant who utilised the non-scientific taxi-driver test:

*There are so many nutritional studies that cannot be done because we cannot withhold nutritional treatment from a patient. We cannot do that. It is therefore very hard to do nutritional studies. A lot of our nutritional studies actually come from World War Two when people in concentration camps starved...that is where our nutritional data came from, from POW camps, and it was seen how people reacted to starvation. But it is hard to do that on real people today. So consequently, because we cannot do that research, it renders the subject a bit void of hard data (Critical Care Physician UK).*

Another briefly mentioned shortfall concerning 'responsibility' involved the recurring theme throughout these interpretation chapters of education regarding end-of-life care. Two participants spoke of 'responsibility' in terms of being responsible for accepting and preparing for the inevitable outcome of dying, that is death by azotaemia (Hospital Chaplain/Ethicist USA; Critical Care Nurse Specialist USA). However, the most interesting consideration of 'responsibility' in terms of nutrition came from an Occupational Therapist (AUST) who described a divergent view of nutrition in hospitals, that is, over-nutrition as compared with malnutrition:

*I think that it is just as big a problem with the overweight people in hospital. I think that greater use could be made of the dietitians in the hospital on the matter of people who are grossly overweight who come to hospital and there is no attempt made to help them lose weight. I think that could come back and bite us one day because I feel that by not helping them out in all aspects of their health care we are not giving them the best care we possibly can. It is a bit like allowing people to smoke while they are patients in hospital (Occupational Therapist AUST).*

Over-nutrition in terms of clinician responsibility was not mentioned by any of the other contributing participants.

## **Conclusion**

This chapter has attempted to explore what the participants meant by being responsible in terms of caring for the basic nutritional status of their patients. The discussion points suggest what can only be described as a certain disinterest or disregard in a subject, and an extension of basic care that is not attached to any significant clinical science. On the contrary, nutritional science is indeed a complex subject that draws heavily on the disciplines of biochemistry and physiology. However, in its most elemental form, nutritional care of the patient appears to have fallen short of the scientific requirements necessarily for serious and responsible consideration by clinicians. Be it the lack of scientific seduction or hospital ward management, it appears that nutritional care of the patient – the most fundamental necessity for homeostasis – has certainly gone awry. This appears to keep happening regardless of care settings as claimed by both the participants and the related literature on malnutrition in hospitals. Certainly these findings suggest what can undoubtedly be a continued lack of importance afforded to clinical nutrition. The shortfalls associated with the responsibilities of nutritional care signify a dire need for appropriate recognition of clinical nutrition curriculum development and ongoing education. The case therefore has been made for the consideration of malnutrition in hospital as an ethical issue. The political question is therefore raised as to whether it would be constituted. Such a question and many others gleaned from these eight interpretative chapters are further explored and discussed in the following reflective chapter entitled 'Implications'.

## **CHAPTER ELEVEN**

### **IMPLICATIONS**

#### **Introduction**

The outcomes of this research information are many and far-reaching. The five main implications for practice have been identified in the previous eight interpretation chapters as being particularly significant for the provision of artificial nutritional support and critically understanding life-sustaining technologies in general. These are:

1. The importance of improving clinicians' understandings of ethics 'at the bedside' via the facilitation of end-of-life curriculum development; and to assist clinicians' abilities in integrating that understanding into clinical practice. Hence the recognition of 'Clinical Ethics' as popularised in much of the North American medical literature.
2. Strengthening institutional policies and procedures regarding the use of artificial nutritional support (and strengthen the delivery of clinical nutrition education) and other life-sustaining treatments, thereby embracing the process of advanced care planning.
3. Supporting the active participation of patients and their families/surrogates in decisions about the way in which they live and die.
4. Improving communication among providers, patients, and families concerning the complexities posed by the availability of artificial nutritional support and other life-sustaining technologies.
5. Delineating appropriate roles and responsibilities for the various disciplines involved in critical/acute and palliative care, fostering teamwork, conflict resolution and mutual support. Hence the bridging of the gap between the 'acute' and 'palliative/hospice' settings in extending 'good death' care.

### **Enacting These Suggestion of the Experts**

The first, and most powerful of these points regarding ethics at the bedside, embraces the need for improved mechanisms of delivering end-of-life education. The second and third points highlight the need for clarification and development of the role of ethics committees and their subsequent development and support, as well as an extension to recipients towards increased participation. The fourth point comprises the need for fostering honest communication and improved advance care planning, as does the fifth point - which essentially highlights the need for clearer lines of responsibility and the recognition of the need for palliation when and where appropriate. Drawing upon the wisdom of the multidisciplinary mix of participants interviewed, it is suggested that there are some important ways of enacting these five areas towards better holistic care.

So how are we to implement these recommendations in evidenced-based practice, recognising that the insights from the participants interviewed provide significant consensus across disciplines and cultural divides? We may identify particular domains of practice, with those domains of practice being identified clearly by the participants in their narratives.

### **Addressing Shortfalls in Education**

Hoefler (1994) maintains that physicians generally do not deal with the subject of death well, which enhances the disconnection between physicians and their patients, he notes, that modern medical training is at least partly to blame. This theme is explored in Chapter Four 'Death' (p.117-118), which recognises that courses in death and dying are not an integral part of medical curricula. Despite some recent developments such as the EPEC Program (1999), and even more recently the ELNEC Program (2001)<sup>23</sup> in the USA, the majority of medical school students receive only brief discussions of dying in clinical courses that primarily deal with biophysical considerations, leaving aside entirely the psychosocial dimensions of death. Death is viewed as a scientific entity therefore being

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<sup>23</sup> ELNEC: The End-of-Life Nursing Education Consortium, established in February 2001 is a comprehensive, national education program to improve end-of-life care by nurses, funded by a major grant from the Robert Wood Johnson Foundation; and in partnership with the American Association of Colleges of Nursing (AACN) and the Los Angeles-based City of Hope National Medical Center. This resource was located during a 'last minute' review of the literature prior to submission of this thesis.



humanly denied. Consequently, formal education in end-of-life care has been absent from medical school and residency training. The experience of being ill-equipped in a holistic sense to care for the dying is epitomised in this following statement by Charles F. von Gunten, Director of the EPEC Project.

*They said there was 'nothing to do' for this man who was 'end stage'. He was restless and short of breath; he couldn't talk and looked terrified. I didn't know what to do so I patted him on the shoulder, said something inane, and left. At 7am, he died. The memory haunts me. I failed to care for him properly because I was ignorant (von Gunten 1999:[www.epec.net](http://www.epec.net)).*

It is clear from the literature that there is no standardisation of education in end-of-life care in medical schools at any level of training. This proposition is seemingly evident in Australia and the UK whereby no associated study into this subject was located in the related literature. Therefore without any training, how can medical practitioners, wherever they may be in the world, become confident and competent in end-of-life care? The absence of end-of-life education therefore breeds an ethic of detachment that emphasises saving lives rather than focusing on the care for and disposition of dying patients and their families. Doctors are consequently socialised to consider medicine's technological 'rescue imperative' (Meyer 1988:10). This classic Cartesian mentality does not lend itself to being skilled in or comfortable with attending to the emotional needs of people in their care.

With the rise of the patient as consumer, individuals may feel that they are not getting everything they want from the medical care that they receive. In short, medical training (both undergraduate and postgraduate) may produce, from the recipient's perspective, a provider that is best described as a stranger or a mechanic, rather than a friend or companion.

Out of the potential barriers to end-of-life care, one barrier in particular is exposed by the participants and is a vital finding of this research. Discomfort, inability and failure in communicating bad news and/or poor prognosis, lack of skill to assist patients with

treatment priorities, and lack of understanding of patients' rights to decline or withdraw treatment have led to frequent misunderstanding and excessive futile intervention. Also, lack of experience, confidence or simple ignorance have prompted some to avoid dealing with patients who are dying altogether. The importance of 'honest communication' is frequently referred to throughout this entire research, yet to be able to fulfil the role of 'honest communicator', health care practitioners require information, education and ultimately support. Without this we shall continue to experience these serious gaps in end-of-life care as the participants in this research all too frequently explain.

The participants remind us that the end of a person's life can be one of the most important times in that life. While the way we die has changed considerably during the 20th century, neither our society nor modern medicine has adequately valued end-of-life care, with the exception of the recent development and recognition of palliative and hospice care. Yet so often palliative care is viewed as a final resort rather than an integral part of a cycle of care. Medical curricula need to equip physicians with knowledge, skills and attitudes that can be tailored to their unique and diverse practice settings. Similarly for nursing and the allied health professions, curriculum development in this area is also timely - such as the previously mentioned ELNEC Program in the USA. The ultimate goal of such dissemination of knowledge is to relieve suffering and improve the quality of the lives of all people on the receiving end of health care, regardless of where they live, who they live with, and what they are of dying of. One possibility in improving this educational shortfall is the development of Internet-based teaching modules for clinical ethics. This would enhance the dissemination of teaching materials, as well as responding to the needs and convenience of clinicians. An example of such a resource was located during a 'last minute' review of the literature. The Ian Anderson Continuing Education Program in End-of-life Care<sup>24</sup> provides numerous teaching modules available online including subject headings such as 'Palliative Care', 'Symptom Management', 'End-of-Life Decision-making', 'The Last Hours', and Indigenous Perspectives on Death and Dying'.

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<sup>24</sup> A joint project of Continuing Education and The Joint Center for Bioethics, University of Toronto, and The Terry Lather Center for Palliative Care, Mount Sinai Hospital, Toronto - see [www.cme.utoronto.ca/endoflife/overview.htm](http://www.cme.utoronto.ca/endoflife/overview.htm)

The ongoing process of curriculum reform in Australian medical schools (Lawson *et al* 1998; Forbes 1994) provides a timely and welcome opportunity to address the deficiencies in end-of-life care teaching. However, as Glare and Virik (2001) maintain, clinicians-in-training are not prepared to assess the clinical and psychosocial factors that indicate to what extent curative, life-prolonging and palliative care are appropriate for a patient, or how they are to be initiated and managed, throughout the course of an illness. Such a shortfall necessitates a concerted effort of curriculum review and development. Examples of this could be the facilitation of grand rounds incorporating more frequent discussion of care at the end-of-life, or more emphasis awarded to topics on death and dying issues at National/International meetings of specialist societies. A review of the 'last minute' literature discovered an entire supplement of the Medical Journal of Australia (November 2001) entitled 'Death and Dying Issues' which is evidence that the subject is by no means a mute point. This coincides with an ongoing series in the same journal entitled '*Clinical Ethics*' which is certainly a positive step towards such confronting subject matter as an engaging discipline, which demands incorporation into practice and education

### **Food for Thought**

End-of-life education is not the only implication for practice drawn from this research concerning education. These discussions have merged artificial nutritional support into the broader area of life-sustaining treatment. More specifically, the provision of nutrition in hospital, regardless of its route of administration also requires attention with regard to education. The chapters 'Symbolism', 'Technology' and 'Responsibility' all highlight the need for more emphasis in medical and nursing curricula on the importance of nutrition in the clinical setting. Such an emphasis would challenge the obvious conception that nutrition as a therapeutic modality is not clinically rigorous or scientific enough to warrant such attention - unless of course it is attached to a machine that goes 'ping'.<sup>25</sup>

Limitations to basic education in nutrition for clinicians (dietitians and nutritionists excluded) have become apparent in this research. Staff providing clinical care are often

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<sup>25</sup> Reference is made here to the infamous hospital machine in the Monty Python sketch 'The Miracle of Birth' from the movie 'The Meaning of Life' see [www.wuzzle.org/python/birth.html](http://www.wuzzle.org/python/birth.html). 'Ping' is an artifactual way of referring to the technological imperative as discussed in Chapter Nine 'Technology' (p. 244).

not aware of basic factors, which may well be contributing to the overall poor condition of their patients. An overburdened and under-educated workforce in conjunction with systemic practices of organisation which fail to address nutrition as a vital component of care, have resulted in responsibility for distribution of nutrients being delegated often to the junior, and frequently to the least well-qualified members of the health care team. Without the emphasis of nutrition being duly stressed, there is a danger of undetected malnutrition – as is attested to in Chapter Ten 'Responsibility' (p. 258-259). Therefore, the nutritional needs of patients should be on the agenda of every clinical educator, and incorporated into relevant curricula.

### **Will the Real Ethics Committee Please Stand Up**

One participant (Oncologist USA) proposed that there would not be any ethical problems if doctors only communicated honestly with their patients (Chapter Three 'Principles' p. 110). This sweeping statement is supported in part by Jonsen *et al* (1998), who explain that in the usual course of the practice of medicine, important decisions are, and should be, made by the patient and physician together, and, that outside parties have no right to partake in those decisions unless invited to do so by the principal parties. However, the growing complexity of ethical issues in clinical care has stimulated the development of ethics committees and ethics consultation. Ethics committees are established in health care institutions as advisory groups on policy and sometimes on cases that involve ethical issues. Jonsen *et al* (1998) argue that it is the responsibility of these committees to be familiar with the literature and methods of the field of bioethics, and to make available the best informed opinions about issues to those who seek their counsel.

As Curtin (1994) suggests, clinical ethics committees are helpful and constructive in resolving ethical dilemmas regarding the provision of artificial nutritional support. Clinical ethics committees can review a case to confirm the responsible physician's diagnosis and prognosis of a patient's medical condition; they can provide a forum for incorporating the broader social and ethical concerns raised by a particular case; such bodies may also have an education role, especially by teaching all professional staff how to identify, frame and resolve ethical issues; they can be a means for formulating policy and

guidelines regarding such decisions; finally they can review decisions made by others, such as physicians and surrogates, about treatment in specific cases. While such a forum, and its function, has obvious merit, the consultative nature of the 'ethics forum' is essentially a North American phenomenon. This is attested to both by the participants and the literature. This representation is also mirrored in the membership of ethics committees throughout the USA, which is in sharp contrast to ethics committee structure in Australia and the UK, which is essentially the 'research ethics committee' or 'institutional review board'.

The very absence of a multidisciplinary forum-style of clinical ethics committee in the traditional Australian and UK hospital model, as well as the paucity of formalised processes such as living wills, durable power of attorney for health care, and advance directives, exposes a certain deficiency in the ethical processes of complex decision-making in end-of-life situations and/or decision-making regarding the provision of all life-sustaining technologies. This may in part be a definitional problem whereby different terminology is used to explain these forums and their functions.

However, the USA participants (and the North American literature: Jonsen *et al* 1998; Singer *et al* 2001) explore the nature of research ethics (Institutional Review Board) and ethics consultation (Ethics Committee and/or Clinical Ethics Committee). The UK and Australian participants (reflected in the UK and Australian literature: BMA 1999; Komesaroff and Cohen 2001) only include reference to the research ethics forum. There is a palpable absence of a forum for ethics consultation in these countries, despite a recent assertion by Slowther *et al* (2001) that clinical ethics support services are developing in the UK. Another possible exception to this is the recent revision of the British Medical Association's guidelines for decision-making which offers a comprehensive set of principles which apply to all decisions to withhold or withdraw life-prolonging treatment (2001). However, on closer examination of this particular text, there is no discussion of 'ethics consultation', rather a physician-driven process of decision-making. This clearly demonstrates a certain deficit in the UK literature reflecting medical

paternalism when it comes to such decision-making. Medical paternalism is not solely to blame for such a deficit.

Yet the lack of end-of-life education for physicians only compounds this. This is no more apparent than in the discussions on medical futility. For physicians who do not have access to such education or professional development, can fall into the trap of paternalistic decision-making (thereby avoiding potentially difficult consultation and discussion) as well as defaulting into continued aggressive treatment and thereby avoid the wrenching discussions that must occur if such treatment is to be abated. As Goodhall (1997) argues, the fact that doctors dominate the ethical decision-making process (in settings where paternalism is the norm) results in an imbalance, which allows the masculine ethic to predominate.

The lack of clinical interface in the Australian and UK descriptions of 'ethics committees' suggests a troubling shortfall, in that those forums that are divorced from the 'clinical coal face' (that is, the practice setting), and embedded in theory and contemplation, risk rendering themselves less than relevant. Accordingly, the clinical consultative nature of an ethics committee needs to be incorporated into those health care delivery systems which only provide a research ethics review function. Despite recent concern that there is a lack of evidence regarding the effectiveness of ethics consultation services (Kerridge *et al* 2001) when questioning a future for such services in Australia, the North American experience, according to the related literature, is certainly positive. Three American articles on evaluations of institutional ethics consultation services in particular support this statement. Scheiderman *et al* (2000)<sup>26</sup> explain that ethics consultations were useful in resolving conflicts that may be inappropriately prolonging futile or unwanted treatments, and are perceived to be beneficial. Dowdy *et al* (1998)<sup>27</sup> similarly report that ethics consultation offers a promising approach to improving decision-making and communication, as well as reducing the length of ICU stay for dying patients.

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In addition, Orr *et al* (1996)<sup>28</sup> claim that ethics consultation provided by clinical ethicists to be helpful in the majority of cases. This particular evaluation documents seven areas of effectiveness: 1) increased clinical clarity; 2) increased moral or legal clarity; 3) motivation to do what they believe is right; 4) facilitation of the process of decision-making; 5) implementation of a decision; 6) interpretation of technical language; and 7) consolation and support (Orr *et al* 1996). More recently, the Baylor University Medical Center conducted a recent review of its Ethics Consultation Service since the incorporation of the Texas Advance Directive Act of 1999 which has witnessed an increase of 57% in general ethics consults and a 91% increase in explicit futility consultations.<sup>29</sup> The consultation utilised in particular has observed the process as a legally sanctioned mechanism as opposed to a process that was simply part of an institutional culture, which in turn clears confusion for clinicians and patients/families. Yet considering this research endeavour the most compelling evidence regarding the effectiveness of such committees and consultation is offered by two of the USA participants. The quotes below are taken from Chapter Three 'Principles' (p. 104):

*It is a win-win situation – like, if the patient wants a good death, they get it, or they get treated if they want (Hospital Chaplain/Ethicist USA).*

*I think that they are a really good thing, and not because of the quality of decision-making, not because we get to the right answers more often than not or anything like that. There is more to it than that...I think though that in terms of what benefits the patient and benefits the family, um, we provide a process for dispute resolution, joint decision-making that brings people into the discussion that clears up factual misconception and allows people a forum to express preferences and beliefs, shows those preferences and beliefs a healthy amount of respect...airs differences, finds areas of agreement, narrows areas of disputation, and um, finds more often than not at least some narrow basis of agreement to proceed with. Then we can reassess it if necessary and see how we all feel about it, and at*

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<sup>28</sup> Unpublished report : 'A Brief Summary of the BUMC Ethics Consultation Experience Before and After the Texas Advance Directives Act of 1999' obtained from the author Dr. R.L. Fine, Director, Office of Clinical Ethics, Baylor Health Care System, in September 2001.

*that, that is a pretty beneficial process for most of the disciplines (Law Professor USA).*

Hence, these research participants make clear that the ethical dimensions of care involve more than a crude consequentialist approach where process is just as important as outcome. Process needs to provide support to patients, families and the health care team, and clinically focused ethics committees in Australia and the UK have a potential to foster what one expert so succinctly put – 'win-win situations'.

### **Improved Advanced Care Planning and the 'Death Taboo'**

Most discussions regarding advance care planning came from the USA participants. They had routine engagement with advance directives as being those statements arising in the context of an increasing need to respect and promote patient autonomy. In the USA, the focus on advance directives can be traced back to the American emphasis on autonomy and truth-telling (Solomon 1999). Indeed, in the USA this is mandatory by law upon hospital admission (American Academy of Family Physicians 1994). Advance directives have received widespread support in the USA, whereby all 50 states now have a statutory basis for such statements (*ibid.*). The very presence of an advance directive promotes dialogue between patient and clinician about what is essentially planning for future care, if not more frank discussions about end-of-life care. This could also be evidence of America's greater acceptance and participation in 'death dialogue' - a claim which is also supported by Sherwin Nuland's previously mentioned text '*How We Die*' winning a National Book Award in the USA. In support of this is an editorial comment located in a recent supplement to the Medical Journal of Australia (November 2001):

*Sex, drugs and rock 'n' roll are no longer taboo in polite conversation or even medical consultations. Death and dying however, still are. Or, if not taboo, then 'technicalised' at least in medical circles (MJA 2001:506).*

Kellehear (2001) also supports this from an Australian perspective when he argues that Australian culture, through its artworks, readily acknowledges death and grief, but not the process of dying - as commonly observed in European artworks. Furthermore, no



special prescriptions or behaviours are portrayed for bridging the transition between active life and death. Is it any wonder that when Australians (or any other country/culture that acknowledges a 'death taboo') face the prospect of dying, they are empty of ideas about what is to be done?

Likewise, the very absence of an advance directive lends itself to the absence of the same dialogue. The Australian situation is testimony to this. Despite three Australian States and two Territories having legislation, which provides for advance directives, the validity of these at common law is yet to be tested in an Australian court (Bielger *et al* 2000). This coincides with the lack of formal education in end-of-life care. Consequently, the recognition of end-of-life care is presumably ignored on two fronts. First, in education as discussed previously, and secondly, in direct patient care. The very discussion that ensues when implementing an advance directive, between patient and clinician, is confrontational and awkward. However, such discussion is needed to ascertain the true wishes of the patient thus respecting autonomy. If such discussion is absent then a situation whereby the clinician assumes autonomy in planning the proposed treatment or cessation of the same, is not difficult to appreciate. Acknowledgement of the 'death taboo' if not a social denial of death only compounds this problem.

According to Gorer (1965:195), in the twentieth century 'death' has become more and more 'unmentionable'. Encounters with death in modern society have diminished, even as violent death has increased unparalleled in human history. Thus, the last century has witnessed an unparalleled degree of human-induced death in wars and concentration camps, a new set of encounters with death by way of automobile accidents, usage of illicit drugs, and a significant rise in the role that violent death plays in fantasies offered to mass audiences, not to mention the modern day phenomenon of mass murder via terrorism.<sup>30</sup>

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<sup>30</sup> Reference is made here to the September 11<sup>th</sup> 2001 terrorist attacks in the USA which occurred just prior to the completion of this chapter.

According to Becker (cited in Buckman 1997), contemporary society is going through a phase of virtual denial. The price of this denial or avoidance is paid by the person whose life is threatened and who has to face death, and by those who care and support the patient. Such death denial could also be a result of the previously mentioned media-hype. Advances in medical sciences are often over-reported in the media and hailed as major breakthroughs. As Buckman (1997) explains, the constant bombardment of the public with news of apparently miraculous advances in the fight against disease subconsciously raises expectations of health and even offers tantalising hopes of immortality. It therefore becomes even harder for an individual to face the fact that he or she will not be cured despite the many miracles seen on television or in the papers.

It is noteworthy that the greatest difficulties will occur when there are formal and informal taboos which inhibit the plain speaking and plain dealing about death, which so characterises palliative care. It will therefore remain difficult to provide 'good death care' to those who for religious, cultural or psychosocial reasons cannot accept their reality. In such cases, 'good death care' is likely to be limited to the essentials of pain control and supportive nursing care. This is not necessarily a failure, rather an acknowledgement and appreciation of the many variables one needs to respect regarding global health care.

Close analysis of the narratives shows that physicians still hold power to control information through their management of information giving. Information giving is selective, so that the information givers can facilitate a discourse which justifies, rather than eliminates, the information control. As such, clinical information control is often about providing information about treatment as opposed to prognosis. Miyaji (1993) supports this claim in explaining that clinicians often give vague information about prognosis. Information about treatment is more readily shared in order to counterbalance the negative impact of the news on patients. The way doctors control information is closely related to the way they handle aspects of the reality of clinical practice, such as their own emotional coping, institutional and legal constraints, and power relationships among patients and other caregivers. Yet the humane dimension to the doctor, although

suppressed in the currently dominant, contractual ethical framework, is still powerful in doctors' narratives. Patients are important.

The need for honest communication is explored throughout the interpretation chapters and the various discussion points of this research. The narratives explicitly depict honesty as being needed not only at initial diagnosis, but that patients and their families/carers should not have to press for information about outcomes of treatment. Developing approaches to disclosure that are appropriate for different cultural groups also needs attention. As one of the narratives in particular teaches us,<sup>31</sup> strongly held views from mainly families/carers either for or against informing the patient of diagnosis and/or prognosis can be expected. This is supported by Campbell (2001) who explains that there may be culturally determined rules (regarding disclosing diagnosis and prognosis) relating to gender, family hierarchies, who should disclose (e.g. eldest son), as well as consideration of linguistic issues. The contested space which is 'food' is also important here. Even when the continued provision of nutritional support may be clinically detrimental, denial of nutrition may be more harmful spiritually. Awareness, appreciation and recognition of the multicultural variances concerning death and dying with regard to 'honest communication' are surely indicated for practice.

### **Palliative Care in Critical Care and the Problem of Death**

Exploring the interface between critical and palliative care also stems from the various narratives about recognising end-of-life care or 'good death care' as being less than optimal in the high technology arena of critical care medicine. Intensive care reflects the modern preoccupation with the mastery<sup>32</sup> of disease and the eradication of an 'untimely death'. It is also the place to which clinicians refer a patient when that person stands at the brink of death or 'circling the drain'<sup>33</sup> and is beyond the reach of conventional therapies. Understandably, the debates of withholding and/or withdrawing treatment in our current climate may well cause clinicians to distance themselves from any actions

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<sup>31</sup> In particular see Chapter Six 'Culture' (p. 166-168).

<sup>32</sup> The masculine metaphor is deliberately used here. For a discussion see Susan Sherwin's *No Longer Patient: Feminist Ethics and Health Care*, 1993, Temple University Press, for a feminist account in power relations in health care.

<sup>33</sup> See Chapter Four 'Death' (p. 116).

that may be interpreted as active euthanasia. However, the most interesting paradox derived from the narratives on palliating patients in critical care stems from why patients might receive protracted and costly multiple organ system support in the hours and days immediately before death (Singer 1994). To add to this, even when death is recognised as certain, it lies within this paradox of what constitutes natural and artificial in contemporary health care with its technological imperatives.

Commentators such as Ashby (1998), recognise that most deaths are managed in some way. The narratives encountered in this research suggest we can, and should, embrace management practices that improve quality of care for patients, their families and carers at the end-of-life. In reality, death in the ICU is neither simple nor natural, and a cultural clash with the principles of palliative care is evident. As Chapple (1999) explains, the problem is that terminal care is the precipice when ICU knowledge and sophistication ends, and that death is not the mission of any ICU. Attending to the dying process (and recognising dying as a multifaceted process) is undoubtedly a challenge to ICU clinicians. Acknowledgement of an ultimate lack of control in the face of death is needed and can indeed be liberating and positive. Clinicians in high-technology, high-stress environments routinely seek to exercise control over the body systems of their patients. The prospect of allowing a patient to deteriorate in his or her care is a source of great discomfort to some critical care clinicians. It runs contrary to the culture. This is well described in those narratives concerning the 'messy' nature of enteral feeding in the ICU whereby nurses would complain about the onset of active bowel function, and how such bowel activity would be both inconvenient and unsavoury.<sup>34</sup> Letting go of that supposed control, thereby avoiding the unnecessary medicalization of death presents as one of the most fundamental challenges for critical care clinicians. Likewise, there is the challenging suggestion stemming from the various conversations of the research participants. The merging of the two disciplines, that is, critical care and palliative care which necessarily occurs when providing optimal care for patients.

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<sup>34</sup> See Chapter Seven 'Dilemmas' (p. 186).

Traditionally, and from the perspective of the research participants, it would be unusual for critical care and palliative care practitioners to be involved in tending the same patient. Despite these two disciplines sitting at opposite ends of the patient care spectrum, the narratives suggest that this is not in the best interests of acutely or severely ill patients. Bridging the distance between critical and palliative care is crucial. Coinciding with this is the extension (however awkward) of advance care planning to the critical and acute care setting, and embracing all those aforementioned ideals of honest communication, holistic care, and not simply the management of symptoms.

The formal recognition and support of palliative care as being a distinct medical and health care specialty, and the embracing of this specialty in acute patient care settings is paramount for the attainment of a 'good death'. The narratives teach us that until this improved recognition, acknowledgement and better understanding is reached, and greater debate and discussion is encouraged about the management of end-of-life care, it will remain the case that clinical behaviour will range from (as according to Ashby 1998:74) '...abrupt cessation of treatment, minimalist palliative care and treatment directed at bringing about a rapid dying process to excessive caution about being seen to be instrumental in causing the death'.

The problem with end-of-life care, or more simply 'death' is not simply about the need for better recognition and appropriation of palliative care. Nor is it simply about the need for better communication between clinicians and patients, and honest communication at that. The actual situation is far more complex than the narratives suggest. The problem of death in Western societies is about the extension of what Foucault called medicine's 'gaze' (1975) - as a cultural phenomenon to advanced age and the end-of-life. As the USA participants explained, 'death' is problematised by the power (and fear) of litigation that influences every hospital activity to complicate decision-making, action and acquiescence to patient surrogates. It is also complicated by the vast gulf between lay and professional understandings of human physiology and the role of technology. The confusion about the nature of the end of human life, and the physiological process of dying, is best explained in the narratives on the role of popular media and peoples' expectations of life-sustaining treatments (including those particular narratives

concerning what constitutes food and what artificial nutritional support is not). This, coupled with medicine's undisputed ability to facilitate survival for many years (especially in those cases without the patient achieving awareness or being able to interact with others), has led to expectations in society about the extent to which it is possible to postpone death, such that death is seen not as a natural, inevitable event, but as a failure of medicine to deliver all that the hype and rhetoric promise.

Adequately tackling the problem of 'death', and embracing the ideals of palliative care for all people at the end of their lives will depend on a broad reconsideration of the dominant role that medicine plays - not just in institutional practices, but also in all aspects of social life. At one time, critical care and palliative care may have seemed to be inherently inconsistent. End-of-life care was simply a sequel to failed intensive care. This is no longer a workable paradigm. The role of medicine therefore, to facilitate, and embrace a transition process from life to death (and one that is highly variable from person to person) is perhaps the most far-reaching implication drawn from this research.

Some aspects of medical treatment will always remain uncertain. Death is a certainty for everyone yet, except in a small number of cases, diagnosis and prognosis are based on probability and past evidence rather than absolute certainty. Societal perceptions also need to embrace a shift away from the view that life can be prolonged indefinitely, towards a realistic acceptance of the inevitability of death as part of life. This need could, in part, be addressed by the formulation and availability of appropriate information giving (by way of family conference and/or the use of information booklets in the clinical setting) to help people understand the principles of care, and to enable them to participate in early and more informed decision-making. Further research into how clinician communication concerning end-of-life care can be improved, regardless of clinical area, is surely indicated from this research. Ashby (2001) and Glare and Virik (2001) offer some timely additions from the Australian literature in support of this claim. Also indicated is addressing the absence of accurate assessment of premorbid health and quality-of-life, and a comprehensive audit of outcome by way of follow up which could include the 'bereavement visit' as suggested by Parkes (1997:685).

## Conclusion

Factors driving continued aggressive clinical care include pressure from patients, media-hype, relatives and referring clinicians, medico-legal concerns or the simple employment of new technologies. These in conjunction with the variances in effective dialogue, honest communication, appropriate education and information giving about what constitutes good holistic care (and not simply the clinical), complicates care. In this chapter, the case has been argued for improved management, care and education based upon the interviewees' expertise, and the literature. We have also encountered the political dimensions of why the status quo exists, and the challenges in providing for coordinated care. The very challenge which emerges is inherently political, in asking if such change will occur and for whom the system operates?

Health care providers cannot assume that their patients understand what they tell them. Essentially what is needed is research into improving our abilities and to embrace communication, truth-telling and advance care planning as interdependent imperatives for quality holistic patient (and family) care and support. Learning the skills to understand patient/family/carer preferences will enhance treatment practices and policies in the management and provision of all life-sustaining modalities, and not just artificial nutritional support.

The overwhelming evidence drawn from this research supports the recognition and further multidisciplinary development of end-of-life care. End-of-life care is appropriate for the practice of health care professionals everywhere, whatever their discipline, their specialty, whatever their culture, and religious beliefs. The appropriate provision of life-sustaining treatments and the relief of unnecessary suffering, whatever its cause, is the concern for us all. In many ways it is indeed a rediscovery of age-old truths. The challenge will undoubtedly remain to confront the many taboos associated with death and dying. The exposure and deconstruction of these taboos is possibly one of the most significant implications drawn from this research. The factors that lead on to this exposure and deconstruction are revisited in a reflexive exercise in the final discursive chapter of this thesis which has been entitled 'Reflections'.

## **CHAPTER TWELVE**

### **REFLECTIONS**

#### **Introduction**

This chapter retrospectively explores those research findings discussed in previous chapters where further analysis aids the thrust of this thesis. These include the utilisation of a principlist discourse to research health care ethics by the participants whereby casuistry is evident; the theme of 'buying time' as outlined in those discussions on death and continued treatment; dissatisfaction within the disciplines; and the confronting suggestions of possible abuses of artificial nutritional support. Also, reflexive critique of the research project's methodology, structure and difficulties is offered. Further discussion is also provided in light of a 'last minute' review of the associated literature and the timely nature of this project. Most importantly, an overview of the research's relevance to the disciplines as well as the wider community is also undertaken.

#### **Challenging the Principles**

Throughout this research the limitations of a purely principlist approach to ethics are evident. In utilising narrative ethics as a methodology and via the close analysis of the participants' stories, it is clear that ethical assumptions that shape practice might well be influenced by the principles, but the discourse of 'principle' is mediated by experience and interaction. A closer analysis of the narratives encountered in the research exposes a broad interpretation by the participants with regards to the 'ethical principles'.

'Principles' is in many respects verbal shorthand with meaning given in the associated text. Ethics, as a discursively shaped and negotiated construct is not solely principlist. Despite the participants embracing the principlist language, they essentially exhibit virtuous behaviour based on what Braunack-Mayer (1999:13) describes in terms of 'casuistry'. This therefore highlights a complexity in that the participants incorporate explicit notions of principlism, yet on exploration of the narratives exhibit tacit virtuous behaviour.



Hence this research embodies various forms of casuistry, which contribute to the ethical reflections on the provision of artificial nutritional support and life-sustaining technologies at large. This practice of casuistry adds complexity to a health care system in which accounts of principlist medical ethics are still dominant but not necessarily practiced. This is evident in those discussions concerning medical paternalism, and the conflict between beneficence and autonomy, where a certain paradox of principles is clear. The discussion concerning ethics in critical care in Chapter Four 'Death' (p.123) is testimony to this. These ethical principles are therefore difficult for physicians to apply in the critical care setting. Beneficence is difficult when critical care technologies that support life also cause pain. Autonomy is difficult to uphold when patients are unresponsive, their prior wishes are unknown, and the pace of medical intervention and its associated technological determinism accelerates. Finally, the interests of patients and society (multi-faceted spaces in themselves) may clash over questions such as the continuation of life support in the face of a poor prognosis and limited bed space in the ICU. This paradox of principles exposes the shortcomings of a principlist approach to medical ethics in these environments.

### **Buying More Time**

Reflecting on the in-depth discussions of this concept within Chapter Four 'Death' (p.125), 'buying time' is a concept not located in those terms within the literature. Accordingly, this key concept warrants further consideration. It is apparent from those narratives regarding 'buying time' in particular, that a dying person may set a date, or identify a goal, and look forward to a significant event, with a slowing of deterioration during that time. This notion was later verified in the palliative medicine literature and referred to as 'psychoneuroimmunology' (Stevens 1997:706). More specifically, psychoneuroimmunology is referred to as the physiologic effects of wish-granting. One hypothesis to this theory is that the wish-granting experience may influence the patient's immune systems and possibly even favourably influence the course of the patient's disease (Stevens 1997).

Wish granting and 'buying time' have obvious similarities within this concept of managing terminal illness, and the dying process. It could be argued that in those examples provided by the participants from their varied practice that the two are one and the same. Regarding psychoneuroimmunology, it is obvious that evaluation of well-controlled and relevant studies will be required to establish this intriguing concept.

'Buying time' is certainly not limited to the continued provision of artificial nutritional support. The process of commencing or continuing aggressive nutritional support in the advent of end stage illness poses similar issues with other treatments, in particular, aggressive antibiotic therapy. It is well accepted in the palliative medicine literature (Morant and Senn 1997) that in clinical situations where antibiotics will result only in a prolongation of the dying process, there is rarely an indication for such therapy. Patients with Gram-negative septicaemia, if untreated, may succumb within hours to their disease (Sickles *et al* cited in Morant and Senn 1997), and aggressive combination antibiotic therapy in such situations is questionable. This approach of withdrawing and/or withholding treatment is 'ethically justified' (Morant and Senn 1997:382), as the result of such treatment is only to prolong patient suffering without truly enhancing quality-of-life. This is also referred to as disproportionately burdensome treatment. However, the notion of 'buying time' provides as exception to this withdraw/withhold approach. The examples provided in the narratives are proof of this.

Within the broader discussions of 'buying time' and such exceptions to the withdraw/withhold approach, some patients may wish to be alive for an approaching family event such as a wedding of a child, a birthday, or an arrival of a relative from abroad. 'Buying time' however, is not a guarantee of prolonged survival as, despite medical knowledge, it is often very difficult to know when a patient has entered the final phase of dying, and its duration and nature.

The monetary discourse associated with 'buying time' needs to be considered here. Whether its metaphorical usage was intended by the participants is uncertain, yet continued treatment in order to gain more time does, undoubtedly, costs money – and

lots of it. Ethics applied to health care cannot escape an involvement with economics, for the practice of medicine and the provision of health care costs money. The cost of health care, however it is provided, is rising in every country of the world. The provision of up-to-date health care facilities, medical equipment, powerful drugs, together with the appropriate salaries for health professionals, all contribute to that cost. The increase in the cost of the practice of palliative medicine may not be so great as in other disciplines, particularly in the acute health care sector. Yet the increased cost of other services in a global health service will decrease the resources available for palliative medicine, or more simply, end-of-life care. Paradoxically, 'buying time' may become increasingly difficult. The following quote provides a succinct explanation of such a paradox:

*It is common experience that increased resources do not result in decreased need and therefore decreased cost: The more health care is provided, the more is required and demanded, and the greater their anxiety about health, the less healthy people are (Wilkinson 1997:502).*

This paradox helps to explain the rising costs of health care and how they are both related to human attitudes and conduct which are the concern of ethics. Cost cutting, down sizing, and all economic rationalism activities must ultimately impact upon 'buying time' practices. This will surely be to the detriment of good death care, where the identification of reasonable goals and wish granting has much to do with the well-documented importance of hope (Speck 1997). 'Buying time' is an important concept revealed in this research. It lends itself to further exploration in other research projects as perhaps one of the least named phenomena in end-of-life care.

### **More Reflections on Money**

Leading on from the discussion on 'buying time' and the suggestions disseminating from the metaphorical associations of money, are those economically confronting suggestions of revenue generation which are discussed in detail in Chapter Five 'Money' (p. 145). The over-prescription of artificial nutritional support secondary to its easier availability does raise the possibility of the advantages of both revenue generation and cost containment. There are indeed numerous ways in which health care professionals could

reduce quantity of care without impairing quality. However, as with the previous suggestions of abusive feeding, proving such a practice would be very difficult. As the various narratives throughout chapter 'Money' teach us, there are many situations encompassing 'money' and artificial nutritional support, that is, whether money can be made or saved. In these complex situations, regardless of health care delivery service model or location, the developments of financial organisation of health care at large do not necessarily come equipped with their own ethical analysis. Just what this means for providers and consumers in medicine's new economics remains unclear. Yet while recognising that economics profoundly affects health care, it should be imperative that all providers can and should avoid compromising their patient's welfare in the name of generating revenue or even cutting costs. As Morreim (1995) reminds us, we can no longer speak of fidelity as a benign requirement that the health care provider refrain from exploitation of vulnerable patients in order to line his or her pocket with a little extra gold, or as a simplistic command – always to place the patient's interests above one's own. This predicament demands serious evaluation and further inquiry – both of which have not been attempted within the confines of this thesis.

### **More Food for Thought**

As frequently mentioned throughout this research, via the narratives of the participants and the extensive literature, the act of providing food and drink is a duty, one proper to human nature, and enjoyed by the strict commands of religion as discussed in Chapter Six 'Culture' (p.170). The assurance of an intake adequate for nourishment is therefore a proper part of medical care, or as Dunstan (1996) claims '...the professional refinement of a common human obligation'. Sometimes there is a clear physiological duty to provide it via enteral or parenteral modes, when the body cannot take nourishment as in intensive or terminal care. Yet the narratives compel us to question this as a duty by prompting us to consider whether such a duty is absolute, one to be discharged without exception or regard to circumstance or consequence? Rather, the duty to 'feed' is ill explored in the literature and not necessarily absolute. The assumption of feeding as an absolute duty drawn from the narratives leads on to those discussions regarding withholding and withdrawing treatment under the rubric of 'palliation' and not abandonment. Thus, to

withdraw nutrition is not to abandon the patient, or to 'leave him to die'. It is to attune the treatment, the management and the planning to suit the patient's condition - not purely from the clinical perspective (thereby honouring the technological imperative), but most importantly from the holistic perspective embracing one's own wishes and needs. The duty of care therefore continues - exercised in palliative medicine, including relief of discomfort, pain, distress, until the body systems fail and the patient dies. For some, this is merely an argument in justification for passive euthanasia, but as Dunstan (1996:255) explains, 'Palliative care is active, skilled. It does not kill the patient; it serves his or her interest in dying a peaceful natural death'. When we explore the narratives in this thesis they compel us to re-examine feeding, not only as a contested clinical and cultural commodity, but as something which reminds us to ask 'for whom do we provide this intervention?'

### **Inquiry into Possible Abuses**

The concept of treatment in such cases as being akin to abuse could possibly be paralleled with discussions on benefits versus burdens of aggressive therapies and their debilitating complications as mentioned in Chapter Three 'Principles' (p. 110). Yet in terms of questionable if not profoundly unethical financial gain, this situation is a 'stand alone' dilemma that demands further exploration and inquiry. How one goes about such inquiry is perplexing, and could possibly create another ethical dilemma in itself. Quite clearly, providing empirical proof of what have essentially been negative assumptions on behalf of the few participants who contributed to such discussion is outside of the research question. However, the issue is worthy of further research.

### **Dissatisfaction with the System**

Attention is also needed considering the suggestion that medicine, if not health care entirely, may not be a satisfying or fulfilling vocation in recent times. According to the participants this appears to be associated with the advent of managed care, and its associated pitfalls. The fact that managed care companies are able to dictate to

providers what care (adequate or otherwise) can or cannot be provided<sup>35</sup> was of major concern and irritation for those participants commenting on the subject. This is supported by a relatively recent comment made in *Australian Medicine* (August 2000), where it is reported from Chicago that in the USA, physicians frustrated with the managed care system are retiring early, which is testimony of one particular participant's plan to retire from medicine prematurely and embark on a career in virtual medical training software design. According to this survey (conducted by Merrit Hawkins, a Texas-based recruitment firm) 38% of doctors aged 50 or older plan to retire within one to three years. Another 16% said they planned to significantly reduce their practice or refuse new patients. The survey indicated dissatisfaction with managed care as the primary reason for quitting. Dissatisfaction was based on the inability to practice quality medicine. This is highlighted in the following example previously provided by a participant (Neurosurgeon USA). Regarding his patients undergoing laminectomy surgery, he explained that they could expect to suffer from footdrop or decubiti as a result of managed care companies not approving postoperative physical therapy:

*Unfortunately now it is common place for some of my patients to develop decubiti or footdrop – I mean, like it is accepted practice that following a complex laminectomy you get decubiti and, or footdrop. Now a couple of years ago that would be totally unacceptable, like bad practice. Now it is almost the norm...or a good example of 'adequate care' as opposed to 'optimal' (Neurosurgeon USA).*

This USA experience provides more than a cautionary tail for the Australian and UK situations. It helps us to recognise the power relations inherent in deciding not just what is quality but what constitutes 'ethical' in modern Western clinical settings.

### **The Problem of Research**

Does the need to assess all implications for practice drawn from this research require further extensive inquiry? The immediate answer is that there are great difficulties in conducting socio-medical ethics research in most environments. Surely there are some

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<sup>35</sup> As suggested by those participants commenting on their interactions with managed care companies regarding approval for treatments and reimbursement. See Chapter Five 'Money' (p. 155-156).

quantifiable aspects, yet much of the suggested inquiry drawn from this project deals with such intangibles as interprofessional relationships, doctor-patient-family-carer attitudes, family dislocation, and cultural variances. Moreover, the problem of making significant inquiry and comment on such matters are just as great in all health care systems as they are in any subset of system regardless of its geographical margins. Most significantly, the confronting aspects of 'death-talk' taboo, and the possible abuses as discussed earlier in this chapter. This does not mean that serious further inquiry is impossible, especially if it is directed at clearly identified issues. For example, the effectiveness of clinical ethics consultation services, or, the incidence of PEG insertion in end-stage patients. However, the collection of empirical data in these two examples alone poses some considerable difficulties regarding clinical rigor. In the case of clinical ethics consultation research in the critical care environment, only one study (North American) was located in a subsequent review of the literature. Schneiderman *et al* (2000) report that ethics consultations seem to be useful in resolving conflicts that may be inappropriately prolonging futile or unwanted treatments and are perceived to be beneficial. Slowther *et al* (2001) also remark that there has been little evaluation of clinical ethics support services either in the UK or in other countries with longer established services. This demonstrates not only a significant shortfall, but emphasises the need for further inquiry. The challenge here is to encourage such inquiry as credible research and not suggestive reportage.

### **Reflections on Method and Meaning**

Some aspects of the methodology employed in this research certainly require critical reflection. This study began in an attempt to contribute to an understanding of the ethical issues associated with the provision of artificial nutritional support from a multidisciplinary perspective. What eventuated, by way of participant offering, was a far broader contribution on the utilisation of the life-sustaining technologies at large, with an emphasis on artificial nutritional support. This was certainly an advantage as the method elicited useful information including those unexpected findings such as the linkage between critical and palliative care. A method of study was sought that would allow, as Greene (1988) put it, 'to break with the cotton wool, of habit, of mere routine, of

automation to seek alternative ways of being, to look for openings' (cited in Munhall 1994:247). This stemmed from a desire to employ other ways of knowing in order to gain insight into what was referred to in the literature as an 'ethical minefield' (Albert 1998:1). The wish to break away from the restrictions of traditional methods of inquiry led to a qualitative approach known as narrative ethics which allowed for the collection of personal stories with all the embellishment, richness and serendipity that these might encompass. The nature of this method is such that although commonalities can be asserted, there may be no such thing as a single meaning. There are instead, different vantage points, different stories, and different voices.

The choice of narrative ethics research was an intentional choice, and it is timely to now reflect on the limitations and strengths of this choice. The eight major thematic headings of Principles, Death, Money, Culture, Dilemmas, Futility, Technology, and Responsibility are used as the basis for this reflection. The identification of themes is, at best, only ever a simplification of the whole, and is therefore perhaps inadequate when being used solely to interpret the issue under study. In this respect the researcher has enjoyed a certain methodological freedom in that participants' stories have not been reduced to abstract generalisations in deriving themes. The participants remain alive in the text, as their narratives and personal moments are intertwined throughout the entire body of this research.

The various criticisms concerning data quality including the question of memory and truthful information have been accepted and acknowledged as potential shortfalls to qualitative research. Likewise, the recognition of researcher bias and accepting that despite all attempts to minimise such bias, it is understood that being totally detached from researcher bias is impossible. As Crotty reminds us, 'researchers cannot deny that they all come armed with prior knowledge, their own beliefs and judgement, preconceived ideas and theories, or personal and theoretical bias (1996:16).

Utilising CAQDAS also requires a retrospective critique. Despite criticisms that such applications can alienate researchers from their data, it was found that the application



(ATLAS/ti) only enhanced this relationship by way of effective retrieval of information. Handling of the massive textual data was therefore enhanced by way of convenience. The burden of interpretation however, still remained a daunting task for the researcher. Therefore ATLAS/ti was primarily employed as a data management system and consequently had no bearing on the actual conclusions of the research.

The participation of sharing and verifying narratives and the themes drawn for this research, was of particular significance to the participants in that they all spoke of how helpful it had been to be able to tell of their experiences. It was as if this type of conversational opportunity had not been previously available to them for various reasons. Perhaps the telling of their stories had provided a sense of validation of experience for the 32 professionals who participated in this study, if not certainly for the researcher. At the broadest level, it was found that participants had points of view they could articulate, that these points of view could be categorised, and were influenced by both life experiences, (personal and professional) and key people. The participants were also changed by both the process of the in-depth interview, in that they thought about their answers as they listened to themselves engage in dialogue through the interview relationship.

As this method employed purposive sampling of health care professionals, it is therefore a biased sample. Recipients of care were not part of this study. Thus, the findings reflect primarily the perceptions of providers and not of those on the receiving end of care. This raises an interesting methodological issue. At the onset of data collection it was the researcher's intention to include several recipients of artificial nutritional support. However, this plan was thwarted by the difficulties in locating actual survivors, as well as the need to address the sensitivities of long term EN/PN recipients with regard to difficult subject matter. It was therefore decided to fine-tune the sample to providers only. It could be argued that this shortchanges the research of valuable consumer information, however as this research is essentially multidisciplinary, its intention is to explore interprofessional perceptions. This does not discount the value of consumer perception. On the contrary, an exclusive exploration in to the perceptions of recipients of care

(including family and carers) would be prudent. As Swigart *et al* (1996) remind us, health care providers need to understand that the way they view the life-support situation may be different from the way their patients, and those who love them, view the situation. This multidisciplinary/interprofessional ethics research is needed and as such, qualitative clinical ethics research is to be encouraged. As the renowned bioethicists Peter Singer, Edmund Pellegrino and Mark Siegler explain, within empirical research (both in ethics and generally), there is growing recognition that quantitative methods alone are inadequate (2001). Qualitative multidisciplinary research also enriches our grasp of the moral complexities of different professional views, and this entire research project is a confirmation of that supposition.

Considering many of the phenomena examined by ethics researchers are deeply entwined into the fabric of professions, organisations and human lives, qualitative methods have begun to play an important role. Ongoing clinical ethics research of a qualitative nature however, faces the daunting challenge of being successfully recognised supported and funded. In the USA, most national funding agencies directly fund only a handful of operating grants and career awards for research into ethical issues. Similar funding schemes and opportunities for ethics research in the UK and Australia are much harder to identify. Therefore, the challenge remains for research into ethical issues as outlined in this project to be appropriately addressed by institutions and funding agencies around the world.

### **The Last Minute Literature and Stolen Thunder**

Keeping abreast of all developments within the areas of ethics and artificial nutritional support, and end-of-life care, necessitated an ongoing review of the literature which proved tedious at times. This was especially apparent towards the final stages of writing up the research findings, which in turn called for what has been termed a 'last minute' review of the related literature. This was achieved by way of various literature searches up until the end of 2001,<sup>36</sup> when it was decided that an appropriate consideration of the

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<sup>36</sup> These included specific subject searches in Medline, University Clinical School databases including Proquest Medical, and various internet resources such as [www.lastacts.org](http://www.lastacts.org); [www.medical-library.org](http://www.medical-library.org); [www.growthhouse.org](http://www.growthhouse.org); [www.onlineethics.org](http://www.onlineethics.org).

recent literature had been achieved. During such a review of the last minute literature, it was discovered that a number of articles had in fact preempted some of the findings of this research. In particular, a series on clinical ethics published in the *Medical Journal of Australia*. More specifically, those articles by Kerridge *et al* (2001 – August) and Kelly (2001 – November) all point to the same assertions made in the interpretation chapters regarding the employment of clinical ethics committees, and the role of end-of-life education for physicians respectively. Despite a feeling of having one's thunder stolen, it is also reassuring that the research findings are in line with the recent opinions of the experts, in Australia at least.

### **Relevance of Research**

The timeliness of this research is obvious considering the onset of much recent discussion regarding end-of-life issues such as ongoing development of palliative care services and the prominence of the euthanasia debate in the public domain. Reference needs to be made here about the deliberate avoidance of any discussion on euthanasia due to the enormity of the polemic it would surely evoke – one not be confined within the bounds of this thesis. However some mention is necessary as to why such a deliberate omission has been made in all discussions throughout this research. Most importantly, 'euthanasia' as a discussion point was never entered into by any of the 32 participants. It was as if the participants all shared the understanding that there is a significant gap between withholding and/or withdrawing treatment and directly killing. There is surely the danger, especially in the critical care setting, that decisions are made to withdraw or withhold treatment too early, or deliberately and wrongly aim to end a life by doing so. However that danger has always been present, and the tradition has expended much attention on where and how to draw the appropriate lines and proceed with the right intentions. Euthanasia utterly changes all that in that it is we, not nature, who kill, with medicine, according to Callahan (1994), becoming an institution that legitimates the taking as well as the saving of life. It is this stark contrast in understanding that explains the absence of the euthanasia debate in all discussions within this research.

The advent of institutional futility policies, the instigation of advance directives, the need for curriculum development in end-of-life education for health professionals, and the ever present 'death-talk taboo' all underpin the relevance of this research. The overall consensus that a monumental lack of communication between provider and recipient still exists surely warrants further research and inquiry into how this shortfall can be improved. The real challenge is ensuring that the results from any such research can actually be implemented into practice.

### **Conclusion**

In conclusion, end-of-life issues in both critical and palliative care offer a rich source of research challenges, and answers must be sought to a number of questions in order that we can improve the quality-of-life (and death), for patients in our care. It is also obvious that treatment decisions regarding the provision of artificial nutritional support, and the life-sustaining technologies collectively, will become increasingly complicated by financial concerns, and the possibilities of certain abuses. Both these areas deserve a certain vigilance by way of ongoing inquiry, systems review and audit. The mere suggestions of certain abuses and 'irresponsibilities' expose shortcomings in the practice of health care that in many ways 'opens up a can of worms'. It is via this very exposure, courtesy of the participants, that this research makes an original contribution to knowledge.

## **CHAPTER THIRTEEN**

### **CONCLUSIONS**

#### **Introduction**

In this thesis we have encountered the thoughts, points of view, experiences, and narratives of 32 professionals from varying health related disciplines in three different countries, and two markedly divergent different approaches to care delivery. These interviews occurred in light of an extensive review of the literature, which was followed by a detailed description of the methodology and its justification. The qualitative methodology revealed a total of eight major themes: Principles, Death, Money, Culture, Dilemmas, Futility, Technology, and Responsibility. These themes enable the management and exploration of the extensive text provided by interviews with the experts encountered in this research, leading to distinct discussion points. For example, we encountered the concept of 'buying time' in prolonging treatment for particular reasons; 'generating revenue' in fee for service medicine; 'food for thought' helping us to understand what should and should not constitute artificial nutritional support; and the 'medicalization of death' in acknowledging the importance of supportive palliation. The discussion points were explored and examined in light the relevant literature, and recognising the gaps in this literature. Accordingly a variety of implications for the practice of health care were drawn from the interpretation chapters. Finally, a reflective discussion followed in an attempt to identify some of the many and varied suggestions encountered within the research. In light of this, a critique of the limitations of the methodology employed occurred, as well as a discussion of the relevance of this research to mainstream health care practices. So, let us explore some of the key insights and conclusions.

#### **Artificial Nutritional Support or Death and Dying?**

In many respects the outcomes of this research departed from distinct discussions on the provision of artificial nutritional support and encompassed wider discussions on death, dying and death care. The research participants introduced us to the concepts of 'death-talk taboo', 'a good death', 'buying time' and 'palliative care in intensive care' – all of

which have been essential foci of this study. However, such an emphasis on death and dying as opposed to more discreet discussion regarding artificial nutritional support was derived from the highly publicised cases of withdrawal of tube feeding outlined in the literature review.<sup>37</sup> Recognising the expertise of the participants in this research, and the way in which they drew upon a variety of sources and clinical experience, much of this research has explored death, dying and the associated issues of ethical treatment decisions.

### **The Cycle Emerges**

At the centre of the participants' narratives was the importance of patient-focused care. Whether the setting be aggressive critical care, palliative care or a home hospice environment, in caring for dying people, everything starts with the patient – including every aspect of communication, symptom relief or treatment provision. There is no doubt that as multidisciplinary professionals we all want to do our best. Yet often the challenges to care arise because we do not know how (or are ill-equipped) to approach the problem. Nowhere is this truer than in communication. A professional who feels ill-equipped or is inept at communication will become part of the problem, instead of part of the solution. One of the biggest lessons derived from this research is that of the importance of addressing shortfalls in 'honest communication', and to do so effectively and sensitively. Across the disciplines it is evident that much improvement is needed in this area which in the past has been considered as being of lesser importance in medicine's scientific gaze and technical focus.

An integral part of optimising communication is found in demystifying death-talk, allowing for death-talk dialogue as part of the demedicalization of death-talk itself. If death is continually medicalized then the ultimate rite of passage will be replaced by a maze of medical ritual so that death, the natural end of life, will become the unnatural end of a succession of medical interventions. It does not have to be this way. As the discussions

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<sup>37</sup> Those celebrated cases involving Karen Quinlan, Nancy Beth Cruzan, Tony Bland and Paul Brophy as discussed in Chapter Two 'Reviewing the Literature' (p. 8-12).

on palliative care and critical care reveal, these two markedly different clinical orientations require a dramatic shift in attitudes and interventions if they are to deliver the best care for a variety of people. Whether in the ICU or elsewhere, hospitals and health care providers have an ethical obligation to provide settings that offer dignified, compassionate and skilled care. This includes death care. Knowing the limitations of medicine needs to coincide with an appreciation of professionals' abilities to change the focus of care, such as providing supportive rather than aggressive clinical care. The role of the health care provider therefore needs a closer analysis.

The role of the health care provider at the end of life was eloquently explained by eminent American surgeon and author Dr Sherwin B. Nuland at a presentation entitled *'Untying the Gordian Knot: A Medical and Ethical Analysis of Authority, Power and Responsibility with Regard to Nonbeneficial, Unreasonable and Futile Therapies'* in Fort Worth, Texas on October 5<sup>th</sup>, 1999<sup>38</sup> – just days after all the data for this research was collected and transcribed. Nuland suggests that the end of life is like the closing act of a play in which the person who is dying has the leading role – or at least that is how it should be. Often the treating physician will assume a major part in this closing act. Nuland offered this explanation:

*Often the treating physician will consider him or herself as a leading player in what is essentially the final act of a patient's life...like assuming they have a major role in a play when in fact they don't. It is not about them. It is about the patient. The patient has the starring role, not the doctor. You see this a lot in the ICU. It is time for the doctor, for the whole medical team to just stand back and let the leading actor(s) play out their final role (Nuland 1999).*

Yet standing back does not necessarily mean withdrawing from an active role. Health care professionals have a crucial role to play in creating optimal circumstances for the final role to occur. For example, in providing a supportive environment which is patient centred. This is far more than just standing back but helps to bring the patient's central

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<sup>38</sup> Sherwin B. Nuland M.D., Clinical Professor of Surgery, Yale School of Medicine, Fellow, Institute for Social and Policy Studies, Yale University. This lecture was a public convocation on health care ethics sponsored by Harris Methodist Fort Worth Biomedical Ethics Program.

role to the fore. Role clarification is therefore paramount in these situations. Nuland suggests that death should be given back to dying people and loved ones, just as birth was given back to women courtesy of the women's movement and midwifery. Nuland's description does suggest a reference to medical paternity explaining that doctors may think that they are actors in this drama '...but in many ways they are groundlings [sic]...who know nothing about death' (1999). In his description of this 'final act' scenario, the interpretation is offered in terms of determining treatments based on whose preferences, decisions, or wishes. Simply put, in end-of-life care, regardless of the setting, the patient's values, wants and needs should always carry more weight than those of the clinician. Death as an active process, therefore must not be permitted to be further disrupted by well-meant yet often misguided exercises in medical futility. Nuland further supports this view in his 1995 text *'How We Die'* by explaining that decisions about continuation of treatment are influenced by the enthusiasm of the doctors who propose them:

*Commonly, the most accomplished of the specialists are also the most convinced and unyielding believers in biomedicine's ability to overcome the challenge presented by a pathological process close to claiming its victim. A family grasps at a straw that comes in the form of a statistic; what is offered as objective clinical reality is often the subjectivity of a devout disciple of the philosophy that death is an implacable enemy. To such warriors, even a temporary victory justifies the laying waste of the fields in which a dying man has cultivated his life (1999:265).*

Questioning whether such desperate struggles should be undertaken is the very basis for the 'medical futility' debate, or just questioning whether suffering is worth the 'success'. As 'groundlings', providers would do well to practice the Golden Rule<sup>39</sup> and project themselves into the places of family and loved ones and re-examine their expectations of what may then appear to be desperate struggles and futile therapies.

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<sup>39</sup> 'The Golden Rule' is often referred to 'Do unto others as you would have done unto yourself'. Within Judeo Christian circles, a formulation may be 'love your neighbour as yourself' resting upon *agape* (selfless love).



Artificial nutritional support is a major component of conversations on medical futility. Despite it being caught up in the theoretical conversations on futility as one of a complex myriad of aggressive therapies, it carries with it a distinct socio-cultural confusion that lends itself to those difficult discussions of starvation, neglect, abuse and medical killing. A necessary component for honest communication between provider and recipient is clarifying what artificial nutritional support is, and what it is not. The informants also strongly suggested that the explanation of futile therapies demands the debunking of the death-talk taboo. This in turn necessitates the educational support of all those partaking in this dialogue. Consequently a cycle emerges. The cycle that is necessary to resolve the misunderstandings of treatment is the same cycle that will improve links between aggressive and supportive care. It is also the same cycle that supports truthful dialogue between all parties and raises their awareness of peoples' rights and responsibilities. It incorporates the imparting of knowledge and experience in thoughtful and sensitive ways, as well as defining those dubious areas which will always be contested spaces. The advantage of such a cycle – one that is underpinned by honest communication and education – is that people may move beyond a narrow medical gaze and appreciate and embrace the broader meanings and responsibilities of illness and treatment. Accordingly, the consideration of medical training is a vital outcome of this research.

The professions however are not totally responsible. Yet encouraging a public dialogue about end-of-life care, dying and death is easier said than done. Many of us find it difficult to talk about such things. In this world of seemingly limitless medical options, good decision-making requires open communication among those who are seriously ill, their families and loved ones, and their health care providers. Yet such a dialogue is not necessarily too complex. We can prepare by taking a step that will ensure our participation in our own health decisions by talking – today. We can talk about our own end-of-life decisions with our families, friends, or just contemplate these realities ourselves.

With the world's future doctors receiving their apprenticeship in a clinical setting, the challenge is therefore cast. Fischer (1992) warns that medical school textbooks must

address ethical problems in the context of health care decisions and not restrict themselves to pathophysiology and practical therapeutics alone. He argues that new areas of ethical evaluation have been raised by the desire of some individuals to pursue prolongation of their lives at high expense to society, such that other people are denied services because of limitation of available resources. This is to be compounded by the evidently inadequate emphasis placed on clinical ethics education as promulgated by this research.

If we are to prepare health care providers to address all the needs of people and to know how to work with the health care system that recognises chronicity, terminal and serious illness as core clinical responsibilities, then that teaching must occur at least in part in the clinical setting. From the standpoint of the medical student (if not the junior doctor/intern or resident) if palliation and advance care planning are not taught during clinical rotations in the hospital, then they are by omission flagged as not important areas of competence. Such a deficiency in training needs addressing.

Yet education is not solely to blame for such a shortfall. There are serious gaps in the delivery of good death care in both socialised and privatised health care delivery settings. In the USA for example, the Medicare Hospice Benefit requires patients to give up curative care and is limited to those with a prognosis of six months or less (Meier 2002). Therefore the 'system' as a whole needs careful and thoughtful reconsideration.

### **Geographical Considerations**

Legal consequence was a key issue for those participants from the USA. They spoke of a lack of discussion and planning that resulted in a reluctance to make decisions in a health care system, which is terrified of litigation, and uncertain of its obligation to the technological imperative. Health professionals practising in other countries should take heed of this supposed American phenomenon.

It is well accepted by both the literature and the various offerings contributed by the participants that the ethical issues surrounding the provision of artificial nutritional

support depend on whether this modality is considered as basic care (and therefore ethically obligatory) or medical care (and therefore required only in certain situations, depending on medical/therapeutic indications). This is not a new concept. However, this research demonstrates the complex variables that both influence and impact upon those decisions of who is to decide what is basic care and what constitutes medical care? These variables are further influenced and subsequently complicated by differences in health care disciplines, models of health care delivery, and to some extent, geographical or global demographics. Despite the international literary commentaries on this subject, there is by no means a global norm as to what is considered acceptable.

## **Conclusion**

From the onset of this research project an open mind was maintained regarding the expected findings and outcomes. Some of these were predictable, others surprising if not completely serendipitous. A narrative ethics approach to this research topic permitted the exposure of 'real' practice and perception, compared with the 'idealist' found in many ethics texts, especially the principlist approach as garnered from the associated literature. The limitations of this 'idealist' approach to the complexities of clinical ethics, such as found in the provision of artificial nutritional support, is well documented throughout this research. The need for reform is not just to be found in Chapters Eleven and Twelve ('Implications' and 'Reflections'). Aspects of the literature help to support the recognition of clinical ethics as a necessary discipline to be embraced by all health care providers. Clinical ethics is an evolving discipline worthy of substantial academic and clinical recognition. Such a gaze requires a critical appreciation of one's strengths and shortfalls. This can facilitate a recognition, and enactment of the cycle which governs the quality of care for the patient.

If the cycle of responsibility advocated by this research is practiced, this will help to bridge the gap between hospital and hospice, acute, critical and palliative care. The result of such a collaboration of care should lead to care that is responsive to what the participants explain that people want from their health care system. This is: relief of suffering; avoidance of burden on and closer relationships with loved ones; sense of

control; avoidance of death prolonging treatment; an increased range of care options; increased insurance coverage for the need of seriously ill persons at home including professional interdisciplinary team care, personal care, prescription medications, durable medical equipment, bereavement support, and greater continuity between care settings. Of course in these times of economic rationalism these aims may be difficult to achieve. However, these properties of health care as described by the participants in this research should be heeded as the goals of high quality care, professional responsibility and consequent service modification.

Ideally, as technology continues to advance and continually change the nature and focus of health care, we will continually need to assess, prepare and come to new terms with death and engage in such open discussion. As the late Reverend Charles Meyer declared:

*Now is the only time we have to discuss these issues; now is the only time we have to make our desires known, our wishes clear; now is the only time we have to plan for our dying, so that we might live, and live fully, from now until then (Meyer 1997:59).*

This thesis commenced in seeking to explore the ethical dimensions to the provision of artificial nutritional support. As part of this we necessarily encountered the demands and complexities of end-of-life care. The wisdom of the research participants has helped to make the case not only for changes which will lead to the good death that we all seek, but that excellence in palliation has much to offer medical care in general as it struggles to provide holistic care which is patient-centred. In conclusion we might still ask if all patients should be aggressively treated with artificial nutritional support? This question can reasonably be answered by claiming that all patients should be received, respected and heard. The ethics of artificial nutritional support, if not all life-sustaining treatments are not an ethics of act only, but also of relationships between doctors, patients, and ultimately society. Accordingly, we discover that the ethical provision of artificial nutritional support is not so much about technology *per se*, but about that which is at the heart of ethics, that is, relationships, and how we are treated in those relationships.

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APPENDIX 1

STATEMENT OF INFORMED CONSENT

Title of Project: Food For Thought: Ethics and Artificial Nutritional Support

Chief Investigators: Dr. Christopher Newell Senior Lecturer, University of Tasmania  
Ms. Sarah Breier Clinical Nurse Specialist, Royal Hobart Hospital

- 1. I have read and understand the 'Information Sheet' for this study
- 2. The nature and possible effects of the study have been explained to me.
- 3. I understand that the study involves the following procedures:  
*I will take part in an in-depth interview which will last approximately one hour. This will be by a second meeting to review the original interview transcript and discuss any issues that arise.*
- 4. I understand that there will be no physical discomfort associated with this research.
- 5. I understand that all research data will be treated as confidential.
- 6. Any questions that I have asked have been answered to my satisfaction.
- 7. I agree to participate in this investigation and understand that I may withdraw at any time without prejudice.
- 8. I agree that research data gathered for this investigation may be published provided that I cannot be identified as a subject.

Name of subject.....

Signature of subject.....Date.....

Statement by the Investigator:

I have explained this project and the implications in it to this volunteer and I believe that the consent is informed and that he/she understands the implications of participation.

Name of investigator.....

Signature of investigator.....Date.....

## APPENDIX 2

### INFORMATION SHEET

#### **TITLE OF INVESTIGATION**

**Food For Thought: Ethics and Artificial Nutritional Support**

#### **NAME OF CHIEF INVESTIGATOR**

Dr. Christopher Newell  
Ms. Sarah Breier

Senior Lecturer, University of Tasmania.  
Clinical Nurse Specialist, Royal Hobart Hospital.

Ph. 62267731  
Ph. 62228218

#### **PURPOSE OF THE STUDY**

**To explore the issues in the provision of artificial nutritional support from a multidisciplinary perspective.**

**This research project is being undertaken as part of the requirements for the degree of Doctor of Philosophy, School of Medicine, University of Tasmania, Australia.**

#### **CRITERIA FOR INCLUSION OR EXCLUSION**

Participants who are health professionals will be those professionals practicing within the areas of: Bioethics, surgery, medicine, palliative care, nursing, pharmacy, health service management, dietetics and law.

#### **STUDY PROCEDURES**

**You will be invited to participate in an in-depth interview of a semi-structured nature. This interview could possibly take up to one hour. During this interview you will be asked a series of questions around the subject of ethical provision of artificial nutritional support. This interview will be tape-recorded. After the interview, the researcher will organize to meet with you for a follow up interview to discuss findings from the first meeting, and to make sure that you agree with these. Your participation or otherwise will not have any impact upon any health care or treatment you receive. You are free to contact the researcher during this time if you have any concerns about the research.**

#### **PAYMENT TO PARTICIPANTS**

**Participants will not receive payment for taking part in this project.**

#### **POSSIBLE RISKS OR DISCOMFORTS**

There are no risks envisaged in taking part in this research.

**CONFIDENTIALITY**

Your participation in this research will remain strictly confidential at all times. The tape-recorded interviews will not include your real name or any other identifiable information. All interview transcripts and tape recordings will be stored in a locked storage compartment for seven years.

**FREEDOM TO REFUSE OR WITHDRAW**

Your participation in this research is entirely voluntary, and you may withdraw from this research at any time without prejudice.

**CONCERNS OR COMPLAINTS**

If you have any concerns or complaints about the manner in which this research is being conducted, you may contact the Chair or Executive Officer of the University Ethics Committee:

|                   |                      |               |
|-------------------|----------------------|---------------|
| Chair             | Dr Margaret Otlowski | (03) 62267569 |
| Executive Officer | Ms Chris Hooper      | (03) 62262763 |

**STATEMENT REGARDING APPROVAL**

This project has received ethical approval from the University Ethics Committee.

**RESULTS OF INVESTIGATION**

You will be informed of the overall results of the research at the end of the study.

### APPENDIX 3

#### The University of Texas Southwestern Medical Center at Dallas Institutional Review Board<sup>40</sup>

#### IRB Form NR1: Application for Review of New Research Involving Human Subjects

(Revised April 1999)

Title of Research<sup>41</sup>

**Food for Thought: Ethics and Artificial Nutritional Support**

Sponsor<sup>42</sup>

**University of Tasmania, School of Medicine, Australia - (Tasmania Research  
Scholarship)  
Beth Mancini, MSN, RN, Senior Vice President**

#### Assurances of the Principal Investigator and Sub-investigators

- To safeguard human subjects involved in this research, I agree to use procedures that conform to the policies of the University of Texas Southwestern Medical Center at Dallas and the regulations of the Department of Health and Human Services and the Food and Drug Administration.
- Unless it is necessary to eliminate apparent immediate hazard to a human subject, I shall seek prior approval from the Institutional Review Board (IRB) for substantive changes in the investigative procedures involving human subjects that may be called for during the research covered by this application.
- I shall agree to follow the advice of the IRB.
- I agree to report immediately to the IRB any unanticipated, life-threatening, or fatal complications with respect to human subjects.
- My signature certifies that I assure compliance with the ethical principles and institutional policies regarding the protection of human subjects in research as stated in Title 45 Code of Federal Regulations Part 46 (revised June 18, 1991; reprinted April 2, 1996) and the Multiple Project Assurance.<sup>43</sup>

#### Assurances of Department and Collaborating Chairmen

<sup>40</sup>The IRB reviews all research involving human subjects for Children's Medical Center of Dallas, Parkland Health & Hospital System, Texas Scottish Rite Hospital for Children, the University of Texas Southwestern Medical Center at Dallas, and Zale Lipshy University Hospital. The Board also reviews all research conducted at the Presbyterian Hospital of Dallas and the Veteran's Affairs Medical Center of Dallas for which a member of the faculty at UT Southwestern serves as principal investigator.

<sup>41</sup>Title printed on the cover of the protocol, including the sponsor's protocol number, version, and date

<sup>42</sup>Complete name of the organization(s) funding the research

<sup>43</sup>Available as an electronic file at S:\PUB\FORMS\IRBFORMS.

I understand that responsibility for assessing the quality of research must be shared by both the department and the IRB.

My signature certifies that I assure compliance with the ethical principles and institutional policies regarding the protection of human subjects in research as stated in Title 45 Code of Federal Regulations Part 46 (revised June 18, 1991; reprinted April 2, 1996) and the Multiple Project Assurance, and that I have reviewed the proposed research for the proper use of human subjects.

This review encompassed experimental design, scientific merit, and accuracy of the proposed research.

Date of Application                      August 19, 1999

**Investigators' and Chairmen's Signatures**

| Name (printed)                            | Dept         | Degree              | Rank                        | Phone            | Mail                                   | E-mail                        | Signa |
|---|--------------|---------------------|-----------------------------|------------------|--|-------------------------------|-------|
| Principal Investigator (PI) <sup>44</sup> | Sarah Breier | RN, BN, MN, PhD (c) | Visiting Doctoral Candidate | 817-451-8360 (h) | C/- 5501 W.Mayfield Arlington TX 76016 | <u>Breiersj@aol.com</u>       |       |
| (Faculty Sponsor) <sup>45</sup>           | Beth Mancini | MSN, RN.            | Senior Vice President       | 214-590-8001     |  | <u>Bmanci@parknet.pmh.org</u> |       |

**PROBLEM UNDER INVESTIGATION**

- (1) Medical condition or scientific problem to be studied:
- Ethical perspectives of the provision of artificial nutritional support. A qualitative study.

**SUBJECTS**

- (2) Specify all classes of subjects included in the research:

| Healthy Volunteers | Patients          | Vulnerable Subjects  | Other                        |
|--------------------|-------------------|----------------------|------------------------------|
| Medical students   | Outpatients       | Pregnant women       | Other class: (explain below) |
| X Center employees | Inpatients        | Cognitively impaired |                              |
| Minors (< 18 yrs)  | Minors (< 18 yrs) | Comatose             |                              |
| Men                | Men               | Traumatized          |                              |
| Women              | Women             | Terminally ill       |                              |
| Proband            | Proband           | Fetus (viable)       |                              |

<sup>44</sup>Investigator responsible for the global aspects of the research. The IRB acknowledges one PI for a study.

<sup>45</sup>If the PI is not a member of the University faculty, a faculty member is required to serve as "faculty sponsor" of the research. Leave blank if the PI is a member of the University faculty.

|     | Proband's family   | Proband's family  | Fetus (non-viable)  |
|-----|--|---|---|
| 3)  | Are all racial/ethnic groups included?   | <div><div>x</div><div>yes</div></div> <div><div></div><div>no (explain in project summary)</div></div>                          |   |
| 4)  | Will people unable to read English be enrolled?  | <div><div></div><div>yes (answer 4A-C)</div></div> <div><div>X</div><div>no (explain in project summary; omit 4A-C)</div></div> |   |
|     | (A) Specify other language(s):   |   |   |
|     | (B) Will a translator be available throughout the process of obtaining informed consent? | <div><div></div><div>yes</div></div> <div><div></div><div>no (explain in project summary)</div></div>                           |   |
|     | (C) Will a translated consent form document be available to subjects?                    | <div><div></div><div>yes</div></div> <div><div></div><div>no</div></div>  |   |
| (5) | Age range (indicate whether months or years)   |   | Center employees above 21 years of age  |
| (6) | Estimated number of experimental subjects to be enrolled locally:                        |   | Approximately 8 - 12 participants employed within the Parkland Health & Hospital System |
| (7) | Estimated number of control subjects to be enrolled locally (if applicable):             |   | N/A   |
| (8) | Expected time to completion of enrollment:   |   | Two weeks from onset of recruitment   |

PROCEDURES

|      |   |   |
|------|---|---|
| (9)  | Duration of each subject's participation: <sup>46</sup> | Approximately 30 minutes  |
| (10) | Will a placebo be used?                                 | <div><div></div><div>yes</div></div> <div><div>x</div><div>no</div></div> |
| (11) | Will subjects be randomized?                            | <div><div></div><div>yes</div></div> <div><div>x</div><div>no</div></div> |

DISCONTINUATION OF STUDY PROCEDURES

<sup>46</sup>Duration of participation encompasses the period of any treatment or other study procedures plus follow-up (the total period during which study data are collected).

12) Specify all conditions for removal from study:

|   |  |
|---|--|
| <input type="checkbox"/> Medical condition unchanged    | <input type="checkbox"/> Investigator's decision                       |
| <input type="checkbox"/> Medical condition worse        | <input type="checkbox"/> Subject's failure to follow study procedures  |
| <input type="checkbox"/> Complications intolerable      | <input checked="" type="checkbox"/> Completion of all study activities |
| <input type="checkbox"/> Subject's voluntary withdrawal | <input type="checkbox"/> Closure of the study by the sponsor/FDA       |

BENEFITS

(13) For subjects? ☒ yes  
☐ no

(14) For others? ☒ yes  
☐ no (explain in project summary)

RISKS

"*Minimal risk* means that the probability and magnitude of harm or discomfort anticipated in the research are not greater in and of themselves than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests" (45 CFR 46).

(15) Code each type of risk to subjects:

- 0 = no / minimal risk
- 1 = more than minimal risk

physical harm      0      psychological harm      0      social harm      0      economic harm

(16) Are subjects exposed to radiation? ☐ yes (Radiation Safety Committee approval required)  
☒ no (omit A and B)

- (A) Purposes:
- ☐ Diagnostic: usual number of studies (standard care)
  - ☐ Diagnostic: extra standard studies done solely for research purposes
  - ☐ Diagnostic: studies unapproved by the FDA / not standard practice
  - ☐ Therapeutic: standard treatments with radiation
  - ☐ Therapeutic: unapproved radiation treatments



(B) Source:

X-rays

Isotopes

Pharmaceuticals

INCENTIVE

- (17) Will subjects be paid an incentive?
- yes (answer A)

x

no (skip A)
- (A) Is the incentive pro-rated if a subject withdraws early?
- yes (explain procedures below)

no

COSTS TO SUBJECTS

- (18) Will subjects be responsible for any of the costs related to the research?
- yes (explain below; specify amount)

no (responsible only for costs of standard care)

x

no (sponsor/investigator pays for all research costs)
- RECRUITMENT
- (19) Specify procedures for recruiting subjects:
- Investigators' patients

Other patients

Bulletin boards

Public media<sup>47</sup>

Letters to community organizations

Letters to physicians in the Metroplex

Proband

Proband's physician

Physicians of proband's family

x

Other (specify below)
- RESEARCH PERSONNEL
- (20) Will investigators diagnose and treat subjects?<sup>48</sup>

yes

x

no (patient's private or referring physician)
- <sup>47</sup>Approval of both the IRB and the Office of News and Publications required
- <sup>48</sup>Leave blank if research does not involve therapeutic intervention.

- 21)

List all other personnel permitted to obtain informed consent:<sup>49</sup>

N/A
- 22)

Is there a conflict of interest between any investigator and the sponsor?

yes (explain below)<sup>50</sup>

x

no (none / unfunded research therefore inapplicable)

(23) PERFORMANCE SITES

Specify the sites where (1) study procedures will be conducted, (2) patients will be seen, and (3) resources (equipment, supplies, personnel, etc.) will be utilized. Indicate whether Form NR2 has been sent to the appropriate authority at the performance site.

| Performance Site                          | Recruitment | Resources                         | Form NR2 sent |
|---|-------------|-----------------------------------|---------------|
| Aston Ambulatory Care Center              |             |                                   |               |
| Children's Medical Center of Dallas       |             |                                   |               |
| Dallas County Mental Health               |             |                                   |               |
| General Clinical Research Center          |             |                                   |               |
| Parkland Health & Hospital System         | x           | Investigator's own resources only |               |
| Presbyterian Hospital of Dallas           |             |                                   |               |
| Sprague Clinical Sciences Center          |             |                                   |               |
| St. Paul Medical Center                   |             |                                   |               |
| Texas Scottish Rite Hospital for Children |             |                                   |               |
| Veteran's Affairs Medical Center          |             |                                   |               |
| Zale Lipshy University Hospital           |             |                                   |               |
| Other (specify below)                     |             |                                   |               |

- (24)

Other approvals needed:

Environmental Health & Safety Committee

Radiation Safety Committee

IRB at the Veteran's Affairs Medical Center

IRB at St. Paul Medical Center

IRB at Presbyterian Hospital of Dallas

<sup>49</sup>Names of personnel authorized to obtain informed consent who are not listed on page 2 of this form.

<sup>50</sup>Notification of the Office of Conflict of Interest required

- ☐ Grants Management (UT Southwestern)
- ☐ General Clinical Research Center
- ☐ Other (specify below)

25) Have all approvals been requested? ☒ yes  
☐ no (explain below)

COMMENTS:

(4) Will people unable to read English be enrolled? - NO

*Researcher only speaks English*

(19) Recruitment of Participants:

*Various health care professionals from the disciplines of surgery, medicine, nursing, pharmacy and dietetics will approached to participate in this research. After explaining the nature of the research and obtaining verbal consent, participants will take part in a semi-structured in-depth interview lasting approximately 30 minutes at a mutually convenient location.*

## APPENDIX 4

### Texas Directive to Physicians and Family or Surrogates

This is an important legal document known as an Advance Directive. It is designed to help you communicate your wishes about medical treatment at some time in the future when you are unable to make your wishes known because of illness or injury. These wishes are usually based on personal values. In particular, you may want to consider what burdens or hardships of treatment you would be willing to accept for a particular amount of benefit obtained if you were seriously ill.

You are encouraged to discuss your values and wishes with your family or chosen spokesperson, as well as your physician. Your physician, other health care provider, or medical institution may provide you with various resources to assist you in completing your advance directive. Brief definitions are listed below and may aid you in your discussions and advance planning. Initial the treatment choices that best reflect your personal preferences. Provide a copy of your directive to your physician, usual hospital, and family or spokesperson. Consider a periodic review of the document. By periodic review, you can best assure that the directive reflects your preferences.

In addition to this advance directive, Texas law provides for two other types of directives that can be important during a serious illness. These are the Medical Power of Attorney and the Out-of-Hospital Do-Not-Resuscitate Order. You may wish to discuss these with your physician, family, hospital representative, or other advisers. You may also wish to complete a directive related to the donation of organs and tissues.

### Directive

I \_\_\_\_\_, recognize that the best health care is based upon a partnership of trust and communication with my physician. My physician and I will make health care decisions together as long as I am of sound mind and able to make my wishes known. If there comes a time that I am unable to make medical decisions about myself because of illness or injury, I direct that the following treatment preferences be honored:

If, in the judgement of my physician, I am suffering with a terminal condition from which I am expected to die within six months, even with available life-sustaining treatment provided in accordance with prevailing standards of medical care:

I request that all treatments other than those needed to keep me comfortable be discontinued or withheld and my physician allow me to die as gently as possible; OR I request that I be kept alive in this terminal condition using available life-sustaining treatment.

**(This selection does not apply to Hospice care.)**

If, in the judgement of my physician, I am suffering with an irreversible condition so that I cannot care for myself or make decisions for myself and am expected to die without life-sustaining treatment provided in accordance with prevailing standards of medical care:

I request that all treatments other than those needed to keep me comfortable be discontinued or withheld and my physician allow me to die as gently as possible; OR

I request that I be kept alive in this irreversible condition using available life-sustaining treatment. **(This selection does not apply to Hospice care.)**

**Additional Requests:** (After discussion with your physician, you may wish to consider listing particular treatments in this space that you do or do not want in specific circumstances, such as artificial nutrition and fluids, intravenous antibiotics, etc. Be sure to state whether you do or do not want the particular treatment.) After signing this directive, if my representative or I elect hospice care, I understand and agree that only those treatments needed to keep me comfortable would be provided and I would not be given available life-sustaining treatments. If I do **not** have a Medical Power of Attorney, and I am unable to make my wishes known, I designate the following person(s) to make treatment decisions with my physician compatible with my personal values:

- 1.
- 2.

**(If a Medical Power of Attorney has been executed, then an agent already has been named and you should not list additional names in this document.)**

If the above persons are not available, or if I have not designated a spokesperson, I understand that a spokesperson will be chosen for me, following standards specified in the laws of Texas. If, in the judgement of my physician, my death is imminent within minutes to hours, even with the use of all available medical treatment provided within the prevailing standard of care, I acknowledge that all treatments may be withheld or removed except those needed to maintain my comfort. I understand that under Texas law this directive has no effect if I have been diagnosed as pregnant. This directive will remain in effect until I revoke it. No other person may do so.

Signed Date \_\_\_\_\_  
City, County and State of Residence \_\_\_\_\_

*Two witnesses must sign in the spaces below.*

Two competent adult witnesses must sign below, acknowledging the signature of the declarant. The witness designated as **Witness (1)** may not be a person designated to make a treatment decision for the patient and may not be related to the declarant by blood or marriage. This witness may not be entitled to any part of the estate and may not have a claim against the estate of the patient. This witness may not be the attending physician or an employee of the attending physician. If this witness is an employee of a health care facility in which the patient is being cared for, this witness may not be involved in providing direct patient care to the patient. This witness may not be an officer, director, partner, or business office employee of a health care facility in which the patient is being cared for or of any parent organization of the health care facility.

Witness (1) \_\_\_\_\_ Witness (2) \_\_\_\_\_

**Definitions:**

**"Artificial nutrition and hydration"** means the provision of nutrients or fluids by a tube inserted in a vein, under the skin in the subcutaneous tissues, or in the stomach (gastrointestinal tract).

**"Irreversible condition"** means a condition, injury, or illness:

- a. that may be treated, but is never cured;
- b. that leaves a person unable to care for or make decisions for the person's own self; and

c. that, without life-sustaining treatment provided in accordance with the prevailing standard of medical care is fatal.

**Explanation:** Many serious illnesses such as cancer, failure of major organs (kidney, heart, liver, or lung), and serious brain disease such as Alzheimer's dementia may be considered irreversible early on. There is no cure, but the patient may be kept alive for prolonged periods of time if the patient receives life-sustaining treatments. Late in the course of the same illness, the disease may be considered terminal when, even with treatment, the patient is expected to die. You may wish to consider which burdens of treatment you would be willing to accept in an effort to achieve a particular outcome. This is a very personal decision that you may wish to discuss with your physician, family, or other important persons in your life.

**"Life-sustaining treatment"** means treatment that, based on reasonable medical judgement, sustains the life of a patient and without which the patient will die. The term includes both life-sustaining medications and artificial life support such as mechanical breathing machines, kidney dialysis treatment, and artificial hydration and nutrition. The term does not include the administration of pain management medication, the performance of a medical procedure necessary to provide comfort care, or any other medical care provided to alleviate a patient's pain.

**"Terminal condition"** means an incurable condition caused by injury, disease, or illness that according to reasonable medical judgement will produce death within six months, even with available life-sustaining treatment provided in accordance with the prevailing standard of medical care.

**Explanation:** Many serious illnesses may be considered irreversible early in the course of the illness, but they may not be considered terminal until the disease is fairly advanced. In thinking about terminal illness and its treatment, you again may wish to consider the relative benefits and burdens of treatment and discuss your wishes with your physician, family, or other important persons in your life.