

New Zealanders making advance directives:  
A discourse analysis

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## **Attestation of Authorship**

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

Signed: .....

Date: .....

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## **Abstract**

Advance directives (ADs) convey consumers' wishes about accepting or refusing future treatment if they become incompetent. The issue of making a particular AD, more commonly referred to as a living will, is the focus of this thesis. The typical direction of the living will is that life-sustaining activities such as the provision of mechanical ventilation should be withheld so that a person may die what is hoped to be a 'peaceful death'. Clearly the whole basis of the thinking behind the recognition of ADs is that patients' wishes should prevail. ADs have been championed by some as a means of preserving both dignity and autonomy at the end of life in the face of increasing medical advances in technology to preserve life indefinitely. ADs are seen as a means of promoting peace of mind in will-makers, of allowing carers and family to honour the person's wishes and of stimulating communication between all involved parties.

While at present there is no statutory right for people in New Zealand to make ADs, it is considered they have rights to do so in common law as consumers of health and disability services in this country. Little is known about the views of New Zealanders making ADs or their justification for doing so. This small qualitative study, using a discourse analysis approach after Potter and Wetherell (1987), aimed to investigate how the participants justified making ADs. Six people were interviewed and the transcriptions were analysed identifying three dominant interpretative repertoires and three corresponding subject positions.

The findings indicated that the participants positioned themselves: as independent self-determining individuals who knew when they were ready to make ADs after witnessing undesirable deaths of close family members; as judges of knowing when inappropriate treatments lead to undignified deaths; and as concerned

parents who want to relieve their families of uncertainty in the future when making surrogate end-of-life decisions for them. Witnessing a prolonged family member's death in the past was a contributing factor to the participants making ADs. The participants' recall of these events led them to make their wishes known in advance so that their families, in turn, would not have to go through a similar experience at the terminal stages of their lives. The overarching motivations for formalising ADs was to avoid having life artificially prolonged by receiving life-sustaining treatments as well as the desire to die a dignified death.

This study highlights the need for healthcare professionals to value the importance of advance planning with well adults before they lose the capacity to give informed choices at the end of life. The taking of a values history as part of this advance planning may inform family and healthcare professionals about peoples' general values and at the same time confirm and record end-of-life choices for future reference.

## Transcription Notation

The following transcription notation has been used in the Extracts.

- ( ) Empty parentheses indicate talk too obscure to transcribe.
- hhh The letters hhh have been used to indicate laughter. Extended laughter will include an 's' after hhhs.
- [ Left-side brackets indicate where overlapping talk begins.
- ] Right-side brackets indicate where overlapping talk ends, or marks alignments within a continuing stream of overlapping talk.
- (( )) A word in double parentheses indicates the transcriber's comments.
- (.) A dot in a parenthesis indicates a pause of less than three seconds.
- (3) A number in a parenthesis indicates a pause of so many seconds.
- Underlining of a word indicates emphasis.

## Key Terminology

The Code of Health and Disability Services Consumers' Rights (**the Code**) became law on 1 July 1996. It is in the schedule to a regulation made under the Health and Disability Commissioner Act 1994.

The **common law** is the basis of the New Zealand legal system and is used to differentiate Judge-made law from statutory law, and differentiate common law from equity. Many statutes are codifications of the common law.

Patients and clients of health and disability services under New Zealand legislation are referred to as **consumers**.

Advance directives are sometimes referred to as **advance statements** (sometimes called living wills) in the UK.

One element in the broad concept of autonomy is that concerned specifically with the ability to make decisions. This element is often referred to as **competence** or **capacity**.

An enduring power of attorney (**EPN**) in New Zealand has equivalent power to a **proxy decision maker** or a **surrogate decision maker** in the UK and the USA.

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## **Chapter 1: Introduction**

Is it possible to die well? To even plan what Henry James on his deathbed called “the distinguished thing”? Welch, 2004

### ***Introduction***

Capron (1998) defines the concept of an advance directive (AD) as “a statement made in advance of an illness about the type and extent of treatment one would want, on the assumption that one may be incapable of participating in decision making about treatment when the need arises” (p. 261). Underlying this definition is the opinion that an AD exists in an attempt to ensure that one’s autonomy and right to consent to medical treatment are respected in the event of incapacity. However, this general definition masks another kind of directive that is the interest of this study.

The aim of this study was to research an instructional advance directive known more commonly as a living will. A living will is a written declaration that consists of two parts: firstly, it is made in advance when people anticipate that they may become incapable of making decisions for themselves at the end of life, and secondly, the living will contains information about the treatments and procedures that people would like to accept or reject at the end of life. A living will is more commonly made to indicate whether a person would want certain treatments withheld or withdrawn if these treatments are prolonging the dying process or if there is no hope of recovery. The overall purpose of the living will is to let the doctor know the person’s wishes concerning certain medical procedures at the end of life.

Capron (1998) claims that a living will should be written so as to convey the person’s values history, a general orientation that would connect issues arising in the dying process with the way the person has lived his or her whole life.

For the purpose of clarity throughout this thesis I will now refer to the living will as an advance directive or AD. The term AD includes all statements made in advance about future treatment options as well as withdrawing life-sustaining measures in New Zealand (Johnson, 2004).

The power to make an AD is conferred in Right 7(5) of the Code of Health and Disability Services Consumers' Rights (1996) (Health and Disability Commissioner, 1996); referred more commonly in the literature as the Code. Right 7 (5) gives the right to consumers to use an AD in accordance with common law; it also gives the right to consumers to withdraw consent to services; and is in recognition of the New Zealand Bill of Rights Act 1990 (s11). The Act claims that everyone has the right to refuse to undergo any medical treatment. These two Rights enable consumers of health and disability services to make an AD for the purpose of declaring in advance the treatments and procedures that they would accept or reject in preparation for a future loss of capacity to participate in decision making. Therefore, the overall goal of the AD is to preserve patient autonomy.

The purpose of the AD is not to simplify end-of-life decisions for doctors or families, nor is it used as a way to reduce end-of-life healthcare costs. It is instead to protect patient autonomy. It is important that end-of-life care planning is ongoing and that the AD is adjusted to reflect the changing health needs of the patient. Ikonomidis and Singer (1999) contend, "the justification for advance directives is grounded in the notion that they extend patient autonomy into future states of incompetency through patient participation in decision making about end-of-life care" (p. 522).

In New Zealand, compared to the rest of the Western world and especially the USA, the particular scope of ADs – including the character and range of advance statements in relation to the end of life – appears new. Over the past decade there has

been a plethora of literature on ADs arising from the USA. I was, however, unsuccessful finding published research from studies involving New Zealand citizens making ADs. One possible explanation for this difference is that ADs have made their way into the statute books in the USA whereas this is not the situation in New Zealand. At present, there is no statutory right for a person to make an AD in New Zealand however, as already stated, the Code gives people the right to use an AD in accordance with common law in New Zealand.

In summary, an advance directive is a way of making a person's wishes about future healthcare known to others, and to have that directive considered in decision making about his or her healthcare and treatment when they are unable to make those choices themselves. Any unreasonable interference with the consumer's valid advance refusal of treatment will be a breach of the Code.

### ***Assumptions***

I had an assumption that in the interest of preserving and actualising their need to be self-determining and autonomous, people in New Zealand made ADs when they anticipated losing their capacity to make decisions at the end of life so that an extension of this need would be respected. I also assumed that people made ADs so that family members or others significant to them would know what their end-of-life wishes were and therefore act as their surrogates or enduring powers of attorney to ensure that those wishes would be carried out as stated in the ADs.

Lastly, I assumed that the term AD, specifically related to directives about end-of-life wishes, would be more commonly understood since it was clearly addressed in the Code of Health and Disability Consumers Services (1996). However, it was not until I had asked people what their thoughts were about the topic that I realised that I

needed to use the term living will if I was to capture people's attention to my research interest.

### *Aims of the Study*

My aim was to investigate how New Zealanders justified making ADs. I wanted to examine the construction of identities New Zealanders used to justify making ADs. By focusing on these identities, or subject positions, I aimed to identify the patterns of language people used to construct their justifications thereby exposing the different ways in which the participants' arguments, or interpretative repertoires, are phrased and/or the kind of logic they were using to justify their positions. The purpose of this last intention is also to uncover the larger patterning of thought that surrounds ADs emerging from the discursive practices within New Zealand society (Potter & Wetherell, 1987). Potter and Wetherell's approach recognises a version of discursive psychology that insists upon seeing all sequences of talk as embedded within some kind of historical and social context (Wetherell, 1998).

The use of language and the particular rules of formation 'to tell it the way it is', are found in the construction of multiple and often contradictory and argumentative versions of truths. In order to investigate the justifications of New Zealanders making ADs I needed to be mindful of language use and the rules of formation to seek out the dominant interpretative repertoires. Wetherell (1998) comments that, "an adequate analysis would trace through the argumentative threads displayed in participants' orientations and would interrogate the content or the nature of members' methods for sense-making in more depth" (p. 404).

## ***The Research Focus***

Discourse analysis is an approach to studying both patterns of meaning and modes of communication. By using this approach it is possible to gain insights into the perspectives of the research participants, by interpreting their use of language and their means of expressing themselves. As an approach to understanding how people justify making ADs in New Zealand, discourse analysis after Potter and Wetherell (1987) can guide this inquiry by encouraging the researcher to focus not only on the overt meanings conveyed by the participants, but also what is covert, implicit and taken –for granted in their modes of participation and interpretation. Potter and Wetherell refute that there is a recipe for analysing discourse and instead claim that it is more of a theoretical perspective than a method.

On the basis that textual interpretation often brings out a hidden meaning that may have a basis in the structure of society, Potter and Wetherell's approach interprets meanings in the light of social and cultural mores and influences to acknowledge the covert as well as the overt meaning-making of the participants' responses. This approach claims that people struggle to develop versions of their reality in the light of cultural narratives. However, when people are making sense of their reality, they are primarily informing others about the collective interpretative resources of their social setting and culture (Wetherell, 2003). Additionally, Edley (1997) clarifies the Potter and Wetherell use of interpretative repertoires by stating that, "Interpretative repertoires are part and parcel of any community's common sense, providing a basis for shared social understanding" (p. 198).

In conclusion, Potter and Wetherell's approach to discourse analysis clearly supports the aims of my study. I wanted to look for regularities in the way the participants justified making ADs; identifying these regularities or dominant repertoires

was, at the same time, identifying the subject positions the participants used to justify their reasons for making ADs. Such a quest required me to also analyse how the participants used the collective interpretative resources of their social world. The findings from the data analysis would possibly offer me insights into the participants' reasons for making ADs in a country where it appears that ADs are not commonly understood or used to make end-of-life choices.

### ***Personal Experience***

I was very familiar with the general concept of a living will. For the past decade, I had lectured in ethics in healthcare in the UK and one of my interests was the nurse's role and the ethical relationship when caring for a patient in a persistent vegetative state (PVS). In the UK at that time there existed many opinions and published comments about PVS and nursing care of these patients. One ethical question raised with PVS was whether the patient had written an AD or communicated his or her end-of-life wishes to those who were close to him or her. Consequently, some of the ethical dilemmas arose around issues of the validity of the AD, for example: whether the patient intended those wishes to apply to the current situation; whether the doctor was obliged to follow the directions in the AD; and whether the family would comply with and honour their family member's end-of-life wishes? Not surprisingly, the topic was contentious, as most ADs referred to withdrawing life support from mechanical ventilation or removing feeding tubes that sustain life when death was considered inevitable and the patient had previously indicated that he/she did not wish to have life prolonged indefinitely thus denying him/her any quality of life. The safeguarding of the patient's autonomy was paramount in the decision-making process as well as being guided by what was in the best interest of the patient.

When I returned to New Zealand a friend contacted me knowing of my interest in the ethical issues surrounding dying patients. She told me of her brother-in-law's death. The brother-in-law had signed an AD about his future intentions of care in the event that he would become incompetent to make his choices known at the time of his dying. The family notified the health professionals of the existence of the AD and that it was a current document held with the family lawyer, however the family felt that this was not acknowledged nor did the attending doctor request any authentication. It was not until the family's lawyer directly approached the doctor in the hospital setting that the document was considered as part of the end-of-life decision-making process. The family felt that it was important that the AD had been legally documented but were anxious that until the lawyer had presented himself personally, the AD wishes were not going to be valued by the doctor. Overall, there was lack of communication between the doctor, the nurses, and the family and without this document the family believed that they would have been powerless to ensure that their member's wishes were respected.

My friend's advice was that I ought to consider visiting my family lawyer and appoint an enduring power of attorney (EPA), as well as make my wishes known in an AD. Consequently, my immediate family members have completed both documents, and we are recorded as organ donors. The last decision was not difficult as we would wish to be able to donate our healthy organs in the event of brain death being diagnosed and confirmed. Having been through the process, I was curious to know how other New Zealanders justified making ADs when it appears that this is not commonly understood nor widely enacted despite being stated as a Right in the Code. I was wanting to examine the discourses people used to justify the positions that they take to justify their actions, how people constructed their identities by describing events (formulating their nature), and accounting for and evaluating those events that led them to make ADs. As



Wetherell (1998) claims, “there is an unceasing human activity of making meanings (the horizon of discourse) from which social agents and objects, social institutions and social structures emerge configured in ever-changing patterns of relations” (p. 393).

### ***Presentation Style***

I have chosen to present sections of this thesis with an emphasis on the first person rather than to continually use the conventional academic style in the third person. The traditional objective style of writing suggests an association with a scientific and rational position (Grbich, 1999). The subjectivity of the researcher in reading and producing an analysis of the text is a recognisable approach in discourse analysis. Postmodern positions favour “a subjectivity that is dynamic, multifaceted, contradictory, decentred and located within particular discourses that are open to deconstruction and reinterpretation” (Grbich, 1999, p. 68). My use of the first person in certain sections of the thesis reflects my desire to indicate my role in the research process.

### ***Structure of the Thesis***

The following outline summarises the content of each chapter in the thesis. In chapter two, I introduce a literature review of the historical background to Ads, comparing the emergence of the topic in the USA and the UK. The purpose of this chapter is to discuss how certain historical events and significant political and legal documentations from these two countries have contributed to the understanding and the making of an AD as a Right in common law in the present New Zealand context. I introduce in the third chapter the underpinning methodology and the Potter and Wetherell (1987) method as a discursive psychological approach where the notions of interpretative repertoires and subject positions are defined and related to achieving the

research aim of this study. In chapter three, I also describe the study setting, how I gained access to the participants, the collection of information in the interviews, the coding of the results, and the process of analysis to identify three dominant interpretative repertoires and the corresponding three subject positions espoused by the participants. The criterion of validity referred to as *fruitfulness*, and the notion of reflexivity will also be discussed in chapter three. In chapter four, I describe in detail the data analysis findings. I present these findings following a particular format as recommended by Potter and Wetherell (1987). Each of the three dominant repertoires is identified separately and incorporates the three corresponding subject positions. To address the issue of validity, I will present extracts from the transcriptions as well as detailed discussion to allow for a comprehensive examination of the process followed and how I identified the emergence of a repertoire and the participants' subject positions. The lines in the extracts are numbered to facilitate reference to the specific sections where cues to the emerging repertoire occur. A discussion of relevant literature and the inclusion of interpretations related to the interpretative repertoire and subject position will be presented as part of the analysis. The purpose of the final, fifth, chapter is to summarise my reflections on the findings, to relate their implications for the nursing profession, to highlight the limitations of the study, and to propose suggestions for further study.

## **Chapter 2: The Historical Emergence of the Advance Directive: A Literature Review**

### ***Introduction***

In past decades, death and the dying process were largely a matter of private decisions made within specific religious and cultural frameworks (Clark, 2002). However, more recently the literature on treatment of terminal patients, brain death and other issues related to dying has expanded significantly (Brown, 2003; Emanuel & Emanuel, 1993; Emanuel, Weinberg, Gonin, Hummel & Emanuel, 1993; Emanuel, Barry, Stoeckle, Ettelson, & Emanuel, 1991; Irvin, 1995; Miles, Koepp & Weber, 1996). The emergence of advance directives (ADs) as living wills that contain anticipatory information about the treatments and procedures that people would accept or reject at the end of life, can be traced directly back to the American emphasis on autonomy and truth telling (Emanuel & Emanuel, 1993). Therefore, ADs were conceived as a way to ensure that the autonomous patients' wishes would guide the kind of treatments they receive near the end of life. These directives have come in two main forms: (1) highly specific documents, often called living wills or medical wills, that stipulate the sorts of treatments patients would or would not want under various future medical circumstances; and (2) documents in which patients designate someone to serve as the healthcare agent, or proxy, for some time in the future when patients are no longer able to speak for themselves. In other countries, such as the UK, the challenge has now been framed not only as one of choice and self-determination, but also as how best to provide a comprehensive set of health services in response to ADs and how to prepare physicians, nurses, and others with the skills necessary for delivering those services (Kendrick & Robinson, 2002; Solomon, 2003).

Kennedy and Grubb (2000) claim the purpose for following an AD in healthcare as:

Honoring such a directive [AD] shows respect for self-determination in that it fulfils two values that underlie self-determination. First, following a directive, particularly one that gives specific instructions about types of acceptable and unacceptable interventions, fulfils the instrumental role of self-determination by promoting the patient's subjective, individual evaluation of well-being. Second, honoring the directive shows respect for the patient as a person. (p. 2043)

There remains, however, a paucity of published literature on how these issues are to be managed by healthcare professionals in Western countries such as the USA, UK, and New Zealand. Cultural factors and social values vary across countries, and in some cases are crucial for end of life policy (Alora & Lumitao 2001; Blank, 2005; Ham, 1997; Webb, Quill & Lynn, 1997).

It is the intention of this chapter to initially define ADs and then trace the historical emergence and legal interpretation of the term in the USA, UK, and NZ for the purpose of demonstrating the influence the former two countries have had upon understanding the present position of ADs in New Zealand society. Further literature sources will be included in the discussion sections of the data analysis chapter as is recommended by Potter and Wetherell (1987) and, according to Willig (2001), when presenting discourse analytic research it makes sense to merge the analysis and discussion sections, including relevant literature, in order to add rigour to the findings. I have followed this suggestion and merged the relevant literature with the findings.

### *Defining an Advance Directive*

The AD is a recent cultural and organisational innovation in healthcare that allows a competent person to declare his or her wishes, and direct medical decision-makers should the person's decision-making capacity be lost in the future (Kendrick &

Robinson, 2002). Maxfield (2003) outlines the definition of an AD and makes the connection between the terms of Living Wills and enduring power of attorney:

AD is an umbrella term for several legal documents that convey the health care wishes of a patient should he become incapacitated and unable to participate in his medical care. These documents include a living will, a durable power of attorney for health care, and an advance medical care directive. (p. 43)

In simple terms these advance statements are a way of making wishes about future healthcare known to others. Significantly, ADs come into force only after the person is considered to be incompetent to state their wishes (Johnson, 2004; New Zealand Medical Association 1995; Stent, 1997). ADs are not confined to decisions to forego life-sustaining treatment but may be drafted for use in any healthcare situation in which people anticipate they will lack the capacity to make decisions for themselves. However, for the purposes of this research, the AD is discussed in relation to people making written or oral statements about future end-of-life issues and the withdrawal of life-sustaining treatments when death is imminent.

In order to clarify the use of ADs in clinical decision making, in 1995 the British Medical Association (BMA) issued a code of practice for the use of ADs in healthcare services. The code emphasised that an AD may take various forms, including: a statement of the general beliefs and aspects of life which an individual values; a requesting statement reflecting an individual's aspirations and preferences; a clear instruction refusing some or all medical procedures; a statement which, rather than refusing any particular treatment, specifies a degree of irreversible deterioration after which no life-sustaining treatment should be given; and lastly a combination of the above, including requests, refusals, and the nomination of a representative known as a

surrogate, proxy, or an enduring power of attorney (EPA), (BMA, 1995; NZMA, 1995; Stent, 1997).

### *Associated Decision-making Factors*

In New Zealand, an EPA is appointed by a person to make decisions on his or her behalf should he or she become incapacitated to give consent for his or herself in the future (Johnson, 2004; The Protection of Personal and Property Rights Act, 1988 (PPPR Act); Thomas, 2001). Nowadays there is some encouragement to all people in New Zealand to grant an enduring power of attorney well before there is any sign of incapacity (Health & Disability Commissioner, 1997; Johnson, 2004).

An underlying message the BMA (1995) conveyed was that not only do ADs comprise of individual patient preferences, but there must also be recognition of the various ways these wishes are expressed. One example of how these wishes are expressed is given by Randall and Downie (1996) “some patients may simply want to give information about their values and priorities, so as to help health care professionals to assess these factors understanding their total good” (p. 133).

An additional statement that may be included in an AD is that, upon death, there is the donation of organs or tissues and/or that the body is to be used in the advancement of medicine or medical education (BMA, 1995). People may be simply expressing their wishes in an AD and trying to convey their values and desires to health practitioners; they are expressing a sense of who they are or a framework by which practitioners can make decisions with the patient’s best interests in mind (Blank & Merrick, 2005; Clarke, Flanagan & Kendrick 2002; Holland, 2003). Ashcroft (2005) contends that the locus of the decision-making, and the trust that accompanies the decision-making, may be what really matters to the patient rather than the content of the decision making per se.

### *Treatment Decisions*

An AD may further indicate that certain treatments should be stopped at the end of life under particular circumstances. For example, some patients may indicate that they would not wish to remain on a ventilator if brain death was confirmed. Howarth and Leaman (2001) specify the different treatments that patients may wish to have stopped if an illness or injury cannot be cured and will lead to death; these might include antibiotics, cardiopulmonary resuscitation (CPR), dialysis, and ventilators. The patient's wishes therefore attempt to anticipate varied future medical situations and, as a consequence, the treatment decisions may be made in a somewhat detailed manner to match all possibilities medical situations occurring at the end of life. However, Grimm (2001) argues that this kind of specific, detailed AD lacks flexibility in that it requires a person to make a decision about medical treatment in advance even though the salient facts or the exact death scenario cannot be known in advance. As a result, Grimm recommends that to avoid making an AD stating the refusal of certain treatments for all possible circumstances, an AD only states general goals. Thus a doctor is able to interpret more widely a person's intentions and values at the end of life, and make appropriate medical decisions in line with the person's general intentions.

### *Limitation to Advance Directives*

Emanuel and Emanuel (1993) have identified the limitations of previously written directives that state specific goals to be applied to specific situations; they claim that there are intrinsic limitations to giving prior instructions in detail. First, patients may find it difficult to understand all the relevant medical treatment preferences in advance when medical technology is forever advancing and, secondly, patients often change their decisions when given up-to-date information in line with medical scientific advances. In many cases, an individual will make an AD if life-sustaining technology at the end of life may mean a disproportionate ratio of burden to benefit for that individual

(Blank, & Merrick, 2005; Howarth & Leaman, 2001; Thiroux, 2004). Further, by means of such documents as ADs, these people hope to relieve their families, doctors, nurses, and hospitals of the burdens (economic, emotional, or moral) of making decisions that would allow them, as patients, to die their own natural deaths with peace and dignity (Kendrick & Robinson, 2002; Enes & de Vries, 2004; Gross, 1998; Haley, Allen, Reynolds, Chen, Burton, & Gallagher-Thompson, 2002).

### *Summary*

In sum, the intention of ADs is to make visible and explicit patients' wishes by bringing these wishes into a position of awareness; the ADs allow the patients' 'voices' to be acknowledged when they become incapacitated and unable to speak for themselves. According to Jezewski, Meeker, and Schrader (2003) ADs are the mechanisms that patients, and ultimately their surrogate decision-makers, can use to make their end-of-life care decisions known. The historical emergence of ADs first began in the USA.

### ***The American Background to Advance Directives***

In America, the AD embodies the individual's right to involvement in treatment at the end of life, when he or she is no longer competent to make a contemporary decision about treatment (Solomon, 1999). The right is enshrined in both Federal and State Law. The Patient Self-Determination Act 1990 (PSDA, 1990) came into effect in December 1991 and was passed with a view to giving patients a number of rights: the right to considerate and respectful care, the right to make decisions involving their healthcare (including the right to accept or refuse treatment, the right to formulate ADs and appoint a durable power of attorney/surrogate to make healthcare decisions on their behalf); and the right to the information they require in order to make treatment decisions (Irvin, 1995). The PSDA requires patients be advised of these rights under



existing state law (Teno, Sabatino, Parisier, Rouse & Lynn, 1993). All 50 states have legislation that authorises the use of ADs and the appointment of a healthcare agent to act as a surrogate. These state laws are reinforced at the federal level by the PSDA.

There were significant historical events in the USA and in medical science that eventually led to the PSD Act being passed. In 1914, to justify obtaining a patient's consent for invasive medical procedures, Justice Benjamin Cardozo invoked the right of self-determination in claiming that every adult human being, who was of sound mind, has the right to give consent before medical procedures (Brown, 2003). Between the 1930s and 1950s there were scientific, technical developments in medicine with the emergence of mechanical ventilators and cardio-pulmonary resuscitation. Thus, the focus of care appeared to shift to the technical pursuit of prolonging life. Brown (2003) claimed that this was seen by some as defying nature's merciful release from death. A possible interpretation of this sentiment is that death was welcome when pain and suffering accompanied the dying process, whereas employing means to sustain life in such a context was hindering what was a natural process. Irvin (1995) states that, "virtually no one was safe from being saved!" (p. 79). Subsequently, concerns about improving care at the end of life were surfacing in the Western world during the 1950s. Clark (2002) stated, "in Britain attention focused on the medical 'neglect' of dying people; whereas in the United States a reaction to futile treatments in the face of suffering and inevitable death began to take root" (p. 905).

According to Brown (2003), the 1960s heralded a general interest in human right movements and this was transferred to the medical arena. The consumer rights movement during this time focused on the rights of individuals and directly affected the growing discourse of self-determination. Interest in death and dying, patients' rights, and hospice care also increased at this time (Clark, 2002; Irvin, 1995).

During the 1960s, opposition to the devaluing of traditional rituals surrounding dying and death led to innovations in end-of-life care being promoted with the rise of palliative care concepts and the birth of hospice care in Britain. Cecely Saunders founded the St Christopher's Hospice in Sydenham, London, in 1967. She was an innovator in the field of hospice care and had the vision to foresee that the principles of hospice care could be applied in a hospice setting as well as in people's homes. From the very outset of hospice care, the attainment of a 'good death' was the principal goal of palliative care (Dickenson & Johnson, 1996). Although it is questionable that the value-laden word good is appropriate in the context of death, a good death – as opposed to the conception of a 'bad' death by the prolongation of pain and suffering during the dying process – was fostered by the palliative care movement to include symptom control and concepts of dignity, with a new openness about the terminal condition of patients (Clark & Seymour, 1999).

### *The Emergence of Living Wills*

It was also during the 1960s that the origin of the term 'Living Will' was first drafted in by a Chicago attorney, Luis Kutner, in 1967. He was an active member of the right-to-die movement. The living will was defined to allow a person to give instructions for medical care in the final days of life. Emphasis was placed on the fact that while still competent, people are able to state in advance that they do not want a prolonged death once they become incompetent. The emergence of living wills flowed directly from a belief in the ethical priority of self-determination in medical decision-making (Brown, 2003).

Capron (1998) claims that during the 1960s, people executing a living will aimed to lift the burden of decision making off anxious family members and diffident physicians. More significantly, publicity about the importance of living wills was seen

to help educate healthcare providers about the public's sense that life-prolonging treatment is not always regarded as a good thing or in the best interests of the patient.

Until the PSDA was passed in 1990, a living will was not legally binding and during the 70s only a small percentage of the American population knew about them. Kutner and other advocates however, believed that the living will's real strength "lay in the reassurance – indeed, courage – it could provide to a patient's family, spiritual adviser and physicians to forgo life-prolonging treatment when death was near" (cited in Capron, 1998, p. 263). It was during the 70s that advocates of living wills started to lobby for legal recognition. Capron (1998) states that as a consequence of the emerging view suggested by Kutner, physicians voiced discomfort and also feared liability from the families if they carried out the wishes of an individual's living will.

#### *Legal Cases in the USA*

According to Kelley (1995), two pivotal cases occurred in the USA in the 70s and 80s that galvanised public interest in making living wills. The first case concerned Karen Ann Quinlan, a 20-year-old who was in a coma after becoming a victim of substance abuse. She had been successfully resuscitated and was on a respirator. Her physicians refused to take her off the respirator on the grounds that she needed this treatment to support her breathing, and they believed that ceasing this treatment would be tantamount to criminal homicide. In 1976, Quinlan's father requested support from the New Jersey Supreme Court to remove the respirator as Karen was in a persistent vegetative state. The Court's decision upheld the father's request as reasonable and held that an individual's constitutional right to privacy outweighed the New Jersey State's interest in preserving life (Kelley, 1995).

The second pivotal incidence related to the acknowledgement of living wills was the Nancy Cruzan case in the USA in 1983. Kohut and Singer (1993) assert that it was

the catalyst for the first legislated policy at a national level by the US Supreme Court in 1990. Nancy Cruzan was a 33-year-old woman who had been in persistent vegetative state for four years. In 1987 her family requested to have her feeding-tube removed. The Court agreed, but this decision was successfully appealed by the hospital. However, that subsequent decision was overturned by the US Supreme Court and it authorised the removal of Nancy's feeding tube. Cruzan died a month later. The decision by the US Supreme Court reaffirmed the right of both competent and incompetent individuals to refuse life-sustaining treatment. As a result of these two pivotal cases, and the courts' decisions, opinion strongly pointed the way to recognise ADs to clarify a person's wishes. The PSDA was passed in 1990, became effective in 1991, and marked the first attempt by the federal government to intervene with laws related to medical decisions (Teno, Sabatino, Parisier, Rouse & Lynn, 1993). Brown (2003) claims, "it was this climate [in the early 1990s] which gave rise to the development of public policy allowing individuals to forego life-sustaining treatment" (p. 5).

### *The Patient Self-Determination Act 1990*

Overall, the intent of the PSDA was to heighten the American public's awareness of individual rights as well as the rights afforded by the state in which they lived (Irvin, 1995). The specific provisions of the PSDA require medical facilities to advise patients of their rights regarding ADs, and also require healthcare providers to provide education for health care personnel and the public about ADs (Murphy, 1992; Teno et al., 1993).

Briggs and Colvin (2002) attest that since the enactment of the PSDA, healthcare organisations in the USA still require a cultural shift to go beyond the mandated focus to inquire whether or not patients had developed written plans for future medical decision making in an AD. The author purports instead that the focus

ought to be on the spirit of the law. The spirit of the PSDA intended to empower patients to be self-determining and autonomous in their decision making and to be provided with accurate information to support the making of informed healthcare decisions. Not surprisingly, recent research (Alpert, Hoijtink, Fischer & Emanuel, 1996; Briggs, 2002; Brown, 2003; Gillick, 2003) has demonstrated that the intended outcomes of the PSDA have not been realised.

Tierney, Dexter, and Gramelspacher (2001) criticised the implementation of PSDA since its enactment, claiming that there existed barriers to the Act's effectiveness ranging from time constraints and communication difficulties between physicians and patients, to physicians' anxiety about patients' reactions to being asked about their ADs (Ott, 1999; Morrison, Morrison & Glickman 1994). La Puma, Orentlicher and Moss (1991) identified the problem of possible inappropriate timing of such discussions, especially at the time of an acute admission. One of their findings stated that acutely ill patients entering hospital were not always in a position to refer to AD documentation – including their living will or their appointed proxy – and still less were they able to participate in rational discussions about their use. Another finding of the study was to suggest that physicians appeared to deny patients the chance to communicate and failed to support the patients in making ADs. It is possible that this last finding arises from physicians believing that they know what is best for a patient who is dying and that they know this better than the patient would know and understand for themselves.

In defence of the doctor's position, Kendrick and Robinson (2002) assert:

The doctor is in a difficult position, being a medical expert who can advise about options and consequences, but not always trained in the non-directive techniques that would ensure the patient's autonomy is developed and maintained. It is particularly important, therefore, that

the doctor is able to communicate clearly and effectively about the nature of any illness and the possible consequences. (p. 114)

Another constraint related to the effectiveness of ADs in the USA is the reliability of proxy decision-making. A randomised, controlled trial conducted by Ditto, Danks, Smucker, Bookwala, Coppola, Dresser, et al. (2001) questioned whether instructional ADs are effective in improving the accuracy of surrogate decisions. The authors concluded that ADs do not ensure that family members will make end-of-life treatment decisions that accurately reflect patients' wishes as outlined in their ADs. Another finding of this study was that, despite the patients' and family members' confidence that they could accurately carry out the patients' wishes, family members without the benefit of an AD inaccurately predicted patients' desires to receive life-sustaining treatment in about three of every ten decisions (Ditto, et al., 2001). These findings clearly challenge current policy and law advocating ADs as a way to honour specific patient wishes at the end of life.

### *Summary*

To summarise the situation in the USA, the most significant historical event that has influenced the advent of ADs in the Western world was the enactment of the PSDA in 1991. The Act attempts to ensure that individuals are informed of their rights under state law; it does not create new rights. Rather, the Act mandates that healthcare facilities communicate to patients their rights to make decisions about their care and this may include end-of-life issues and palliative care (Brown, 2003; Jezewski, Meeker & Schrader, 2003; SUPPORT Principal Investigators, 1995).

### ***The United Kingdom Background***

Although it appears that the experience of America has been somewhat ambiguous, complex, and confusing for the healthcare provider and for the citizens in

recent years, the UK has attempted to clarify some of the issues surrounding ADs. In 1994 the House of Lords Select Committee on Medical Ethics examined this area, calling – amongst other things – for a code of practice on ADs for health professionals (Kendrick & Robinson 2002). A code was produced in 1995 by the BMA, followed in 1996 by the Patients' Association producing a guide for patients. The Law Commission's report on mental incapacity was published in 1995, followed by a consultation paper concerning who makes decisions on behalf of mentally incapacitated adults (Lord Chancellor's Department, 1997). Consequently, the UK government produced a report that will form the basis for legislation in the future (Lord Chancellor's Office, 1999). What this means is that health professionals are obliged to respect the wishes of patients regarding which treatments they would like to receive or reject as set out in a living will (Kendrick & Robinson 2002).

#### *Advance Directives and the Law Commission*

Overall, the aim of these reports was to refine understanding of the different issues involved in ADs. However, although it has not led to a demand for any actual legislation, the language of the Law Commission's recommendations in particular, is written in the form of legal recommendations concerning mental incapacity and the law's adequacy to represent persons without capacity. The Report is directed to the 'duties' of healthcare providers, particularly with regard to the boundaries of medical decision making and the need for doctors to acknowledge ADs. The Law Commission Report (1995) states:

One of the principles on which the Commission has proceeded is that people should be encouraged and enabled to take those decisions which they are in fact able to take. This principle embraces anticipatory decision-making by the person while competent in order to make arrangements for his or her future incapacity. (Section 1.12)

Where specific problems or disputes arise between medical personnel, surrogate decision-makers, or families concerning a patient without capacity, the Law Commission Report (1995) clearly recommends that a single court of law should be available to arbitrate on the problem. The Law Commission Report is directed mainly at doctors acknowledging that the quantity and quality of the clinical care provided in any health system is determined by doctors' decisions (Salter, 2004). The Report appears to be wary about the exercise of medical power in decision-making when mentally capable people – who initially make decisions to withdraw from medical treatments – become incapacitated and then rely on doctors to carry out their wishes. In an attempt to safeguard these vulnerable people, the Law Commission recommends that “magistrates courts and single justices of the peace should be able to grant warrants or make orders for the protection of vulnerable people” (1995, Section 1.49). Although the Law Commission contends that vulnerable people must be protected by the law, the Report also recommends that doctors refer difficult end-of-life decision-making to the Courts for final judgments. I would argue that the power of the legal language in the Law Commission's document appears to express a hidden notion of the legal dominance over medical decision-making as it tends to reflect and reinforce the need for society to turn to the judiciary for trustworthy medical decision-making, especially at the end of life. Above all, there appears to be an assumption that the law is fair and neutral, and as a result of these qualities will make the right decisions.

The term 'living will' is used interchangeably with 'advance directive', and 'advance statements'; the latter is more commonly used by health authorities in the UK (Kendrick & Robinson, 2002).



### *Advance Directives and Common Law Cases in the UK*

ADs, in the form of refusals of treatments, are recognised in common law in the UK. Common law is law made by judges who adjudicate in different cases (BMA, 2004). Three particular cases have established this precedent in terms of doctors being bound by consent: *Airedale NHS Trust v. Bland* [1993] AC 789, – *Re T* [1992] 4 All ER 649, and *Re C (Adult Refusal of Treatment)* [1994] 1 All ER 819.

#### *The Tony Bland Case*

The Bland case made it clear that competent adults have the right to refuse treatment, including taking into account previous oral wishes that, if they were brain dead for example, they would not want to remain on life support. The Bland case ruled that if it was ascertained by rigorous medical assessment that the patient had no hope of recovery then withdrawing life support and treatments, including food and fluid, was permissible.

#### *Re T*

In another case, known as *Re T*, the Court established the principle that where an informed and capable patient makes a choice that is clearly established and applicable in the circumstances, medical staff would be bound by the patient's choice in an advance statement. Every adult has the right and capacity to decide whether or not he or she will accept medical treatment even if a refusal may risk permanent injury to his or her health, or even lead to premature death (Lord Donaldson, cited in Kendrick & Robinson, 2002).

#### *Re C*

The significance of the ruling on the *Re C* case was that the law found it irrelevant whether a directive contradicted the views of others, including medical personnel. If the person, C, was able to decide on a particular matter in question, even if

he lacked insight into other aspects of his life, then decision-making on that matter in question was valid. Hence, incapacity was not to be equated with irrationality.

As a result of the three cases the following criteria for valid ADs include that the person: must be mentally competent, not suffering from mental stress, and be over 18 years old when the request is made; the person must be fully informed about the nature and consequence of the AD; the AD should apply to all situations or circumstances that may arise at a later date; and the person is able to make the AD without undue pressure or influence from others (BMA, 2004; Wilson, 1999).

Treatment can be given, in the UK, in the patient's best interests to preserve his or her life or to prevent deterioration in health – provided this does not contravene a patient's valid expression of views. For example, the refusal of blood transfusions must be clearly stated in an AD. Kendrick and Robinson (2002) assert that concern for the patient's best interest is not necessarily to be seen from a paternalistic, medical stance; rather, a patient's past and present wishes and feelings are recommended to be included as part of the doctor's decision making when considering the best outcome for the patient (BMA, 1995, 2004; Law Commission, 1995).

### *Age Concern and Advance Directives*

Age Concern England (2002) advocates the use of the term 'personal best interest' so that a person's wishes are routinely taken into account when defining what is in his or her best interest. By including the word 'personal', Age Concern appears to mistrust health providers considering the individuality of the person's advance statements. However, the best interest criteria ought to ensure that patients would not be deprived of new treatments of which they had been unaware when they first made an AD. The Lord Chancellor's Department (1997) states that:

The advance statement is not, therefore, to be seen in isolation, but against the background of the doctor/patient dialogue and the involvement of other carers who might be able to give an insight into what the patient would want in the particular circumstances of the case. (p. 4)

Although guidance on advance statements about medical treatment was initially published by the BMA in 1995, the legally binding status of ADs is currently upheld in the UK (Luttrell & Sommerville, 1996). Nevertheless, a survey of 214 general practitioners in 1998 found that only 49% of the practitioners were aware that ADs carry legal force (Bowker, Stewart, Hayes & Gill, 1998). Diggory and Judd (2000) highlight the concern that although the National Health Services (NHS) Executive and the General Medical Council (GMC) in 1999 issued guidance on withholding consent to treatment as well as the current legal position of ADs, it remains unclear how the NHS Trusts have responded to this guidance and to what extent patients can expect that their ADs would be respected. Hence, a survey was developed and sent to 463 NHS Trusts resulting in responses from 247 Trusts. Of the 247 responses, 187 Trusts believed national guidelines on ADs would be useful; only a half of the overall responses indicated that they were taking any action at all (Diggory & Judd, 2000). This raises a significant issue about what place and value ADs have within the healthcare settings in the UK, or whether there is any intention from healthcare providers to ascertain whether a patient has made an AD. Significantly, too, there appears little assurance that the wishes of the patient, even if known, would be followed.

#### *Awareness of Advance Directives in the UK*

Schiff, Rajkumar and Bulpitt (2000) purport that it is not currently possible to know how many people are aware or unaware of ADs in the UK. Consequently, these authors used questionnaires and interviewed 74 elderly medical inpatients in two

London hospitals. The conclusion was that if people are informed they then become interested to hear about and make ADs. Ninety-two percent of the participants indicated that it would be their wish that their lives would not be prolonged unnecessarily by life-sustaining medical treatments. Schiff, Rajkumar and Bulpitt reported, “our elderly participants found many disabilities unacceptable, stating that they preferred comfort-only care, even if they might die, to [life prolonging] treatment” (p. 1641).

### *Summary*

Although the difficulties of writing and interpreting ADs should not be minimised, their place in healthcare planning is important in clinical practice in the UK. With increased understanding and awareness of the purpose of ADs, patients’ wishes will increasingly be taken into account and respected when end of life decisions are to be made (Clarke, Flanagan & Kendrick, 2002). A major contribution to understanding the purpose of ADs that has emerged from the UK has been the recommendations from the Law Commission Report (1995). The report was the culmination of a five-year study by the Commission into the adequacy of the law and health providers’ procedures for decision-making on behalf of persons without capacity.

### ***The New Zealand Position***

Tollemache (2002) claims that the situation of ADs in New Zealand differs greatly from the American position:

Accident Compensation legislation, as administered by the Accident Compensation Corporation (ACC), has virtually eliminated medical malpractice litigation. Litigation has been one of the drivers behind the increasing emphasis in the USA on patient self-determination and the legal recognition of advance directives as a mechanism by which health providers can avoid liability by carrying out the wishes of the patient.  
(p. 5)

As has been previously stated, the UK has also developed this branch of law through litigation.

### *Legal Position of Advance Directives in New Zealand*

In New Zealand law, competent patients have a right to refuse medical treatment. The right is now enshrined in the New Zealand Bill of Rights Act 1990, section 11, which states, “everyone has the right to refuse to undergo any medical treatment” (s11). The New Zealand Code of Health and Disability Services Consumers’ Rights 1996, known as the Code, gives every health and disability consumer the right to use an advance directive except where any enactment, the common law, or another provision of that Code provides otherwise (Johnson, 2004). According to Right 7(5), consumers may make an AD in accordance with the common law. An AD is defined under clause 4 of the Code as “a written or oral directive by which the consumer makes a choice about a possible future healthcare procedure; and that is intended to be effective only when he or she is not competent” (Johnson 2004, p. 102). Consequently, Johnson reports that health practitioners are “ideally placed to educate consumers about advance directives” (p. 102).

Right 7(7) in the Code provides that “every consumer has the right to refuse services and to withdraw consent to services” (Stent 1997, p. 103). Right 7 (5 and 7) in the Code is derived from Section 11 of the New Zealand Bill of Rights Act 1990 which not only provides the right to refuse to undergo treatment but also upholds the principle of consumer autonomy.

Consumers are presumed to be competent to make an informed choice and give informed consent unless there are reasonable grounds to believe otherwise (Right 7[2]). Therefore, there is a requirement that when people make ADs they are deemed competent to make their choices freely and without undue pressure. Johnson (2004)

cites the previously mentioned English case of *Re C*, 1994, whereby a person is not competent if he or she is unable to comprehend and retain the necessary information about the procedure or treatment and is unable to weigh the information, and balance the risks and needs, to arrive at a choice.

Johnson (2004) further highlights that in New Zealand, the validity of an AD in common law is unclear and therefore she recommends involvement by the patient's family, general practitioner, and lawyer because the validity of the AD is much more likely to be given effect. Presently, there is no legislation that specifically addresses ADs and, although case law has established guidance for the creation of ADs, the doctors' duty to follow them has not been tested in the NZ courts (NZMA, 1995; Skegg, 1993; Stent, 1997).

In the New Zealand context, Johnson (2004) argues that legal advice is helpful if the practitioner believes that there is strong family opposition to the contents of the AD and states, "a valid advance directive must be made, without undue influence, by a competent person, who is fully informed about refusing the service in the future" (p. 102). It strengthens the argument that the advance directive is currently valid if the consumer made the AD fairly recently, and if it applies to the consumer's current condition.

However, while analysing the discourses surrounding the New Zealand literature on ADs (NZMA, 1995; Skegg, 1993; Stent, 1997) the emphasis is that ADs primarily must meet the legal requirements to be valid and if the ADs do not meet all the requirements they are regarded as invalid. Consequently, health professionals are not required in these cases, to carry out the instructions in the ADs. This literature reports there is little priority given to respecting autonomy and acknowledging peoples' wishes in ADs or creating opportunities for people to discuss their end-of-life choices.

Instead, the power of doctors and lawyers to legitimise a consumer's AD appears to be promoted in the first instance. A doctor might well throw doubt on the applicability of the AD by questioning the medical information on which the patient based the directive (Hollows, 1995; Hunt, 1994; Johnson, 2004; Tollemache, 2002).

### *An Enduring Power of Attorney and Advance Directives*

As previously stated, an enduring power of attorney (EPA) and welfare guardianship are defined under the Protection of Personal and Property Rights Act 1988 (the PPPR Act). The EPA is relevant when a person who is currently competent (the patient) grants power to another to make decisions when he or she may later become incompetent to make decisions; the patient's wishes endure when he or she becomes incapable of decision making. Johnson (2004) clarifies that the power does not take effect until the donor is incompetent to make personal and property decisions. In contrast, a welfare guardian may be appointed for someone who *already* lacks competence.

Both an EPA and a welfare guardianship permit the proxy to consent to treatment, unless this power has been expressly excluded (Johnson 2004; Thomas, 2001). Importantly, the proxy cannot *refuse* consent to standard medical treatment to save the person's life (Bray and Dawson, 2000). Thomas (2001) contends, "in New Zealand, a person who does not wish to receive life-prolonging treatment in certain circumstances should not rely on an EPA due to the limitations that are placed on the attorney" (p. 237). A valid, written AD in the possession of the EPA enables the attorney to represent the patient's wishes from a stronger position.

Professor Peter Skegg reiterated that, according to s98(40) and s18(1)(c) of the PPPR Act, a person holding an EPA may refuse non-standard treatment on behalf of the patient but does not have the power to refuse consent to "the administering to that

person of any standard medical treatment or procedure intended to save that person's life or to prevent serious damage to that person's health, even if such a power has been expressly granted" (Skegg 1993, p. 3). Therefore, the PPPR Act significantly limits an EPA's authority to refuse life-prolonging treatment. Interestingly, Professor Skegg maintains that he would rather appoint a healthcare proxy in whom he had confidence than make use of an AD. Professor Skegg appears to express doubt that an advance written statement would have any impact on medical decision making, and that he would rather rely on the EPA or healthcare proxy to speak on his behalf when his mental capacity was lost (Skegg, 1993).

### *Summary*

In summary, according to the Code (1996) a competent health and disability services consumer in New Zealand is granted the right to make written or oral instructions clarifying future decisions related to healthcare procedures (including end-of-life choices) and that these rights are defined broadly as:

any health treatment, health examination, health teaching, or health research administered to or carried out on or in respect of any person by any health care provider; and includes any provision of health services to any person by any health care provider. (Stent, 1997, p. 6)

The AD is simply the patient's advance use of his or her right to make a healthcare choice according to Right 7 (5) of the Code and that this is intended to be effective when the consumer is not competent. The fundamental right of consumers to refuse medical treatment under the Bill of Rights Act (1990) and the statutory and ethical obligations on doctors to provide the necessities of life under s151 of the Crimes Act (1961) potentially raises contentious medical decision-making problems, especially at the end of life. The Crimes Act sets out a number of legal duties of which the following may apply to individual health practitioners:



A person in charge of another person who cannot provide himself or herself with the necessities of life has a duty to provide that person with the necessities of life. (s 151)

The obligation is on doctors to provide not only the necessities of life, but also to provide medical treatment that could cure, alleviate, or prevent deterioration in health (NZMA, 1995; The New Zealand Law Society, 2002; Tollemache, 2002; Young, 2004). Johnson (2004) clarifies the legal stance of a doctor who complies with a patient's refusal to undergo medical treatment by stating that they should not be liable to criminal consequences if the consumer was an adult who was assessed as competent to make the decision as well as knowing the consequences of the decision.

Hence, common law in New Zealand recognises the patient's right to make an AD; as such, doctors are obliged to consider the patient's advance statements and must be careful not to draw conclusions about the consumer's capacity, or susceptibility to undue influence, based solely on the health provider's personal feelings about the correctness of the patient's choice (NZMA, 2004).

## ***Conclusion***

This chapter has reviewed the literature on ADs, considered the historical emergence of ADs from the American and British backgrounds, and includes the present position of ADs in New Zealand. The interpretation of advance statements, or directives, in these three countries – focusing on end of life treatment preferences and medical decision making, patients' rights to make ADs, and the role of surrogate decision makers – were compared and discussed. Overall, the literature defines ADs as a mechanism whereby competent people can give instructions about what they wish to be done if they should subsequently lose the capacity to decide for themselves, especially at the end of life. Generally, the literature claims that the purpose of ADs is

to provide a means for patients to continue to exercise autonomy and shape the treatment they will receive if they become incapable of expressing their wishes in the future.

## **Chapter 3: From Methodology to Method**

### ***Introduction***

Discourse analysis is a relatively recent approach to the examination of a regularised system of knowledge. Lupton (1992) defines discourse as, “groups of ideas or patterned way of thinking which can be identified in textual and verbal communications and can also be located in wider social structures” (p. 145). In the first section of this chapter I will identify the major components of the discourse analysis method and link the method to the poststructuralist paradigm, as well as referring to Jonathan Potter and Margaret Wetherell’s (1987) approach to discourse analysis. In the second section of this chapter a more detailed discussion on Potter and Wetherell’s approach to discourse analysis will be examined, including a rationale for choosing this approach to identify what discourses were drawn on by the participants to evaluate and justify making ADs. Whilst this chapter will focus on the broad concepts of Potter and Wetherell’s approach, a more detailed application of their discourse analytical concepts will be linked in the data analysis chapter to illustrate how data were analysed from the interview extracts. According to Hollway and Jefferson (2001), to make the interpretation of the data robust, the discourse analyst must present texts as evidence to support and challenge the data analysis.

Potter and Wetherell (1987) propose, “discourse analysis is heavily dependent on craft skills and tacit knowledge” (p. 175). This means that discourse analysis needs to be understood, first of all, in terms of its “broad theoretical framework concerning the nature of discourse and its role in social life” (p. 175). This is the intention of the discussion in this chapter.

### *The Qualitative Paradigm*

Qualitative research is concerned with meaning in context and is characterised by epistemological diversity. The differences between the various approaches and their epistemological underpinnings are significant (Antaki, 1988; Billig, 1987; Cheek, Shoebridge, Willis & Zadoroznyj, 1996; Edley, 1997; Edwards, 1997; Silverman, 1993). Qualitative studies explore phenomena within natural contexts. As a result, qualitative research tends to be holistic and explanatory rather than reductionist and predictive. It is concerned with description and explanation but not with prediction. To evaluate a qualitative study, it is crucial that the researchers are clear what the research question intends to ask and what kind of knowledge they are trying to generate. The research method must be appropriate to the research question and compatible with the epistemological position (Denzin & Lincoln, 1994; Morse, 1999; Silverman, 2000, 2001; Wolcott, 1994).

### *Epistemological Underpinnings of Discourse Analysis*

Discourse analysis is described as an epistemology in that it explains how we know the social world. It is a compelling theoretical frame for observing social reality. Social reality is produced and made real through discourses and social interactions and cannot be fully understood without reference to the discourses that give them meaning (Edwards & Potter, 1992; Edwards, 1997).

The overall task of discourse analysts, therefore, is to explore the relationship between discourse and reality (Phillips & Hardy, 2002; Silverman, 1993, 1997). Furthermore, Wilkinson and Kitzinger (2000) claim that, “a discursive approach explores talk as a form of action designed for its local interactional context, and pays detailed attention to statements and what they actually mean for speakers in the contexts in which they occur” (p. 797). In this research it is my intention to explore, by using

Potter and Wetherell's approach to discourse analysis, the ways in which talk about making ADs is used by the participants and how they construct meaning in their language to justify and evaluate making ADs. The aim is to uncover the larger patterning of thought that structures the way language is used from the participants' subject positions. The recurring and dominant themes – or 'bodies of instances', also referred to as utterances – constructed by the participants from their subject positions are located in broader discourses and referred to as interpretative repertoires (Potter 1996a, 1996b; Potter & Wetherell, 1987; Wetherell, 2003). When the participants speak about making ADs, it is my intention to demonstrate that the accounts that are produced are context-specific and drawn from a wide variety of social and historical influences. Wetherell (1998) recognises that when people talk, they do so using a lexicon, or repertoire of terms, that has been provided for them by the social and historical contexts. Edley (2001) defines the repertoire of terms embedded in the social and historical contexts as, "a language culture [that] may supply a whole range of ways of talking about or constructing an object or event" (p. 190). Because there exists such a range to call on in talk, people are bound to make choices (Edley & Wetherell, 2001).

In summary, the discourse analytical approach of Potter and Wetherell (1987) captures the paradoxical relationship that exists between discourse and the speaking subject. It acknowledges that people are at the same time both the products and the producers of discourse (Billig, 1991). Therefore, Potter and Wetherell's approach to discourse analysis is underpinned by the postmodern/poststructuralist paradigm of qualitative research.

### *Discourse Analysis and Poststructuralism*

Grant and Giddings (2002) describe poststructuralist research as "situated squarely in the impossibility of universal truths about the social. This paradigm is

sometimes called deconstructivism or postmodernism” (p. 20). Postmodern approaches “have recognised the multiplicity of voices, views and methods present in any representation or analysis of any aspect of reality” (Cheek, 1999, p. 385). According to Cheek (2000) postmodern approaches are ways of thinking about the world that shape the type of research that is done and the types of analyses that are made. Therefore, Cheek (1999) purports that what postmodern approaches do are to provide a challenge to the view that it is possible to represent any aspect of reality in its entirety, speak for others, make truth claims, and attain universal essential understandings. However, Savage (2000) contends that there is no universally accepted definition of postmodern. Instead she would argue that there exists a range of theoretical approaches which emphasise that reality is manifold, and there is no single way to view, interpret, or characterise that reality.

Grant and Giddings (2002) prefer the paradigmatic term of poststructuralism and claim that poststructuralism includes a range of theories which infuse the paradigm, whereas postmodernism describes an historical era.

According to Lupton (1994) the poststructuralist concept of research marries the structuralist semiotic concern with the form and structure of language and the ways that meaning is established with an understanding that language does not exist in a social vacuum, but is embedded in social and political settings and used for certain purposes. Willig (2001) concurs that discourses are able to be analysed and examined from an unlimited number of ways, and that what is common to the range of theories and approaches which come under the umbrella of poststructuralism, are that objects and events are constructed through language in a social context.

### *Discourse Analysis and Variability of Language Construction*

Language constructs social objects and each person may bring his or her version of that reality. What differentiates people towards a social object or event is the way in which they construct the object or event through language rather than any 'fixed' cognitive structure within the human mind; cognitions are considered relatively enduring, stable, and predictable from day to day (Wooffitt, 1993). In contrast, discourse analysts argue that language is productive and performative and not 'fixed' and unpredictable (Willig, 2001). Willig states, "...people say, tell us something about what they are *doing* with their words (e.g. disclaiming, excusing, justifying, persuading, pleading, etc.) rather than about the cognitive structures these words represent" (p. 90).

Wetherell (2001) claims that the major components of discourse analysis are: function, variation, and construction. Language function involves the concept that people use language to *do* things, for example, to order and request, persuade, and accuse. The analysis of function cannot be seen as a simple matter of categorising pieces of speech, it depends upon the analyst 'reading' the context. Edley (1997) contends that language function in discourse analysis can be global, that is, a person may wish to represent her/himself in a favourable light or represent someone they do not like in a poor light. The person may construct a subject position and 'work' the text to justify their position. However, there are many and contradictory discursive practices that each person could construct at any one time and because the participant is able to exercise this choice in the construction of their subject position, variation in the discourse will be evident (Edley, 1997; Potter & Wetherell, 2001).

Davies and Harre (1990) describe this variation in discourse by purporting that as a conversation unfolds through the action of the participants, they try to make their own and others' actions socially determinate. The individual emerges through the

processes of social interaction as “one who is constituted and reconstituted through the various discursive practices in which they participate” (p. 46). Once a particular position is taken up as one’s own, a person inevitably sees the world from the vantage point of that position and may construct that viewpoint using particular images, metaphors, story lines, and concepts which are made relevant within the particular discourse in which they are positioned to make sense of their own and others’ lives (Edley, 1997).

Davies and Harre (1990) claim, “stories are located within a number of different discourses, and thus vary dramatically in terms of the language used, the concepts, issues and moral judgments made relevant and the subject positions made available within them” (p. 46). Therefore, by using a discursive approach under the umbrella of poststructuralism, a researcher is required to be flexible and open to analysing the many perspectives and varied interpretations of phenomena. At the same time, the researcher acknowledges that different and varied discourses are used at any one time by participants to explain and justify their positions to the truth as they see it; the variations in the participants’ positions are influenced by different social and historical discursive practices.

Reflecting poststructuralism’s construction of subjectivity as fragmented and contradictory, discourse analysis does not take for granted that accounts reflect underlying attitudes or dispositions. Therefore, discourse analysts do not expect that an individual’s discourse will be consistent and coherent, rather the focus is on the discourse itself, how it is organised, and what it is doing for the speaker (Potter & Wetherell, 1987).

Granted that any examination of language over time reveals considerable variation, a person’s account or subject position will vary according to its function;



therefore, it will vary according to the purpose of the talk. There is variability in accounts – different forms of description may be right for different occasions, but the person may be just “doing what comes naturally [embedded in their social and historical contexts] rather than intentionally deciding this, rather than that, form of language will be appropriate” (Potter & Wetherell, 2001, p. 200). As stated previously, people will be drawing on a wide range of choices of rhetorical devices and linguistic structure, the ‘style’, as well as the subject matter of verbal communications that is ‘natural’ to them. Lupton (1992) draws on the work of Van Dijk (1987) to explain the composition of the two main dimensions of discourse analysis:

Discourse analysis is therefore composed of two main dimensions, textual and contextual. Textual dimensions are those which account for the *structures* of discourses, while contextual dimensions relate these structural descriptions to various properties of *the social, political or cultural context* in which they take place. (p. 145)

Whilst variability of language use is an acknowledged component of discourse analysis, persuasive orientation and disclaimers are techniques of language purposely employed by speakers to emphasise descriptions of events or objects (Potter & Wetherell, 1987). Persuasive orientation draws upon what Pomerantz (1986, cited in Potter & Wetherell, 2001) has called “the *extreme case* formulation” (p. 204). This means that whatever evaluative dimension is being adopted by the speaker is taken to its extreme limits. For example, if it is a question of numbers, then the words ‘everybody’ or ‘only one’ are employed for emphasis. The use of the word ‘just’ as part of a sequence of speech is another example of persuasive orientation. Potter (2001) claims that this deliberate emphasis in speech, represented in this extreme case formulation, is often used to make criticisms appear more justifiable and acceptable for the listener. It is used also as a persuasive feature to soften the impact of any

controversial position that the speaker may be arguing from (Potter, 2001; Potter & Wetherell, 2001).

A disclaimer is another verbal device which is used by a speaker to ward off potentially negative attributions to the position they are holding. Even a small amount of additional information about context can throw into question what, at first, appears to be a reasonable interpretation of a person's utterance. Since discourse has an action orientation, the disclaimer is constructed in such a way that particular tasks, such as blaming and disclaiming responsibility for the obnoxious effects of the blaming are facilitated (Potter & Wetherell, 1987). An example of the use of a disclaimer in a text could be: "I think to a degree that issue is right, **however**, ..." or, "I am not a racist, **but**, ...". The use of the disclaimer is also an example of the variations that appear in a speaker's accounts and illustrate how it is difficult to assume that any one statement represents the speaker's position (Potter, 2001). Potter further contends that disclaimers are used when the truth of an account that is being constructed could be challenged, "it emphasises the relation between a description and alternative descriptions and how relationships may be worked up in argument" (p. 107).

Reissman (1993) claims that discourse analysts "deal with ambiguous representations of another's experience through talk, text, interaction and interpretation" (p. 8). Therefore, in discourse analysis, the variation in the text would not lead the analyst to attempt to identify and interpret phenomena lying 'beyond' the text. Rather, the focus is on the discourse itself, how it is organised, and what it is doing. (Billig, 1987; Edley, 1997; Edwards, 1997; Potter & Wetherell, 1987; Wetherell, Taylor & Yates, 2001a).

### *Discourse Analysis and Subject Positions*

Potter and Wetherell (1987) contend that it is untenable to retain conceptions of language as a neutral medium for the transmission of information, values, and beliefs about a world 'out there'. The approach adopted by Potter and Wetherell examines discourse from all forms of verbal and textual materials as well as all forms of spoken and written accounts. This approach describes the way that such texts are constructed by subject positions. A subject position incorporates both a conceptual repertoire and a location for a person to use that repertoire (Wetherell, 2001). Therefore, it appears that there is no reason to suppose that consistency in accounts is a sure indicator of descriptive validity (Cheek, 2000).

Underpinning the speaker's discourses to construct reality through talk, are reflections of the embedded social order from which these decisions are valued and understood. Central to this critique therefore, is the notion that what individuals say is partly constrained by the social context in which they interact and live (Wetherell, 2000).

Part of the analysis of discourse is to identify the action orientation of accounts (Edley, 1997; Potter & Wetherell, 1987; Wetherell, 2001). To be able to do this, the researcher needs to pay careful attention to the discursive contexts within which such accounts are produced and to trace their consequences for the participants in a conversation. According to Willig (2001) this can only be done satisfactorily on the basis of an analysis of *both* the interviewer's and the interviewee's contribution to the conversation. Therefore, discourse analysis requires an examination of language in context.

### *Reflexivity and Discourse Analysis*

A notable feature of qualitative methodologies is that they can be differentiated according to the extent to which they emphasise reflexivity and by the importance they place on the role of language. These two features are related in discourse analysis as a research method within the poststructuralist paradigm. Reflexivity requires awareness of the researcher's contribution to the construction of meanings throughout the research process, and an acknowledgement of the impossibility of remaining 'outside of' one's subject matter while conducting research. Reflexivity, then, urges us "to explore the ways in which a researcher's involvement with a particular study influences, acts upon and informs such research" (Nightingale & Cromby, 1999, p. 228).

A major challenge posed by Wetherell, Taylor and Yates (2001) is how far the researcher can be separated from the research. These authors claim that the separation seems impossible. Discourse analysis not only requires the researcher to uncover the larger patterning of thought behind language, but also the researcher's position and contribution during the data collection. The argument here is that a basic feature of social research is its reflexivity, namely, the way that the researcher acts on the world and the world acts on the researcher. Heslop (1997) describes the discourse analyst as needing to have a 'non-judgemental' relationship with the participants. This is significant if misunderstandings are to arise.

### *Personal Reflexivity*

Personal reflexivity requires researchers to reflect upon the ways in which their own values, experiences, interests, beliefs, political commitments, wider aims in life, and social identities have shaped the research. Detachment is impossible, so the researcher's influence must be taken into account and even utilised (Hammersley & Aitkinson, 1995, p. 19).

The researcher needs to be self-aware and this involves standing back to observe oneself as an actor within a particular context. The researcher attempts to understand how her or his own presence and actions influence the situation. This includes relevance of the researcher's identity to the research – an important area for discourse analytic research, particularly for studies which involve interviewing (Wetherell, Taylor & Yates, 2001, p. 17). Reflexivity also involves thinking about how the research may have affected and/or possibly changed the researcher and the participants. Therefore, the researcher's role is one of a central and visible position requiring rigorous personal reflexivity.

There are many ways that Weatherall (2000) describes how the identity of the researcher becomes relevant to discourse analytic research. To begin with, the researcher is likely to conduct a project which relates to his or her own personal interests, sympathies, and political beliefs. These personal interests are a probable starting point for the project. From the beginning, the researcher needs to state his or her position and acknowledge the relationship to the topic and the participants. The researcher's identity is also relevant to data collection, and how it affected the interaction and meaning during the interviewing needs to be acknowledged. For example, a participant may feel ill at ease with the topic and the interviewer. This could possibly result in the participant/interviewer dynamics being strained and the ethical requirement of consent to participate in the process being compromised. Willig (2001) argues, therefore, that the interviewer should not try to approach participants as an insider who shares their situation or interests, but simply as an outsider. The researcher is therefore assessing and qualifying claims as they are made, rather than presenting them as statements of truth (Reissman, 1993).

To overcome this situation, a more honest acknowledgement of the power differences between the participant and the interviewer may need to be addressed. I acknowledged to the participants my interest in the subject of creating an AD as I had already made one, and that I wanted to know how others had come to their decision to make one. I consciously did not present my personal views or judgments, however, when I listened to the transcripts, it was clear that my responses were less objective than I had realised; and so, when doing future research, I will speak less and be less directive in the questioning.

Overall, I had difficulty separating myself from the research question during some of the interviews, especially if there were gaps and silences. I had positioned myself as a nurse, making a nursing assessment of what end of life treatments a participant would want, rather than taking a more neutral position as a researcher. I needed to be more self-aware and understand that my use of language and the direction of the questioning involved standing back to observe myself as an actor within a particular social context. Hollway and Jefferson (2001) noted, “it follows that the information of our feelings in and around the interview are of value for understanding the dynamics of the research relationship. Therefore, they are important to how the data are produced” (p. 45). I felt uncomfortable raising the topic of dying and end of life decision-making during the interviews and was hesitant to use the words death and dying, but at the same time I was conscious of wanting the participants to express their thoughts about their end of life wishes.

### *Summary*

In summary, data in discourse analysis is generated by paying attention to the constructive and functional dimensions of discourse. To facilitate a systematic and sustained exploration of these dimensions, context, variability, and construction of

discursive accounts need to be attended to and examples presented in the report. Potter & Wetherell (1987) argue that the researcher looks at how the text constructs its objects and subjects, and how such constructions vary across discursive contexts.

Antaki, Billig, Edwards and Potter (2003) identify diverse constructions of subjects and objects in the text, and state that attention needs to be paid to the terminology, stylistic, and grammatical features; preferred metaphors; and figures of speech that may be used as participants' construct their responses. Antaki et al. (2003) comment that analysis means a close engagement with one's texts or transcripts and the illumination of their meaning and significance through insightful and technically sophisticated work.

In the end, discourse analysis means doing discursive analysis. Discursive psychology is primarily concerned with *how* people *use* discursive resources in order to achieve interpersonal objectives in social interaction. People use language in order to negotiate and manage social interactions so as to achieve interpersonal objectives, for example, to justify an action.

Discourse analysis is not simply a research method. It also provides an alternative way of conceptualising language and it indicates a method of data analysis that can tell us something about the discursive construction of social reality. Billig (1997) states that discursive analysis is more than a methodology, "it involves a theoretical way of understanding the nature of discourse and the nature of psychological phenomena" (p. 43).

## ***The Potter and Wetherell Discursive Analysis Approach***

### ***Introduction***

Potter and Wetherell's (1987) rationale for analysing data using discourse analysis was that there exists many versions of reality and the study of a phenomenon

involves studying the way it has been constructed. They utilised a discourse analytical method that examined discourse in an open sense. All forms of spoken interaction, formal and informal, are included as data; the use of laughter at the end of a sentence or the use of a metaphor to summarise a viewpoint when the speaker no longer wishes to add further information. Potter and Wetherell maintain that because there are many versions of reality, it is impossible to study the phenomenon (making ADs) itself. Rather, it is possible to seek how the phenomenon is constructed, how it is employed, and what functions or purposes these factors achieve. Potter and Wetherell (1987) propose that discourse analysis asks two questions: “how is the participant’s language constructed?” and “what are the consequences of different types of construction?” (p. 50).

Campbell and Arnold (2004) have observed the development of Potter and Wetherell’s work which mirrors changes in social psychology and linguistics. Initially Potter and Wetherell’s work was concerned with ‘performance utterances’ – descriptions within sentences that direct action; more recent work is now focussed on how people actively produce what is going on in conversations (Wetherell, 2001).

### *Influences on the Potter and Wetherell Approach*

As social psychologists, Potter and Wetherell were influenced by the work of John Austin’s Speech Act Theory in 1962 (Redwood, 1999). Austin was concerned with sentences as descriptions which can be verified or not, and his interest was in a sentence which performed an act. He called these ‘performance utterances’. Austin claimed that the general theory of speech acts was that all utterances state things and do things; language is a tool to get things done.

Another influence on Potter and Wetherells’ work was ethnomethodology, which was the work of Harold Garfinkel in 1967 (Redwood, 1999). Fundamentally,



ethnomethodology claims that participants actively produce what is going on in conversation. People, therefore, skilfully choose and use certain words and phrases to achieve desired social outcomes. The third influence on Wetherell and Potter's work is semiology; the linguist, De Saussure (1996) is attributed to this work. He stated that language is dependent on a system of relationships and that there are rules of acceptable sequences and combinations.

### *The Theoretical Perspectives*

Discourse analysis, using Potter and Wetherell's approach, is characterised by the use of text, not as an avenue to reach the true meaning of a phenomenon, which arguably does not exist, but as something to be studied in its own right. Discourse is thus seen as both the means and the topic of enquiry (Potter & Wetherell, 1987). Further, Potter and Wetherell proposed that discourse analysis was more of a theoretical perspective than a method; hence their more preferred term of 'approach' rather than 'method' when describing their enquiry of discourse analysis.

Potter and Wetherell's (1987) approach to data analysis is to look for regularities in the way participants interpret their responses during the interviews. The main analytical concept used to guide this search for regularity is termed interpretative repertoires. This term gives rise to the notion of searching for repetition of use of phrases/words, motives, or versions of events that reflect similarity. However, Wetherell (2001) contends that people's accounts of events, their motives, and the reasons for their actions are variable, even within the same interview. The participants 'speak' the repertoires and construct particular identities or subject positions using diverse constructions in pursuit of different social objectives.

### *Variability of Language Use: Interpretative Repertoires and Subject Positions*

As well as elucidating the variability of language use, Wetherell (2003) claims that the discourse analyst must be mindful of how a discourse is read, as the discourse or framework of meaning used by the speaker at any one time is constructing meaning for a purpose at the time the utterance is being made. Wetherell, Taylor, and Yates (2001b), would regard these meanings as having been ‘fabricated’ for a purpose at the time they are made, rather than the utterances representing the true nature of the world.

The purpose of data analysis is to examine human speech/writings, actions, and products (texts) and to identify and analyse these ‘ways of understanding’, or interpretative repertoires, used by the speakers. Therefore, interpretative repertoires represent not only alternative constructs of subjects and objects, but also often contradictory versions of events on the same topic within the same interview. To understand why and how a speaker is using a particular theme, the discourse analyst needs to look to the rhetorical context within which the participant is deploying it (Potter, 1996b; Willig, 2001). It is for this reason that I have included a detailed discussion in the data analysis chapter of how I have analysed how the subject positions of the participants construct the dominant repertoires making ADs. Underpinning this notion is the view that when participants speak, the repertoires they speak, form positions (Potter & Wetherell, 1987).

### *Summary*

In summary, Potter and Wetherell (1987) attest that people use language to do things such as to order and request, to persuade, and to accuse; and as a consequence, the focus on language function is one of the major components of discourse analysis. People use written or spoken language to construct versions of the social world and in so doing, will employ a variation of language use for this construction (Potter &

Wetherell, 2001). Potter and Wetherell are mindful that the intended audience will influence the way the language will be constructed (Antaki, 1988).

So far, I have discussed the notion that to enter into the study of discourse is to enter into debates about the foundations on which knowledge is built, and how subjectivity is constructed. These debates about the nature of meaning are underpinned by the theoretical and methodological foundations of the qualitative paradigm. The focus of discourse analysis in discursive psychology is on *how* participants use discursive resources and with what effects. In other words, discursive psychology pays attention to the *action orientation* of talk (Cheek, Shoebridge, Willis, & Zadoroznyj, 1996; Cheek, 2000). If meaning is constructed, then White (2004) claims that meaning can be deconstructed and that the ‘making of meaning’ is necessary for purposeful action. Humans construct ‘frameworks of meaning’, ‘interpretative repertoires’, or ‘discourse’ to make sense of the world.

Underpinning Potter and Wetherell’s (1987) approach of discourse analysis is that these interpretative repertoires are shaped by subject positions of the speaker and, in turn, the interpretative repertoires shape human action and determine the nature of the social world. Therefore, the purpose of my data analysis is to demonstrate what evidence exists of the formulating and reformulating of emerging repertoires from the participants’ subject positions when justifying and evaluating their making ADs in New Zealand.

### ***Establishing Trustworthiness***

The criteria for establishing qualitative research validity and reliability were derived from quantitative research (Koch, 1997). Koch argues that the trustworthiness, or rigour, of a study may be established if the reader is able to audit the events of the researcher. Sandelowski (1986) claimed that the issue of trustworthiness has become

synonymous with rigour within qualitative research. Similarly, Scheurich (1997) contends, “the essential meaning of validity came to be the warrant of trustworthiness. If a research study had the appropriate validity, the results could be trusted” (p. 81). However, the notions of reliability and validity have not been unproblematic in qualitative research. Payne (2002) quotes Sandelowski (1993) as questioning the assumptions underpinning the criteria for consistency or reliability in qualitative research. Sandelowski’s position is that assumptions are based on the belief that there is only one ‘tangible’ reality, which can be located by the researcher as she/he explores differences and questions why they exist (Payne, 2002). Such notions of the existence of multiple truths and multiple realities are characteristics of the poststructuralist paradigm. A poststructuralist perspective considers that the presentation of findings is tentative and limited when claiming validity and reliability to the ‘truth’ (Koch, 1994; Parker, 2004; Payne, 2002; Sandelowski, 1986; Scheurich, 1997).

It is my intention, in the data analysis chapter, to include extracts for the reader to establish how rigorously I attempted to be trustworthy to the findings according to Potter and Wetherell’s (1987) approach. I can only show how each interpretative repertoire was derived from the participants’ conversations, including what positions they chose to take to ‘speak’ the repertoire. In order to clarify my interpretation of the data, I have included extracts from the taped interviews to highlight the significant ‘talked’ sections that illustrate the function, construction, and variation in the participants’ use of language to create their versions and events of reality. This can only be done by returning to the original spoken texts and explaining the interpretative scheme. Such an approach explores the ways in which social reality is constructed within particular contexts through language (Potter & Wetherell, 1987).

### *Textual and Contextual Dimensions to Discourse Analysis*

Discourse analysis is composed of the textual and the contextual dimensions (Powers, (1996). By attending to the textual domain, I will be accounting for the structures of discourses the participants used to speak the repertoires; the extracts will be cited verbatim in the data analysis chapter as I seek for linguistic evidence to form hypotheses about the functions and effects of the 'talk'. Willig (2001) states, "detailed discussion of the researcher's analysis of the extracts must be provided. It is important to remember that extracts never speak for themselves...it makes sense to merge *analysis* and *discussion* sections" (p. 97). The contextual dimension will be discussing the various properties of the social, political, and cultural contexts in which the repertoires appear to be placed.

### *Summary*

Overall, my aim is to be faithful to the discursive strategies of Potter and Wetherell's approach in order to claim that rigour and trustworthiness were established as I try to ascertain the 'truth' from the transcripts and identify the organisational features of the texts. However, this is not to say that the criteria for claiming the truth in my findings are watertight or infallible. As has been stated previously, Savage (2000) contends that there exists a range of theoretical approaches which emphasise that reality is manifold, and there is no single way to view, interpret, or characterise that reality.

### *Ethical Approval and Ethical Considerations*

Confidentiality was assured and maintained throughout the study period by keeping the list of participants' names and addresses separate from the audiotapes and transcripts. To maintain anonymity the participants were each assigned a pseudonym; which was known only by the transcriber and me. The participants had the assurance that if they wished they were free to withdraw from the research. If they requested they

would be given a copy of the transcript to verify that it was a true and correct account of the interview, and to alter or remove any information that they wish not to be included in the study.

Once the data from the audiotapes were transcribed, the audiotapes were locked in a filing cabinet and were wiped after analysis. The consent forms and the data were kept separately in locked filing cabinets at AUT and after six years they will be shredded and destroyed, as required by AUT's ethics committee. The participants were assured of these details before they were asked to sign the consent forms.

I had anticipated that since the sensitive nature of the topic and the implications of making end of life decisions could lead participants to become upset during the interview, I was prepared to stop the interview immediately. The participants would be asked whether they wished to continue at a later date and would be given the option to withdraw from the study. Appropriate counselling by AUT services would have been offered if required. The participants, however, were comfortable with the interviewing and did not appear distressed at any stage of the discussions.

Ethical approval was obtained from AUTECH on 20 July, 2004 and granted until July 2006 (Appendix E).

### ***The Participants***

Criteria for the selection of the participants were: that they would be English-speaking adults; able to give their informed consent to participate in the research; that they would be people who lived in the community; and who had made, or were considering making, an AD. I did not want to specify an age bracket, although all the participants were over 50 years of age. All participants had appointed an EPA, three had made an AD, and three were considering making one. Since the interviews, two of the latter three participants have made ADs. In total, there were six participants. According

to Grant and Giddings (2002), when utilising a qualitative methodology, a small number of participants is desirable to ensure the collection of information-rich data. Potter and Wetherell (1987) maintain that the richness of data collected is more important than the number of participants in the study. After gaining permission from a community centre management, a flyer (Appendix A) inviting volunteers for the study was placed on a local community centre notice board. Three people responded to this flyer and the other three participants were obtained through snowballing sampling, using word-of-mouth. The flyer had information about the study and my contact details. When a respondent rang to express an interest I provided further information and sent them the information sheet (Appendix B). After two weeks, as stated on the information sheet, the volunteers were contacted to determine their continued interest and willingness to participate.

### ***Interview Process***

A date was set by each participant for the audiotaped interview and the consent form (Appendix C) was signed before the interview began. The interviews occurred in the participants' private homes. Most of the interviews lasted for one-and-a-half hours. The style of interviewing was semi-structured and informal. I had prepared some opening questions, asking them to tell me what led them to make an AD. My aim was to create a open forum for the participants to freely express their ideas.

### ***Data Analysis Process: Reading, Coding, and Analysis***

Procedural guidelines for the analysis of discourse was followed as suggested by Willig (2001). Each transcript was read before any attempt was made to analyse the data and the audiotape was listened to at least three times to check any gaps and errors from the transcribing. An independent transcriber was employed and a confidentiality

form was signed by her (Appendix D). The transcription notations were later added by me, and words or phrases that were emphasised by the respondents were highlighted, possibly indicating the presence of significant interpreted repertoires for coding. Willig (2001) claims that “reading [and listening to] the text before analysing it allows us to become aware of what a text is doing” (p. 94).

Coding involved the selection of material for analysis. It involved reading the transcripts for common repertoires referring to, for example; how the participants constructed utterances about making end of life decisions, how they constructed ADs, how they constructed who else would be involved in the decision making, what they believed was the purpose of making ADs, and how they constructed future choices if they lost competence at the end of their lives. It was important to make sure that the material was relevant to the research question and that I was being faithful to Potter and Wetherell’s approach by asking the questions, ‘why the utterance here?’ and ‘how is this person constructing this sequence of talk?’ (Potter & Wetherell, 1987). Potter (1996b) states, “people package their lives into narratives which they tell for a whole range of different purposes. The focus is on the **way** people construct descriptions as factual” (p. 6). I was mindful of the concern that talk and texts are part of social practices and are influenced by past events and historical discursive practices. For example, many of the participants told stories of significant events in their lives such as witnessing a death of a close family member. Consequently, these past experiences influenced the way they constructed and evaluated their subject positions making ADs.

Willig (2001) claims that the research question identifies a particular aspect of the discourse which is then explored in detail. Coding helped me to select relevant sections of the interview material which eventually constituted the data of three dominant interpretative repertoires.



Analysis proceeds from the coding by more in-depth interaction with the text. Potter and Wetherell (1987) recommend that “throughout the process of analysis the researcher asks the following questions, “Why am I reading this passage in this way?” and “What features of the text produce this reading?” (p. 168). Analysis involves paying attention to how the textual data is being generated or constructed from the speaker’s subject position, including ascertaining what features of language construction the speaker is using to construct the repertoire. In chapter four, I have identified the functional and constructive dimensions of discourse, with examples taken from the participants’ extracts followed by analyses of the texts.

Part of the analysis of the discourse was to identify the action orientation of accounts by including how the language constructed an account. Acknowledging reflexivity in the interview encounter was to acknowledge which accounts were produced, in what part of the conversation were they ‘worked up’, and for what purpose (Potter, 1996). Therefore, I analysed both my contribution and the interviewee’s contribution to the conversation. Wetherell (1999) claims, “the nature of the talk will be set partly by the conventions of interviewing” (p. 268).

### ***Constraints and Tensions of the Study***

I found the reading, coding, and analysis demanding as I was constantly re-reading and returning to the coded data for clarification over a period of nine months. The presence of contradictions and tensions among the interpretative repertoires used by the participants is illustrative of the many conflicting discursive practices and rhetorical contexts that can be deployed by speakers at any one time. Willig (2001) asserts that in discourse analysis “the analytical focus is upon the variability across contexts and the action orientation of talk” (p. 96). As a consequence, contradictions and tensions exist for the researcher. Potter and Wetherell (1987) and Billig (1997)

claim that writing a report is, itself, a way of clarifying analysis. It allows the researcher to identify inconsistencies and tensions and generate new insights for further study.

My primary concern of identifying dominant interpretative repertoires that are derived from the subject positions of the speakers using Potter and Wetherell's (1987) approach is reflected in the structure of chapter four presentation; I have merged the data analysis and the discussion sections, including relevant literature to support the discussion. This structure allows a more meaningful presentation of the analysis to take place within the context of a discussion of the insights generated by the analysis (Potter & Wetherell, 1987; Wetherell, 1998, 1999; Willig, 2001).

## ***Conclusion***

In this chapter, a general introduction to discourse analysis was discussed as groups of ideas or patterned way of thinking, which can be identified in textual and verbal communications that can also be located in wider social structures and influenced by past events. Language was viewed as productive; that is, language was seen to construct versions of social reality and to achieve social objectives. Wetherell, Yates and Taylor (2001a) claim that at the heart of discourse studies are some complex but potent and profound discussions on what it means to be human, what counts as *real* and what the *social* is (p. 5).

In the first section of this chapter the major components of the discourse analysis method were identified and the method was linked to the poststructuralist paradigm. A notable feature of qualitative methodologies is that they emphasise reflexivity and the important place reflexivity has on the role of language in the research process. I explored the ways in which I, as the researcher, could influence the outcomes of the research findings. Further discussions on reflexivity will be explored in the data analysis chapter.

In the second section of this chapter a more detailed discussion on Potter and Wetherell's approach to discourse analysis was examined, including a rationale of why this approach was chosen to identify how New Zealanders used discourses to evaluate and justify making ADs. Potter and Wetherell (1987) maintain that there are many versions of reality and they claim that it is impossible to study the phenomenon (making ADs) itself, rather it is possible to investigate how the phenomenon is constructed, how it is employed, and what functions or purposes these factors achieve. The objective of the next chapter is to analyse the data with these three factors in mind.

## **Chapter 4: Data Analysis**

### ***Introduction***

Willig (2001) recommends that the presentation of the analysis constitutes the most extensive section of a discourse analytic report. The structure should reflect both the research question and the emphasis of the analysis. The aim of this section, therefore, is to interrogate the texts in the interviews using Jonathan Potter and Margaret Wetherell's (1987) discursive approach, and to uncover the dominant interpretative repertoires from these texts.

When analyzing the data I looked for regularities in the way the interviewees justified making ADs in New Zealand. Wetherell (2003) purports that the 'subject positions' are located in sequences of talk. The participants were constructing their positions to justify their reasons for making ADs. To achieve this aim, the participants' talk was intensely situated using verbal devices of claiming, disclaiming, and evaluating the positions they held when making ADs. Notably, Potter and Wetherell (2001) claim that the notion of construction emphasises the potent, consequential nature of accounts and that most social interaction is based around dealings with events and people and are experienced only in terms of specific linguistic versions.

Verbal devices like blaming and justifying are not necessarily consciously used by the participants, but the devices emerge as the participants are merely trying to make sense of phenomena they are constructing. This accounts for the variability of language use for a purpose in a particular setting. Therefore, the interpretative repertoires emerge from particular identities or subject positions constructed by the participants. Interpretative repertoires are relatively global patterns of explanation, evaluation and description, or sets of connected arguments from the participants' subject positions (Billig, 1987).

The interpretative repertoires are described to have three interconnected concepts of function, construction, and variation (Antaki, 1988). The fact that discourse is oriented to different functions means that it will be highly variable; what people say and write may be different according to what they are doing or aiming to construct for what purpose at any one time. Speakers often give shifting, inconsistent, and varied descriptions of their social worlds. Potter and Wetherell (1987) assert that identifying variability in accounts has a crucial analytical role.

I will use examples taken from the transcripts to validate the emergence of interpretative repertoires followed by a discussion on how the participants deployed the interpretative repertoires to justify making ADs. To validate the presence of an interpretative repertoire I will be including corresponding extracts from the transcripts. A discussion of relevant literature that ‘constructs’ and reiterates the interpretative repertoire and subject position will be identified as part of the analysis.

When analysing the data, initial attention was drawn to what was going on for the participants themselves. This version of discursive psychology insists upon seeing all such sequences of discourse as embedded within some kind of historical and social context (Wetherell, 1998). Willig (2001) succinctly summarises what needs to be taken into account when analyzing interpretative repertoires:

we need to take into account *both* the availability of interpretative repertoires within a particular social and cultural formation and the participants’ local concerns *and* their realization through discourse within a specific interaction. While a focus on *discursive practice* helps us to understand *how* speakers construct and negotiate meaning, a focus on *discursive resources* helps us to answer questions about *why* speakers draw on certain repertoires and not others [italics added]. (p. 10)

As well as identifying interpretative repertoires, subject positions are also considered in the analysis. Edley (2001) proposes that the way people experience and feel about themselves (their subject position) and the world around them, draws people into particular positions or identities. Wetherell, Taylor and Yates (2001b) make a similar point and argue that people are re-constituted as subjects when they encounter discourses; the discourses are not 'pre-formed' before the encounter. Payne (2002) contends that "just as there are multiple discourses there is the possibility of multiple subject positions. Subjectivity has the potential then, to be contextual and contradictory" (p. 19). Therefore, the function of the participants' language is to construct their subject positions. "Subject positions can be defined quite simply as 'locations' within a conversation. They are the identities made relevant by specific ways of talking" (Wetherell, Taylor & Yates, 2001b, p. 210).

Hence, Potter and Wetherell's approach to discourse analysis does not take for granted that the accounts reflect underlying attitudes or dispositions and therefore there is no expectation that an individual's discourse will be consistent and coherent.

The focus of this approach is on the way people construct descriptions as factual. However, according to Potter (1996a), it takes work from the speaker to produce a description that is convincing and factual. Even though natural conversations appear messy with hesitations, incorrect grammatical use, and pauses, they are still organised in a subtle and artful way. The transcribed detail, such as an underlined word to indicate that the speaker emphasises the word, is an example of an intrinsic and essential part of the interaction that is captured by the transcriber (Potter 1996a).

### ***The Findings***

There were three dominant interpretative repertoires and three associated subject positions that emerged from the findings and these were evident in the transcripts. The

six participants worked across these repertoires, demonstrating that they drew variably and flexibly on all three.

### ***Interpretative Repertoire No.1***

Readiness to make an informed decision after witnessing an undesirable death

**Subject position:** the strong, self-determining decision maker.

The following extracts are examples of the participants' subject positions as they justified what led them to seek information and what eventually led them to make ADs. The extracts illustrate not only the participants' accounts of events, their motives, and the reasons for making ADs, but also how the interpretative repertoire of readiness to make an AD was a significant notion that emerged as the participants constructed their arguments. The subject position at stake here constructs a person who is a strong, self-determining decision-maker.

Penny was at the time a 55-year-old woman who had made an AD and who valued being an independent decision maker.

#### ***Extract 1:***

- p. 1    **1.    Int:** ....I just wondered what lead  
2.       you to, to seek this information or to get an Enduring  
3.       Power of Attorney or make an Advanced Directive?  
4.       Was there any event or did anyone tell you about it or...?  
**5.    Penny:** No there was no event and look when we went to the  
6.       lawyers to update our will we had had quite a few  
7.       events and we thought was you know it does give  
8.       you that little shift to do it and, and he gave us the  
9.       information and I chose after reading the  
10.      information and my husband didn't.  
**11.   Int:** So there was no real event?  
**12.   Penny:** I have really strong feelings that I should make  
13.      decisions about myself.  
**14.   Int:** Yeah, yeah.  
**15.   Penny:** Um. I've had to make decisions for other people at  
16.      times and I think that it is emotionally difficult.

At the beginning of the excerpt Penny positions the lawyer as someone who holds information on EPAs and ADs, and who needs to prompt someone to use this

information to make an informed choice. She recalls that it was after this encounter with the lawyer that she was determined in her resolve to make a written AD.

In the first extract, Penny sees herself as knowing what she wants and she speaks from a position as a self-determining individual. This is implied again in L. 12 as she constructs this position, calling on a discursive strategy known as ‘persuasive orientation’. Potter and Wetherell (1987) claim that this strategy, which they refer to as an extreme case formulation, is an example of how participants actively produce what is going on in conversation. Penny deliberately emphasises the words and raises her voice to state that she has ‘really, strong feelings’ to justify her reasons why she acts independently – if the feelings are ‘*strong*’ enough it will lead a person to be independent in decision making. She justifies this stance by claiming that decision-making on behalf of others is emotionally difficult, therefore by making decisions herself, she relieves others from having to make decisions on her behalf.

Penny went on to say:

*Extract 2:*

- p. 2    48    **Penny:** He ((husband)) didn’t disagree with it he just did, yeah, yeah.  
          49    He just said ‘I’m not ready’ and I knew that didn’t
- p.3    1       really mean he wasn’t ready for that, that meant a  
          2       whole lot of other things, and that’s fine.

Penny portrays her husband as someone who, even though he has read the information, has chosen not to make an AD. Further on in the interview, Penny justifies why the husband’s choice is not to act on the information. She claims that he is simply not ready. An AD is constructed as a ‘discursive object’ that is made only when it is the right time and when a person is in the right frame of mind and time to be ‘ready’ to make and write decisions of this nature.



There is evidence of the variability of language in that Penny then positions herself as judging and contrasting her husband's reasons for not acting on the information as related to a 'whole lot of other things' and not just 'readiness'. However, she concludes this section of 'talk' by claiming that she comes from a position of understanding about his reasons for not making an AD and then concludes by stating that 'and that's fine' (p. 3, L. 2).

It appears that this interpretative repertoire is being constructed as it shifts between her position as an independent person who has inner strength and confidence to make decisions, to being able to judge why another person would not be ready to make decisions. The motivation behind this sequence of talk is that Penny is constructing a position of being a person who can evaluate others with understanding and quotes her husband's indecisive position as an example of her understanding his reasons for not making a written AD. The extract demonstrates the claim that talk consists of a complex linguistic structure of conditions and contrasts (Potter & Wetherell 1987; Wetherell, Taylor & Yates, 2001b).

Molly was in her mid-60s when her lawyer initiated the topic of appointing an EPA and making an AD. The lawyer advised Molly and her husband to act on the information he was giving them.

*Extract 3:*

- p. 1    7        **Molly:** ...the lawyer advised us to get it and to do it  
          8        **Int:** Right and did he say why he thought it was a good idea?  
          10       **Molly:** Yes  
          11       **Int:** Yeah  
          12       **Molly:** Well, he explained it but we never realised the significance of it  
          13       till later, (3) yep!

Molly appears to be justifying why they did not initially act on the lawyer's advice. They had to **witness** an event to understand the significance of the lawyer's information. The use of the word 'yep!' in L. 13 seems to indicate her need to confirm

to herself why they eventually were ready to act. The three second pause before ‘yep’ was a possible indication of her needing to think first before she confirmed that it was right to act on the lawyer’s advice. However, this information was not in itself enough to lead to action, there was a significant event that Molly witnessed, of a family member’s death, that led her and her husband to act on the lawyer’s advice. Later in the interview, Molly said:

*Extract 4:*

- p. 1 21       **Molly:** Um the people running the hospice decided that he  
22       should have the cocktail....  
23       and his wife didn’t really  
24       want him to be put down like a dog  
25       **Int:** Mmm
- 43       Well she had got the Power of Attorney some  
??       months ago before...  
47       and he[doctor] insisted that she ring the lawyer...
- p. 2 1       yeah, she had to go home and produce the written  
2       evidence that she had...  
3       **Int:** [that she had it written down  
4       **Molly:** Mmm, yes.  
5       **Int:** And did she come back with it?  
6       **Molly:** Yes.  
7       **Int:** And how did he see that?  
8       **Molly:** Um (.) well he lost it a bit. I think he was more  
9       annoyed than anything, that he didn’t have the  
10       complete control that he thought he had.

This fourth extract locates the significant event in a hospice setting where Molly’s sister, as the EPA for her dying husband, is requested by the medical personnel to produce evidence that she has this power to act on behalf of her husband. Molly positions herself as a witness to the event, and constructs the following account to justify why she needed to return to and act on her lawyer’s advice to appoint an EPA. Molly had not indicated at this stage whether she had made a written AD with the lawyer.

The event is situated around the doctor's decision to give Molly's brother-in-law increasing doses of morphine near the end of his life. The family believed that the brother-in-law was not in pain and did not need to be given larger doses of morphine which they feared would end his life prematurely. In L. 24 the association is that dogs are given drugs for the purpose of ending their lives. Molly associates this medical decision making as the same as terminating a dog's life. Molly represents the situation in a deliberate extreme way by using the idioms, 'to be put down like a dog' and 'to have a cocktail'. She employs this discursive strategy of idiom usage to emphasise the significance of the event that she has witnessed. Drew and Holt (1989) have studied the use of idiomatic expressions when people make complaints. They maintain that idiomatic use emphasises the importance of the complaint.

### ***Idiom Use in Conversation***

An idiom is defined as a group of words whose meaning cannot be predicted from the meanings of the constituent words; it is considered linguistic usage that is grammatical and natural to native speakers of a language (Collins English Dictionary, 1991). This discursive strategy of idiom usage is noteworthy in discourse analysis since the speakers are constructing concepts that have 'locations' in their historical and social backgrounds (Billig, 1991). Molly is from a farming background and although she would have witnessed putting the farm dogs 'down' to bring on their deaths in a peaceful way, she equated this idiom of 'to be put down like a dog' in less favourable terms when she applied this to her brother-in-law's situation. By using this idiom, Molly was possibly inferring that her relative was considered by the health professionals as past any further medical intervention and death was seen as a welcome relief.

Wilkinson and Kitzinger (2000) highlighted several features of idiomatic usage to understand how people use them in conversation; first, that idioms are vague and general and are often used to summarise a repertoire of talk to convey the overall substance of what has been said. Jefferson (1995) proposes that idioms are simply invoked and are not engaged by careful introspection. A second feature of idiom usage is that their use is not neutral but intended to move the conversation on in a particular way (Edwards & Potter, 1992; Potter, 1996). Notably, Wilkinson & Kitzinger (2000) claim that to contradict an idiom is to run the risk of challenging the shared cultural membership on the basis of which conversation is assumed possible.

Molly had worked as a nurse, and from a discursive perspective, when she describes what the dying situation is like for her brother-in-law, she differentiates herself as an onlooker as a past nurse from the other family members involved. During the interview her use of idioms with me is an example of a commonplace generality upon which both of us, knowing the culture of nursing, can concur; it could be seen as positioning the interviewer in a context of a presumed-shared norm and a sense of belonging to a culture where the idiom is understood in a specific, medical setting.

Molly witnesses the significance of producing a written, legal document that she sees stops the doctor having complete control over end of life decision-making. Molly recalled the strained atmosphere between the doctor and the family when she said:

*Extract 5:*

- |      |    |  |
|------|----|--|
| p. 2 | 39 | <b>Molly:</b> because they were insisting on doing their own thing           |
|      | 40 | and she ((the daughter)) called her mother to come up for support. <u>It</u> |
|      | 41 | <u>was terrible.</u>   |
|      | 11 | <b>Int:</b> And then what did he do with that ...                            |
|      | 12 | information, did he acknowledge  |
|      | 13 | it and say well  |
|      | 14 | <b>Molly:</b> [well yes, because he had to, but the                          |
|      | 15 | atmosphere was (3). <u>Yeah, yeah</u>  |

p. 3    26    **Molly:** ...and I only know what I saw.  
           27    **Int:** So therefore that led you to what, witnessing that  
           28    and sort of feeling well could this happen to me?  
           29    **Molly:** Yes I rang to see what we had to check up that we  
           30    had  
           31    **Int:** [( ) personal care and welfare  
           32    **Molly:** Yes, yeah.

The representation of the legal document is constructed as an object of power, which the family had to produce to gain back some independence and gain some position of power in decision making as advocates for the dying family member. Notably, a verbal assurance by the wife that she was the EPA and knew what was best for her husband, appeared not to be accepted or valued by the doctor.

Eventually in Ls. 39 – 41, p. 2, Molly evaluates the significance of witnessing this scene in an emotionally charged way, claiming that it was terrible to witness. Because she was there, Molly takes up a subject position as an informed witness who now understands the significance of owning the legal document of an AD and appointing an EPA.

In L.15 Molly's position shifts the emphasis to the atmosphere around the undesirable death rather than the medical encounter. This is an example of the potent consequential nature of accounts being constructed to produce active selection where some information is included and some may be deliberately omitted (Potter & Wetherell, 2001). Molly appears to choose not to complete the sentence but instead utters to herself, 'yeah, yeah'.

It was as a result of witnessing her brother-in-law's death that Molly felt ready to see her lawyer to make an AD and appoint an EPA. She positioned herself as being strong and determined in her resolve to make her end of life decisions known in a written AD. She trusted that a written AD and the appointment of an EPA was one means of having her wishes respected.

Both William and Anna, who are husband and wife, had each made an AD and appointed their son as the EPA. Although William tended to dominate the conversation, Anna was clear about her own views and positioned herself as being an independent decision maker who did not necessarily share the same thoughts as her husband. At the beginning of the interview, William read his AD in order that I, as the interviewer, was left in no doubt that he spoke from a position of a self-determining, strong, and informed decision maker about what he wanted if his dying was being prolonged unnecessarily.

*Extract 6:*

- p. 9    11    **Int:** ...they can go over your  
           12    wishes if they believe that in your best interest it  
           13    might be better not to um – what's another term I  
           14    could say – let you die  
           15    **Anna:** let you die, yes, in other words they have an idea  
           16    **Int:** yeah  
           17    **Anna:** that you could  
           18    **William:** [but surely once you go on the um  
           19    **William:** I think my reaction would be no.

William concluded that he was definite that he would not want his death prolonged and his answer in L. 21 would be 'no' to future life-prolonging treatments.

Later he added:

*Extract 7:*

- p. 11    5    **William:** I think there is a certain responsibility of the legal  
           6    fraternity, is that when they prepare a will, equally  
           7    the same they should carry on with the enduring  
           8    power of attorney etc and this (.) um – I gather at the  
           9    time when we went into it wasn't a thing that the  
           10    legal people said, they would do it for you if you  
           11    asked.  
  
           14    **William:** But wouldn't brought up like a will, arh, which I  
           15    think it should be part and parcel of the legal ( ).

In extract 7, Ls. 5 – 11 are examples of discourse that is neither coherent nor consistent. Interestingly, William now shifts his focus to explaining what the legal

fraternity ought to do and when it should be done. He changes his position of being responsible for his own decisions, to claiming that lawyers have a responsibility to inform people so they are able to make informed decisions about ADs and EPAs. He states that it is not for people to initiate this discussion, but instead, he attributes blame on the legal profession for not initiating these discussions. William appears to continue to blame lawyers for being selective about what information they share to inform people about the existence of ADs and EPAs. By using the idiom in L. 15 ‘part and parcel’, William concluded his discussion about the legal responsibilities of giving clients that right information to help them to make an AD. During the interview Anna claimed:

*Extract 8:*

- p. 11 47     **Int:** and to you that’s important, to be able to be in  
        48     control  
        49     **Anna:** You have to be independent as much as possible.

Anna’s concluding remark highlights her position to speak of the value of being independent. She makes a general declaration and emphasises the ‘have to’ to stake a claim of fact. Stating this in L. 49 as, ‘as much as possible’ is the extreme case formulation to add persuasion to the claim. This sequence of talk in L. 49 illustrates the emerging dominant interpretative repertoire that strong people maintain their independence.

### ***Discussion***

The interpretative repertoire of readiness to make an informed decision after witnessing an undesirable death emerges from the participants identifying themselves as strong, self-determining individuals who have a clear sense of how they wish to be treated in similar circumstances to those deaths they have witnessed. Because they

value these attributes, they are able to make informed decisions about end of life treatment choices in the ADs.

When analysing this repertoire further, questions arose; what other contributing qualities enable people to make future decisions about their end-of-life care and what triggers them to do so when they are well and not terminally ill? Witnessing a former undesirable death and a state of readiness to make an AD were alluded to by the participants. The conclusion, therefore, is that an AD is a means of avoiding an undesirable death. The power of legal discourse and the witnessed role of medical decision making at the end of life appeared to be other contributing factors as to why the participants made ADs. Although I acknowledge there may be other related repertoires or themes emerging from the above extracts, I would argue that these two factors are significant.

Miles, et al. (1996) – in a research review of advance end-of-life treatment planning – stated that the most common reasons for not having an AD are procrastination, apathy, and a belief that the family will and should decide what is best for them near the end. The research uncovered people's discomfort in discussing the topic of refusing life-sustaining treatments at the end of life. According to Miles, Keopp, and Weber, one of the major fears stated by people is the fear of the irrevocability of an AD.

#### *Who Completes an AD?*

The participants in this study appeared physically and mentally well and they did not express any fear or discomfort about making ADs. Once they were informed about the legal details involved in the making of ADs by their lawyers, the participants positively embraced the right to do so, and stated that they did not want invasive life support if their inevitable death was being prolonged.



Although this study consisted of a small group of participants, it did represent some similarity to other studies that identified what kind of people complete written ADs. Despite not directly asking the participants for demographic information, I did know that one was a practising health professional, four were retired professionals from nursing and teaching, and one was a retired qualified engineer. They all appeared to be European, middle class New Zealanders and would seem to be similar to the profile suggested by Stelter, Elliott & Bruno (1992). Studies from the USA have claimed that people with ADs are better educated (George, 2002; Nolan & Mock, 2004; Stelter, Elliott & Bruno, 1992; Tulskey, 2005) and come from higher socioeconomic classes (High, 1993). Miles, et

al. (1996) respond to these claims by purporting that this may suggest a greater trust in the healthcare system, a better ability to complete documents, or values especially favourable to ADs. People with ADs are less inclined to accept aggressive life-sustaining treatment, especially in the instances of permanent dependence on invasive life support (Schneiderman, Pearlman, Kaplan, Anderson, & Rosenberg, 1992; Walker, Schonwetter, Kramer, & Robinson, 1995).

### *Lawyers and Legal Representation*

It has been claimed that lawyers were the professionals who initially raised the discussion about ADs and EPAs and not the participants' doctors. Although I acknowledge this is anecdotal evidence, it may indicate the powerful, and yet trusted position most lawyers appear to have in New Zealand society in matters of will-making. The law and legal regulation appear to permeate almost every aspect of life. It could be argued that they are so dominant in our society that they are taken for granted and accepted as is. The way the participants talked about visiting their lawyers and their

trust in their advice may be used as an example of the way talk is constituted of social life and cultural discursive practices (Edwards & Potter, 1992).

In summary, law dominates the experiences of the everyday, including anticipated end-of-life decision making, and constructs them into legal issues that a client needs to be informed about. Smart (1989) contends that it is principally this power – the ability to claim its ‘truths’ over others – which gives law its ideological dominant status. This is represented by the participants’ positioning their legal advisors as having privileged knowledge about ADs and EPAs.

Zussman (1992) claims that presently there tends to be a shift away from medical dominance in healthcare to a focus on patients’ rights and legal rulings. Medical science advances and medical dilemmas often require legal clarity before clinical judgments can be made. However, clinical judgments in the medical setting are just as important in the shaping of a judgment, as is recourse to legal ruling (Capron, 1998). Legal notions of autonomy and informed consent dominate the delivery of care in the health service (Melia, 2004). It could be argued that as Western societies become more litigious, there is a need for medicine to turn to the law courts for judgments, including clarification of decision-making in ADs and end-of-life treatment decisions (Kendrick & Robinson, 2002). The clarification could possibly relate to the patient’s right to autonomy to make end-of-life decisions and the health provider’s responses to a patient’s previous consent written in an AD (Johnson, 2004).

The participants appeared comfortable speaking to their lawyers about life and death decisions. Only one participant, Penny, mentioned that she had told her doctor that she had made an AD. Penny perceived that her doctor was uninterested in her AD. Broadwell, Boisubin, Dunn, and Englehardt (1993) maintain that doctors are not comfortable discussing end-of-life issues with their clients and tend not to initiate such

discussions. Docker (2000) claims that doctors have difficulty considering whether to withdraw life-sustaining treatments and are therefore not comfortable discussing these outcomes with clients and the families. Ott (1999) found that significant barriers to the discussion of ADs between doctors and patients are two-fold: the first is doctors' erroneous beliefs that ADs are unnecessary for healthy patients, and secondly, doctors' lack of knowledge about how to formulate ADs when requested by their patients. Doctors' time constraints and lack of comfort with issues relating to decisions about death and dying were significant issues contributing to the barriers put up by doctors (Morrison, Morrison & Glickman, 1994).

### *Timing the Discussion of Advance Directives*

Inman (2002) purported that discussions concerning ADs were often not held in advance with healthcare professionals, and as a consequence, it was not until an individual became incapacitated that the issues were raised by the family or the EPA. Concluding remarks from Inman's research suggest that discussions about ADs ought to occur at clinic visits where extended, sensitive dialogue about end-of-life treatment decisions can occur with well patients. For Penny and Molly, part of the undesirable deaths that they witnessed involved poor communication or discussion between doctors and the family. These deaths may have been less traumatic for them to witness if sensitive dialogue had occurred earlier between the patient, family members, and the doctors before the dying patient had become incapacitated.

Helping the older adult to understand their treatment options and to plan end-of-life care in advance, as well as assisting them execute an AD and review their decisions, is part of the pivotal role of health professionals (Mezey, Bottrell and Ramsey, 1996). Rather than this ideal, however, the participants indicated that they relied instead on the legal profession to initiate AD discussions.

### *Autonomous Decision-makers*

Another feature of how the participants justified making ADs was their value in being autonomous decision makers. Autonomy and self-determination are the ethical and legal bases for ADs. The concept of autonomy is a fundamental ethical principle, closely related to the freedom of the individual to make a choice and decide what treatment and care they want for themselves in the future (Castledine, 2003). Everyone is entitled to decide what should and what should not happen to them and people can expect to have the decisions they make respected. Beauchamp and Childress, (2001) suggest that autonomy has acquired meanings as diverse as self-governance, liberty, privacy, individual choice, and freedom of will. Despite the different interpretations, the autonomous person can generally be considered to be free from the controlling influences of others and from limitations that restrict meaningful choice. The participants spoke of a readiness to be autonomous. Penny positioned herself as being free to make an AD without the influence of her husband's lack of readiness to make his.

### *Summary*

In summary, evidence suggests that people who wish to have a strong voice in determining the nature of the medical treatment they receive, and to exert control over their living and dying, appear to be strong, competent, autonomous individuals (Castledine, 2003). This is congruent with the subject positions taken up by the participants when they rationalised their reasons for making ADs. Although the repertoire emerged from these subject positions, the justification for making an AD was derived from the majority of the participants first witnessing an undesirable death, and after considering their own deaths in the future, becoming determined in their resolve not to replicate that undesirable death at the end of their lives. The next step was then a

readiness to seek informed legal advice to formulate their end-of-life treatment wishes in ADs. Therefore, it is arguable that the interpretative repertoire emerged from the regular way the participants described these sequences of events of witnessing and readiness from positions of strong, self-determining, and autonomous individuals who can make independent decisions.

Closely associated with the first interpretative repertoire and the notion of witnessing an undesirable death, is the following repertoire, which emerges from judgements the participants made about the futility of inappropriate treatments given to dying family members. The subject position taken up in this interpretative repertoire was 'the judge of a dignified way to die'.

### ***Interpretative Repertoire No.2***

Desiring to determine the appropriate and inappropriate treatments at the end of life.

**Subject position:** the judge of a dignified way to die.

Closely associated with the first interpretative repertoire and the notion of witnessing an undesirable death is the following repertoire, which emerges from judgements the participants make about the futility of inappropriate treatments given to dying family members.

The interviewees developed sequences of talk concerning appropriate and non-appropriate treatments that they would want at the end of life. The participants were generally ambivalent toward life-sustaining procedures that they judged resulted in a precarious and burdensome existence for the dying patient. The participants themselves were concerned that in the future they could be condemned to live indefinitely in a 'vegetative state'. They claimed that this was living in an undignified way and therefore

they would choose to have life-sustaining measures withdrawn even if that resulted in their deaths.

According to Antaki (1988), speakers are doing three things when they speak a repertoire: firstly, they are invoking a social identity; next, they are negotiating what the features or boundaries of those identities are; and thirdly, they are accumulating a record of having those identities. In the following extract is a clear example of these three processes in action when Penny positions herself as a judge when boundaries around prolonging life unnecessarily are decided.

*Extract 1*

- p. 1    24    **Penny:** Um (.) I think that fact that we were so lucky that we  
25    had, I had three siblings that agreed with us when we  
26    were asked questions like do you want, you know,  
27    well I considered over the top care to keep life going  
28    when it's probably been over and I was grateful for  
29    that, like we all agreed and when you hear about  
30    people who don't and I – yeah I'm just aware that  
31    there can be a lot of hiccups along the way and I  
32    don't want that. I don't want to put that on my kids  
33    basically.  
34    **Int:** Yeah  
35    **Penny:** Mmm.  
36    **Int:** So is there anything in particular and you say that  
37    you would find that you would not want, in  
38    particular like um any treatment that comes to mind?  
39    **Penny:** Well basically I don't want to be put on life-support  
40    if I am brain-dead or if I'm – you know, if my life  
41    quality is gone, yeah. Um to me it's pretty – it's an  
42    easy thing but I know for people it isn't. They think  
43    being alive is okay. I don't think just being alive is  
44    okay, yeah.  
45    **Int:** So part of that's really talking about dignity?  
46    **Penny:** Yeah it is, it is and also there are a lot of treatments  
47    that are forced on people that really they save them  
48    for three months and I'm not interested.

Penny's social identity was as part of a sibling group that could agree to withdrawing end-of-life treatment for a family member. This account appears to influence her present position by clearly stating what she would or would not want for

herself at the end of her life. She constructs the event, not so much from the angle of the dying relative, but as someone who was lucky and grateful that she was part of an agreeable family group that did not want 'over the top care' for their dying relative. She clarifies her position by stating that a dying person's identity is realising and accepting that life is over, and that there is nothing to be gained by keeping life going for the sake of it. This is an example of Penny negotiating the features about where the boundaries lie for her identity as a dying person in the future.

Penny then adopts a position of evaluating what it must be like for others not to be in agreement. She uses the idiom, 'there can be lots of hiccups along the way'. By using this idiom, Penny attempts to summarise the consequences for people who cannot agree amongst themselves when end-of-life decisions need to be made. The idiom is used as a discursive strategy to summarise the ongoing problems that a dying scenario can have for all involved, and to draw a conclusion to this particular repertoire of 'talk'.

Antaki's third point of speaking a repertoire by accumulating a record of past identities to justify a present and a future position is evident when Penny returns to her present identity by concluding that her future position is definite about decision making at the end of her life when she states, 'I don't want that' (she is recalling the past memories of watching her dying relatives being given what she considered 'forced' treatments near death) and, 'I don't want to put that on my kids basically'. The experience of family or surrogate decision makers not knowing what someone would want is avoidable if a person's dying wishes are known in advance by the family. The expectation is that fewer problems ought to arise for surrogate decision makers if they are asked what the dying, incapacitated person would have wanted. Penny states that as a mother she does not wish to cause anguish for her children when she is dying, and that

they know that she has made an AD clarifying her wishes for them so that they make the right decisions on her behalf.

The extract above demonstrates how Penny is drawing on past experiences of being present when close family members died in what she identified as witnessing ‘in anguish’ deaths when over the top treatments were being offered to her dying relatives. Penny is accumulating a record of identities from these past experiences to justify why she is adamant that she would not want her children to be in similar positions as she was positioned in the past. The highly context-specific descriptions of Penny’s accounts from Ls. 24 to 38 are purposely constructed to justify her position for making an AD: this is captured in Ls. 39 and 40. Penny uses the word ‘basically’ to emphasise her stance that if in the future she had no quality of life she would not want life-sustaining treatment.

In Ls. 42 to 44 Penny denies that making decisions for a dying relative is hard – instead, she claims that for her it is easy, however, for others she thinks it is potentially hard. For these ‘others’ she constructs and evaluates them as having problems because they appear not to know what to do in the situation. Penny then concludes that it may be okay for them, but not for her. I believe that she is attempting to emphasise that she is in a different position to others, in that she can ward off potentially uncomfortable attributions associated with making death and dying decisions for others. Penny uses the discursive strategy of persuasive orientation, by employing the word ‘just’ in L. 43, to emphasise the point of what would be unacceptable to her. Although I asked her whether what she was really talking about was dignity, Penny instead, in response, constructed another situation, and contends that treatments are forced on people. What appears to emerge is that she views the forcing of treatments on people as a socially undignified act when the only gain is giving a person a few more months of prolonged



dying. She then introduces and evaluates an exact time factor of ‘three months’ which, according to her, is an unacceptable period of time to keep someone ‘saved’. The time and the purpose for keeping someone alive are constructed as examples of undignified death, which she evaluates would not be in her interests. The model of identity that she constructs is a version of medical practice in New Zealand, where she states that it is acceptable to have a ‘wait and see’ approach, while at the same time forcing treatments on dying people with no good outcome to be gained. This ‘talk’ from Ls. 24 to 48 indicates a complex construction of using, for example, discursive strategies of blaming others and justifying her responses but intermittently emphasising where she is placed – L. 32, ‘I don’t want that’; L. 39, ‘I don’t want to be put on life support’; L. 43, ‘I don’t think just being alive is okay’; and on to the final evaluation that summarises her overall subject position in relation to this repertoire cited in L. 48, ‘I’m not interested’.

Penny continues to elaborate on the ‘forceful’ inappropriate treatments offered to dying persons; treatments that she judges are not giving them quality of life:

#### *Extract 2*

- p. 4    5        **Int:**...I don’t know how  
           6        you feel about their [doctors’] decision making about other  
           7        people, in that do you think they have a right or go  
           8        over what people might be asking?  
           9        **Penny:** Well I know they do because I’ve seen it, I’ve seen  
          10       it. With my own father they were talking about  
          11       putting a pace-maker in and I knew he was in kidney  
          12       failure he didn’t want to be there. I mean they  
          13       talked about it, I just looked at them  
          14       **Int:** [so how did that  
          15       **Penny:** [but there wasn’t any force to resist ‘oh you know  
          16       maybe we will do a pace-maker’ and I said ‘( ) over my dead body’  
          17       um hhh you know. So I know they do try. I  
          18       mean  
          19       **Int:** [How do they react to you then?  
          20       **Penny:** Well only that he just said, he just stopped talking  
          21       about it and moved on.  
  
          30       **Penny:** ... I don’t know  
          31       because you know doctors are forceful people when they

32     so decide they want to play God.  
 33     **Int:** I suppose what they are driven with it is making sure  
 34     they've covered everything that  
 35     **Penny:** [yeah also what is it  
 36     their job to do, it's to save lives and sometimes they  
 37     just lose track, well yeah, but you know and some are  
 38     great, you know I mean you find doctors who are in  
 39     palliative care are fantastic because they understand  
 40     that process.  
 41     **Int:** Yeah  
 42     **Penny:** but not all doctors are exposed to the process.

Penny is adamant that the situation of inappropriate treatments given to dying people (as she illustrates, above) exists because she has been a past witness to such an event. Potter (2001) discusses the features of claiming to be a witness to an event:

One of the effective features of witnessing as an identity is that the witnesses' description is a report of the scene as perceived as opposed to being a broad formulation or interpretation of events. It provides the details that were seen or heard and allows the recipient of the description to make the inferences. The role of judging and evaluating is seemingly passed on to the recipient. (p. 70)

Penny recalls an event where she positions herself as an advocate to contradict the doctor's decision making, as well as a powerful opponent to what the doctor is proposing. She positions the doctor as having to acknowledge her resistance to what she considers unnecessary treatment. She evaluates why doctors see themselves as powerful but, in L. 36, she appears to contradict her former stance by qualifying that doctors do have a worthwhile purpose, but then accuses doctors of, 'just [losing] track'. This is an example of the variation in language that exists in the construction of different versions on the same topic.

Potter and Wetherell (2001) contend that when a person provides an account of how they see reality, variations and contradictions in the account often emerge as they try to make sense of a phenomenon for the listener. This may account for the

considerable variation in Penny's account of blaming, extolling, and then accusing doctors of over-treating people at the end of life. Initially, Penny appears passionate about the negative consequences of a doctor's powerful role in decision making without thinking of the futility of the outcomes. She later describes a palliative care doctor's purpose in society as warranted and 'fantastic' – L. 39. This sequence of talk illustrates the comment by Potter and Wetherell (2001) that the researcher must be wary that an attitude stated by a person at any one time is enduring; instead, they contend that enduring attitudes are theoretically redundant.

A significant task in discourse analysis is to study how people, cultures, and societies 'do' emotions through the study of their discourse in relevant situations (Edwards & Potter, 1992). In effect, Edwards and Potter claim the study of emotional talk is the study of what emotions are for, and what experiences – even of traumatic encounters with doctors described above – can be in the broader discursive context. Penny's version possibly signifies the broader discursive context of palliative care doctors' role in New Zealand as one of understanding experiences around death because they are constantly exposed to the needs of dying people. In L. 40, Penny clarifies this difference 'because they understand that process'. The 'process' refers to the knowing and understanding of appropriate treatment decision-making for dying people and providing expert palliative care aiming to treat the symptoms and keep dying people comfortable.

For William the ideological image of a 'good death' is not being subjected to being put on a life support machine.

### *Extract 3*

- |      |    |   |
|------|----|---|
| p. 4 | 20 | <b>William:</b> yeah and as far as I'm concerned and I think it's the |
|      | 21 | same with you]  |
|      | 22 | [ <b>Anna:</b> hhh, yeah]   |
|      | 23 | <b>William:</b> [and if um they put me on <u>that</u>                 |

24     machine and it's just prolonging things for nothing I  
 25     mean I can't even have gin and tonic ( )  
 26     **Int:** Well exactly  
 27     **Anna:** hhh  
 28     **Int:** Well we probably could arrange  
 29     **Anna:** [hhhhh]  
 30     **William:** it won't taste as good though that's all.

In this extract, William considers a wider notion when speaking about this second repertoire and positions himself in opposition to 'that machine' – L. 24. He objectifies 'that machine' as an obnoxious symbol and it becomes anathema to his idea of what he would want at the end of his life. Using the metaphor of 'that machine' includes a broader notion of not only the actual ventilator machine itself but all those health professionals associated with its use. William is constructing an argument against the power of others to make a decision that the machine would be the best treatment for him. William's subject position is to justify why he is against being put on ventilation by stating that 'just prolonging things' is futile. He then adds value to this statement in L. 24 and claims that the prolongation is 'for nothing'; prolonging life for the sake of it is worthless in William's eyes. William became animated and spoke loudly to emphasise his point 'for nothing'. His position, therefore, was to argue strongly the pointlessness of attaching him to a ventilator in the future.

William then changes his position and attempts to clarify the term 'for nothing', by introducing humour to justify his previous opposition to be put on life support in L. 23; 'I mean I can't even have gin and tonic ( )'. William appeared to employ humour to overcome a problematic, emotive moment, as well as to cope with any stress caused by the interview situation (Mulkay, 1988). I would suggest that the use of the metaphor 'gin and tonic' was culturally-specific humour to evoke meaning-making between the interviewees and the interviewer. The metaphor of drinking alcohol represents pleasure

for William and is the antithesis of being potentially placed on ‘that machine’ when he is dying and consequently denied any ‘pleasure’ which may mean dignity.

Further on in the interview, William takes on a doctor’s position and speaks the repertoire using the doctor’s ‘voice’.

*Extract 4*

- p. 10 21     **William:** ...but unnecessary situation probably within the  
22     medical field oh yeah ‘perhaps we’ll keep it going a little  
23     while longer’ where in actual fact they’ve got to be  
24     realistic (.) um because if you are down that road very rarely  
25     anyone comes back. hhh  
26     **Anna:** Yeah.  
27     **William:** no matter what’s pumped into them.

William then judges medical decision making as unrealistic – implying that giving treatment to a dying person is futile. William is not constructing a neutral description of ‘dying’ as an object of thought, but instead his version involves evaluating the decision making of doctors when death is inevitable. This is an example of a discursive act that uses a complex linguistic structure of conditionals and contrasts to construct an evaluation of a potential event (Potter & Wetherell, 2001). However, the temptation for the interviewer is to assume that William has an enduring attitude about doctors’ unrealistic approaches to dying. The poststructuralist paradigm claims the existence of the contradictory nature of ‘truths’ and any assumptions arising from the different versions of these ‘truths’ ought to be questioned (Grant & Giddings, 2002).

Another participant, Charles, constructs his version of the prolongation of death as an object of thought, by using emotive language and the use of repetition to persuade the listener of his stake in his position about people being kept on respirators. He stated in the following extract:

### Extract 5

- p. 5    23    **Int:** Now I don't know how you feel about it, have you  
24    ever read anything I talked about these people that  
25    are kept on respirators?  
26    **Charles:** I have indeed I have, yes, yes, yes.  
27    **Int:** And you've got any thoughts about it Charles?  
28    **Charles:** Arrh I think it's very sad if they are sort of kept  
29    on and on and on and on, yes, yes, no, no I think that's  
30    arh not right, not right at all.

Charles initially claims that the situation is 'sad', and then he evaluates the overall situation and calls on a moral position of wrong-doing to justify his own stance. As a researcher, I needed to be more self-aware which involved standing back to observe oneself as an actor within a particular context. On reflection I had actively constructed the context by claiming that people 'are kept on respirators' in L. 25. It is possible that I had inadvertently evoked an emotive response from Charles by implying that doctors control people against their will on respirators. He repeated words to create an emphasis of negativity to this situation. It appeared that he was thinking through the situation and then made a final evaluation in L. 30 of, 'not right, not right...'.

Charles went on to say:

### Extract 6

- p. 8    1    **Charles:** Yes well I don't want a long, long lingering time  
2    that's number one I think  
3    **Int:** Yes.  
4    **Charles:** I don't mind having a try for a you know maybe a  
5    few weeks or something but certainly not over  
6    two or three years  
  
15    **Charles:** ...but that's the main thing I think I  
16    would, would come to my mind and I know if I was  
17    dying I don't want to spend blimmen two years  
18    dying.

Charles then clarifies what he would judge is an unacceptable time factor regarding prolonging life. However, in positioning himself as a dying subject, he evaluates what is acceptable by varying time factors. He uses days and weeks as a

comparison against years. This variation exists as Charles clarifies his ongoing construction of what he would accept as right for him if he potentially ends up in a lingering, dying position. Charles draws on the repertoire of the futility of keeping life going at any cost and he does this by objectifying what a doctor's position ought to be in keeping him alive within what Charles considers to be a morally acceptable time frame.

Initially, when I read George's transcript I found it difficult to identify sequences of talk that related to this second repertoire. It wasn't until I listened to the audiotape and re-read the transcript that I became aware how George had constructed his version of witnessing doctors deciding what was appropriate or inappropriate life-sustaining treatment for his dying sister-in law. He stated:

*Extract 7*

- p. 5    46    **George:** so a few hours later the next call I made  
          47    through was to say 'well the hospital want me to say  
          48    yes or no whether to pull the plug on the life-  
          49    support' and I said 'what do you think' and he said  
          50    'is there any hope of recovery' I said 'well no there has been  
p. 6    1    such a terrible massive haemorrhage that there is  
          2    definitely no sign of um, no hope of any recovery at  
          3    all and the best – she would be most likely more  
          4    comfortable taken off the life-support and just  
          5    allowed to drift away on her own'. So I said to the  
          6    doctor that was in the Intensive Care Unit, I said  
          7    'Well look you know you're the professionals and I  
          8    would be guided by what your decision is' and he  
          9    said 'Well I think it would be better if she was taken  
          10    off'.  
          11    **Int:** So you felt that they were quite supportive in giving you time?  
          12    **George:** Oh yes.

There are several things that need to be noted about this exchange of information; firstly, George had positioned himself as a story teller and narrated others' positions to 'manufacture' his version and ideas, and secondly, it was up to the listener

to detect what versions they wish to get from this story telling (Potter & Wetherell, 1987).

At first, being a novice to this approach, I had difficulty with this highly context-specific account, and had set aside the transcript thinking that it was not relevant to the topic. It seemed that George did not wish to respond directly about his values and end of life wishes. Instead, he told past stories that were significant to him in order to explain what he judged was appropriate end of life decision making.

Edwards (1997) argues that it is significant to analyse the way the discourse and the talk are constitutive of social life and this may be stated in the form of story telling. The need to respond with a story to a social event is another discursive strategy used to answer a question posed by the interviewer (Edley, 1997). George recalled his story to represent his position of a judge of what he claimed was appropriate or inappropriate decision making for his dying relative.

Wetherell (2003) expands on the notion of interpretative repertoires emerging from different identities, “they [speakers] will be negotiating identities for themselves and these identities will not be fixed and permanent, reflective of an essential and true self, but fluid and shifting constructions reflecting the contingencies of their accounting situation” (p. 288). It was these elements of the ‘fluid and shifting’ constructions which at first eluded me when reading George’s transcript.

George recalls his experience of as an EPA being involved with a decision when his sister-in-law was terminally ill in an Intensive Care Unit. The sister-in-law’s children were not living in New Zealand, but the nephew became involved with the decision making via a phone call to the USA. George was the only close relative that the doctors could consult with. George constructs the context using a reconstruction of the actual conversations that took place between the doctor and himself to demonstrate



how he came to the decision to permit the withdrawal of life support for his relative. He evaluates in positive terms the doctor's supportive professional advice to give him a reasonable time frame to make the decision. He gives the decision making power back to the doctor to 'take her off'. George constructs the doctor's role as one of understanding and support. The function of including the metaphor 'allowed to drift away on her own' was to affirm his confidence that his decision, guided by the professional advice of the doctors, was morally right and in the best interest of his relative. Contrary to George's experience, Breen, Abernethy, Abbott and Tulsky (2001) have identified that conflict can exist over decisions to limit life-sustaining treatment in intensive care units. As with what appeared to happen for George, Curtis (2000) claims that if physicians allocate time and conference with families in the intensive care setting this opens opportunities for discussion and improves the end-of-life surrogate decision making and consequently the families feel supported and understood.

## ***Discussion***

### ***The Right to Die a Dignified Death***

Avoiding excessive treatment over a prolonged time when death is imminent is a concern that emerged as the second dominant repertoire. The participants believed that in the future their deaths could be temporarily halted by trialling treatments and life-prolonging medical techniques, which I believe could imply that such measures would cost them their dignity and respect. The constructions of their possible future demise under these circumstances led the participants to make verbal or written ADs stating, above all, their resistance to life-sustaining measures that appeared futile and not in their best interests. The participants judged that they did not want to die in this undignified way and that it would be more appropriate to let nature take its course when death was inevitable.

The claim to a right to die when death is inevitable is perhaps an expression on the part of the claimants that their self-determining wishes concerning withdrawal of life-sustaining treatments in certain circumstances, such as when in a persistent vegetative state or brain death, ought to be respected.

The claim to this right to die is grounded in the moral principle of respect for people (Beauchamp & Childress, 2001). Patients should be able to have some assurance that healthcare professionals responsible for their treatment at the end of life will at least take into consideration their wishes and desires. Therefore, according to Zimbelman (1994), the right to die is largely a claim that people ought not to be burdened with inappropriate procedures that go against their wishes and what they perceive is not in their best interests. Indeed, the purposes of ADs are to elaborate, clarify, express, and provide guidance of people's preferences.

In situations where a patient is, for example, in an irreversible coma and death is imminent, or where it might be considered that treatment is futile, the reasonableness of limiting or withdrawing such treatment may be argued, with the AD acting as a guiding tool with the patient's wishes in mind, (Way, Back & Curtis, 2002; Zimbelman, 1994).

The use of the word 'reasonableness' denotes that there is a weighing up and gives the end of life decision-making process validity and power to those involved in decision making; not necessarily placing the patient's wishes in the forefront. Similarly, Hackler and Hiller (1990) contend that even if a patient's preference should be initially and presumptively respected, it does not mean that any and all the patient's desires for treatment or non-treatment need to be acted on. Although an AD made by a competent person has legal force, a medical practitioner is bound to comply only when the AD specifically addresses the medical situation that has arisen (Kendrick & Robinson, 2002).

### *The Medical Position*

Johnson (2004) states that a medical practitioner is expected to take reasonable steps to establish a patient's views, but if this is not possible she claims that the medical power of therapeutic privilege to provide services in the best interest of an incompetent consumer is upheld. The medical profession's sphere of influence and power in end of life decision making appears to be captured and justified under the term of therapeutic privilege. Consequently, therapeutic privilege, as a broad discursive notion, places a doctor in a central, powerful, and non-negotiable position to make medical decisions without necessarily consulting with 'marginal' others, such as getting in touch with distant relatives when the incompetent patient has no close family to consult with.

Thomas (2001) alludes to medical power by stating that:

A doctor [in New Zealand] who has the power to make the decision as to when the point has been reached at which the advance directive is activated is in a position of ultimate power. Most advance directives contain wording such as 'terminal condition', or 'incurable illness' and the interpretation of these phrases is left to the doctors. (p. 235)

### *Futile Treatments*

The central concern of the participants in the second repertoire is that they feared that they would receive inappropriate treatments at the end of life that they judged as futile and not in their best interest. According to Ardagh (2000) the harm/benefit balance needs to be considered to weigh up the utility of the procedure. Ardagh purports there exists a risk of harming the patient's autonomy by using futility as an overriding force in decision making at the end of life; rather, the utility of the treatment endeavours ought to be considered for the benefit of the patient; as a result, the benefit/harm balance would be patient centred, and not focused on the futility of the treatment itself. If patients have indicated in an AD what they consider is in their best interest then, according to Ardagh, a doctor ought to be aware of the wishes in the AD.

Schneiderman, Faber-Langendoen and Jecker (1994) argue that a physician who offers a treatment that is almost certain to fail is not only misleading the patient, but also violating his or her duty of care. A physician's primary responsibility is to relieve pain and to care for the dying patient appropriately, hopefully in an empathetic way (Tomlinson & Brody, 1990). This last comment is consistent with the views expressed by the participants in this study who would prefer comfort care and pain relief rather than life-prolonging procedures at the end of their lives.

This view also concurred with evidence from a study of 74 out of 76 medical inpatients who were approached in two hospitals in London. The aim of the study was to determine the patients' knowledge about living wills and what their healthcare choices would be should they write advance statements. The vast majority stated they would refuse all life-sustaining treatments such as artificial feeding (93%) at the end of life and preferred 'comfort only' care (Schiff, Rajkumar & Bulpitt, 2000).

### ***Summary***

In summary, the second dominant interpretative repertoire was a discussion about desiring to determine between the appropriate and inappropriate giving of life-sustaining treatments when a person is dying. The participants spoke this repertoire from positions of being judges of a dignified way to die. This appears to have originated from their previous experiences witnessing deaths where they claimed dying patients were given futile treatments. Zimbelman (1994) summarises what the participants had socially constructed was their overall subject positions in this second interpretative repertoire:

In a good death we want treatment and care that can really help, that increases the chances that we will be better off after medical and nursing treatment than before. For most of us a good death is not one

where there is no technological support. Rather, it is a death absent of heroic treatment that is futile or that prolongs our life when there is no chance of any meaningful interpersonal or spiritual existence. (p. 22)

### ***Interpretative Repertoire No. 3***

Relieving the family of uncertainty in future decision making.

**Subject position:** the concerned parent.

Willig (2001) contends that different repertoires are used to construct different versions of events, and the same speaker may use one or more repertoires in the pursuit of different social objectives. The third dominant interpretative repertoire emerges from a combination of intertwining sequences of talk around two social objectives; firstly, that an AD is constructed to inform the family of what the participant would want or not want at the end of life, and secondly, that as a consequence of making the AD the family would be relieved of the burden of making any uncertain decisions on behalf of the dying parent. All of the participants spoke of how burdensome it was for them in the past not knowing their relatives' wishes when they had been asked to choose between life-sustaining treatments or to agree to withdraw treatments when death was inevitable.

There is evidence from three of the participants of a complex negotiation of different parental identities as they construct their positions within the repertoire. There are two identities that indicate a paradox in the participants' positions, that is, between the participants' concerns to inform their children of what is in the ADs, thereby relieving the family of uncertainty, and their concerns over whether their children would in fact carry out their wishes in the ADs. Consequently, there is evidence in the third repertoire of the paradoxical nature of ADs. Interestingly, the participants position themselves as needing to take the lead in formulating their end of life wishes, however they also express doubts over the efficacy of making ADs.

Penny constructs a version of her two children as not wanting to talk about the AD, not only about the significance of her wishes in the AD, but also that she will die one day and they ought to know what she would want at the end of her life. She responded with:

*Extract 1*

- p. 3    3        **Int:** Now what about your children?  
4        **Penny:** Well our children really haven't been in the country.  
5        **Int:** Yeah  
6        **Penny:** And apart from telling them were our will is at and  
7        where to find things which my daughter didn't- I mean,  
8        you know, she didn't want to know about. [Son]  
9        probably listened and (.) thought 'oh yeah' hhh. They  
10       don't think their parents are going to go anyway  
11       despite what they've been and seen. They think well  
12       it's a numbers game and we've had enough numbers  
13       in our family so their parents are going to be fine...  
  
15       and I mean, they are only young.

Her justification for this version is related to the fact that the children are young, away from home and, there has been enough death in the family to reduce their [Penny and husband's] chances of dying. Penny appears to use an illogical argument to construct this, but on closer attention, this construction would suggest that she is drawing on a commonly understood metaphor in L. 12, 'the numbers game' to help understand the illogical, but socially acceptable, excuses her children are espousing. Penny is attempting to justify her children's position by using this metaphor to summarise and to make sense of their perceived lack of interest in the fact that everyone is going to die and that it is not left to chance.

The metaphor is an example of the flexible deployment of language to summarise a distinctive way of justifying a judgement. Penny is very keen to be seen as a concerned, understanding parent. In turn, the listener is positioned to fill in the gaps that surround why the metaphor is significant in this part of the conversation. Wilkinson

and Kitzinger (2000) claim that metaphors are simply invoked by speakers to endorse vague formulaic sayings rather than attempting to engage in careful introspection and reporting in more detail.

In L. 15 Penny excuses her children's indifference to her AD by stating that, unlike **her** past experiences of witnessing undesirable prolonged deaths, the children are inexperienced and are too young to understand the social reality and 'emotional hassle' of witnessing similar deaths and therefore they are not ready to understand why she made her AD.

#### *Extract 2*

- p. ?      34    **Penny:**...I  
             35    don't know that um our kids – because they have  
             36    been away so there is a removal factor. I'm not sure  
             37    that they would have that understanding of what  
             38    it really means, what you want.  
             39    **Int:** Other than they know where to find it?  
             40    **Penny:** Yeah, yeah  
             41    **Int:** and that's important and I would imagine they  
             42    would read it knowing that you had freely  
             43    **Penny:** [Yeah, yes, you know I'm not overly concerned  
             44    **Int:** [No  
             45    **Penny:** about them but I would be  
             46    **Int:** [a conflict  
             47    **Penny:** No I don't, I don't because I think they are both  
             48    intelligent people and that's what you've got to rely  
             49    on.

Although Penny throws doubt on the children understanding her wishes in the AD, she attempts to dispel any concern she has. The use of the word 'but' in L. 45, demonstrates a variation of this evaluation as well as some self-doubt in her previous sequences of talk. Overall, there is considerable variation in the function of the language used by Penny, and it appears to indicate her need to construct different versions of what her children's positions might be in the future. She claims that they are intelligent and, as a consequence of this version, she then persuades the listener that this intelligence is what she has 'got' to rely on. There appears to be evidence of a paradox

for Penny as she constructs an identity of being uncertain about how her children will make decisions following her instructions in her AD.

Later in the interview Penny claims that the consequences of deciding on life-sustaining treatments are emotionally difficult for families to witness:

*Extract 3*

p. 8    15    **Penny:** No, no and they don't understand the emotional  
          16    hassle for family sometimes, just to say 'no' and if  
          17    they don't say no they then end up with long-term  
          18    commitment to not a very nice situation.

This extract relates to Penny's experience with her dying parent, and I believe that this experience is related to Penny's present stance about why she justifies making an AD, as well as her hope that her family will understand her reasons for doing so. She uses the discursive technique of persuasive orientation (Potter & Wetherell, 2001) to present an extreme case dimension to her account by using the words, 'the emotional hassle' in Ls. 15 and 16. This phrase is employed to emphasise her criticisms and her concerns that her family ought to avoid a 'long term commitment' to a 'not a very nice situation' that she had experienced and witnessed in the past with her parents. This past, negative experience may explain why Penny stated at the beginning of the interview that she valued being a self-determining individual making an AD. She is adamant that she would not want her family to experience the emotional turmoil she had been through with end-of-life decision-making. Therefore, Penny is ready to take the lead by making an AD. Similarly, William and Anna have taken the lead in making their ADs and, like Penny, they too are unsure what their family's role will be as future surrogate decision makers.

William questions whether his family will fulfil his wishes in the AD. He ponders:



*Extract 4*

- p.1 29 **William:** ...but it's only the um – with that of course of the  
30 family turn around and sort of say 'no we don't want  
31 it to happen' they can – [...]
- 35 **William:**...it's legal in this respect if  
36 no one – what am I trying to think of – no one opposes  
37 it.  
38 **Int:** Yep and do – the family happy – that you've  
39 discussed it with them?  
40 **William:** Yep, yeah they know all about it  
41 **Anna:** Oh (3) I think so, I think so in fact I don't really think  
42 they took, hhh, much notice because I don't think we've  
43 spoken to them just recently. I mean when we first  
44 made it and you know
- 46 **Anna:** [they knew we were going to die anyway, 'hhhhhh',  
47 yeah.

William positions his family as possibly not fulfilling his wishes in the AD. He constructs the 'family voice' in L. 30, to test what might happen in the future. Potter (1996) contends that this is a discursive technique known as distance footing. By using the 'voice' of another identity – in this case the family's voice – the technique allows the speaker to distance their accountability to what might actually happen in the future. It is one way the respondent can solve a problem by quoting verbatim how another person might possibly act.

William attempts to understand why they may oppose his wishes and draws on the view that 'they can' purely for the reason that there is no statutory law to say they cannot. He evaluates his family as being within their rights to contradict his AD.

There is less certainty in Anna's response in L. 41 'oh, (3) I think so'. Anna evaluates the situation in a light-hearted way by claiming (interspersed with laughter) that since the making and the signing of the ADs were some time ago, she doubts the family has any ongoing concern about it. Anna interrupts my next (inaudible) question summarising this sequence of talk by implying that the family know they are going to

die, so it appears irrelevant to discuss the AD with them at present. The laughter at the end of L. 46 possibly indicates Anna's acceptance of the inevitability of her death, regardless of what the family do or not do according to the instructions. Laughter at the end of a sequence of talk can make it easier for a respondent not to expand any further on the answer (Gronnerod, 2004).

The fifth extract consists of responses related to my questioning around quality of life and the family dynamics that might take place if they were asked to make surrogate decisions.

*Extract 5*

- p. 9    39    **Int:** And I suppose at the bottom of that is to do with  
40           something about the quality of life?  
41           **Anna:** Oh, it is  
42           **William:** Oh that's the main thing I think  
43           **Anna:** Yeah, that's not my wish to just exist.
- 48           **Int:** So I would imagine that's how you both feel about  
49           that?  
50           **Anna:** Yeah, there is nothing worse – nothing worse  
51           for the family
- p. 10   29    **William:** but I think it's just a –really it's not fair on the family  
30           either if they are hanging around there and they are  
31           waiting um  
32           **Anna:** [of course not it's not  
33           **William:** for something to happen

Both William and Anna locate their subject positions in the social context of being left in a lingering, dying state and being 'watched' by the family. William's position is to judge this potential situation as unfair on the family. In agreement, Anna's position is to repeat the claim that there would be nothing worse for the family. It seems that she makes these claims from the family's position of being burdened if they see her death prolonged and this is noted in L. 50 'there is nothing worse'.

Glaser and Strauss (1965) observed families preparing for the death of a family member in a hospital setting. The authors claim, "when lingering is very prolonged,

family members may finish grieving before the patient is dead, which may be a source of strain to the family members. They may begin almost to resent the constant visiting” (p. 173). I would argue that Anna is referring to this potential strain on her family and the resentment that they may feel towards her if her death was prolonged.

The significance of a past event which influences a present subject position appears evident as William constructs a similar repertoire to Anna. He recalls a social event of his family ‘hanging around there’, on p. 10, L. 30. He creates the family’s position as having to ‘wait’ around for the inevitable death. It was not until near the end of the interview that William constructs a future image of his family ‘waiting around’ and ‘watching’ his death, and judges this as being an unfair situation for the family. The significance is historically located in his vivid recall of his grandmother who had Alzheimer’s disease. He blames others for not realising how burdensome it was for his mother caring for the grandmother. Alzheimer’s disease is constructed as having no quality of life and a burden on the family. He equates the ‘waiting around’ for a death to occur as creating the same burden on the family. William’s position seems to be that such an event as a prolonged death is likened to a prolonged chronic illness and that both are undesirable and viewed as burdensome. William then evaluates his grandmother’s life as having had no purpose since her quality of life had gone. His recall of this past event is a persuasive means to evaluate that he would not want a prolonged death since this kind of death could cause the family unnecessary burden in the future, and this would seem to him as worse than death itself. Later William adds:

*Extract 6*

p. 12 34     **William:** it’s not only the quality of life for yourself it’s the  
35     quality of life of the people around you.

The impact from this past family event is justification for William to take the lead and make his wishes known in an AD to protect his family from potentially

resenting having to ‘watch’ and ‘wait’ over his dying. One utterance at the end of the story in Ls. 34 and 35 verifies William’s position for taking the lead and making an AD so the family would be certain about making surrogate decisions on his behalf, ‘it’s not only the quality of life for yourself; it’s the quality of life of the people around you’. By stating that he would not want life-sustaining measures near his death, William, like Anna, is hoping that the family will respect his end of life wishes. He does not want his family to view him as a burden when he is dying. He appeared to view this potential family response to his dying as worse than death itself.

## ***Discussion***

### *Surrogate Decision making*

The third repertoire emerges from the participants’ subject positions as parents who claim that they have taken the lead in making ADs so that their families will be certain about acting in their best interest at the end of the parents’ lives. On one hand the participants are hoping that their families will honour their decisions in the Ads; however, this hope was overshadowed as the participants also wondered whether their families would regard and act on their wishes. These ponderings created a paradox for the participants in the third repertoire.

A similar paradox is expressed by Professor Skegg (1993) in his conclusion to a commentary on living wills and the New Zealand law. He claims that it is regrettable that the current state of the New Zealand law may encourage people to make ADs when their interests could better be served by the appointment of an EPA. This EPA would have the power to prohibit any form of life-prolonging treatment where such a power had been expressly conferred. Skegg then outlines the advantages of a carefully worded AD, not for helping family members to be more certain by making the right decisions, but instead, for preventing doctors from overriding the person’s wishes, thereby

committing a criminal assault on that person. Professor Skegg states that, “there is every reason to believe that a suitably worded advance directive will be effective in New Zealand law, to prevent a doctor lawfully administering treatment that would otherwise be appropriate” (1993, p. 1). However, he then disputes the benefits of an AD by claiming that an AD could prevent a doctor working in the best interest of the patient.

There is one important limitation in the appointment of an EPA in that the people who hold such powers are prevented from refusing any standard medical treatment or procedure intended to save the life of the consumer (Skegg, 1993). Therefore the only means by which a consumer can exercise Right 7(7) of the Code is to refuse lifesaving treatment in the event of future incompetence by way of an AD (Stent, 1997). Incidentally, the participants had appointed close family members as EPAs, but four of them had also claimed the need to make written ADs and two had informed their EPAs verbally about their intentions at the end of life.

### *The Surrogate Role of the Family*

International literature examining the surrogate role of the family in decision making at the end of life, includes the morality of substituted judgement of one agent for another in a family unit (Bailey, 2002; Basile, 1998; Degrazia, 1995; Hardwig 1993; Hare, Pratt & Nelson; 1992) Hardwig (1993) defines ‘family’ in the surrogate decision making role as those persons who are emotionally intimate or familiar with another. This definition includes blood or marriage relations as well as intimate friends and partners. The participants in this study referred to ‘family’ as their immediate blood relations such as their sons or daughters or married partners.

Therefore, I would argue that the substituted judgement principle protects and respects a patient’s autonomous agency making an AD. The proxy decision-making process should be unambiguous and open to scrutiny, and as Bailey (2002) states:

This is particularly so where the surrogate decision maker is designated as such simply as a result of that surrogate decision maker's relationship to the patient, rather than the [*patient*] having appointed the proxy to possess durable powers of attorney as would be required by advance directives. (p. 491)

Hardwig (1993) claims that family members are commonly considered to be best placed to make proxy decisions on behalf of a patient because they are potentially able to predict accurately the person's preferences for treatment and thereby upholding the patient's self-determination.

This claim of appointing a trusting family member as a surrogate decision maker was upheld recently in the New Zealand Returned Services Association (NZRSA) Autumn review: "Only individuals (not organisations) can be appointed your [enduring power of] attorney. We advise you to select a member of your immediate family, or somebody that you trust implicitly to make the best decisions for you" (Snow, 2005, p. 8). Clearly this article is 'speaking' to the readers and encouraging them to select an immediate family member. The article constructs families as, first and foremost, being attributed with implicit trust to make the right decisions. This theme of implicit trust in the family is also present in the third interpretative repertoire. However, the results of some studies have contradicted the claim that families are best positioned as decisional makers for an incapacitated, close, and dying family member.

Meyer (1993) claims that substitute decision makers are not necessarily the perfect executors of the patient's wishes. Meyer's study found that surrogates correctly guessed what the patients wanted 68% to 80% of the time. A significant factor that contributed to this situation, according to Meyer, was a lack of discussion between the health professionals and the family. As a result from this poor communication practice families felt pressure to continue treatment even though they sensed that it was not what

the dying person would have wanted. I believe that the participants were aware (from their own previous experiences) of this potential problem for their families and therefore were concerned that they would not be left with this uncertainty when making surrogate decisions on their behalf.

Surrogate designation has the potential to represent the patient's wishes and promote successful family involvement in decision making when options exist as to the patient's medical management (Azoulay & Sprung, 2004; Azoulay, Prochard, Chevret, Adrie, Annane & Bleichner, et al. 2004; Azoulay, Chevret & Leleu, 2000; Way, Back & Curtis, 2002). This successful family involvement can only occur when there is adequate and effective communication between health professionals and family members (High, 1994). In the first interpretative repertoire, Molly's position of suspecting the good intentions of the doctor to control her brother-in-law's destiny could have been related to the poor communication between the doctor and her family.

Grossman (2005) supports the need for families to have conversations about end of life wishes and treatment choices earlier than when medical crises occur. Otherwise, he purports, if a family's substituted judgement is required and the dying patient's wishes are not known, a decision of whether to prolong death with medical technology often results in pain and confusion for the family. "The family gathers. They hear 'alive', they hear 'chance' and '1 in a million' and '1 in a million' is always interpreted as 50–50 – always. And nobody can handle the probabilities" (Grossman, 2005, p. 6 D). Penny justified taking the lead by making her AD so her family would be relieved from the pain and confusion that she had experienced previously with her dying family members.

Grossman (2005) would suggest the highly emotive experience of a close family member's death is interposed with uncertainty and complexity for the family. Even

armed with the knowledge of the wishes in an AD there is no reliable way to predict how an individual patient's values, knowledge base, or treatment preferences might vary from majority positions (Emanuel et al. 1991; Miles et al. 1996; Star, Pearlman & Uhlmann, 1986).

Hines, Glover, Babrow, Holley, Badzek, and Moss, (2001) contend that surrogates believed that the best way to prepare for decision making was through written or verbal instructions from the patient. This result concurs with my data analysis in that the participants had positioned themselves as taking the lead by making ADs so that their families would be relieved of uncertainty and therefore be prepared to make decisions in the best interest of their parents.

### *Trusting the Family to Make the Right Decision*

The participants evaluated trust as the core attribute underpinning their faith in their families to know their wishes and to make the right decisions for them if they became incapacitated at the end of life. This position of trust corresponds with Miles, et al. (1996) findings that the moral authority of a family proxy need not be contingent on their ability to recount or predict a patient's choice but on his or her ability to be trustworthy. However, I would claim that there was evidence of paradox in this concept of trustworthiness. William was one participant who stated that he was not sure whether his family would honour his wishes in his AD. William appears to question the family's trust in his AD as guiding them in surrogate decision making.

### *Summary*

In summary, the third dominant interpretative repertoire emerges from a combination of intertwining sequences of talk from the participants' subject positions of justifying making ADs to inform the families of what they wish at the end of their lives should they become incapacitated. The participants' major purpose for doing this was



stated as wanting to relieve their families from uncertainty if they had to make surrogate decisions in the future. The past experience of witnessing a prolonged death and choosing between agreeing to life-sustaining treatments and withdrawing treatments when death was inevitable, had contributed to the participants' readiness to make ADs.

In the third repertoire the participants spoke from positions of concern in that they did not wish their families to experience this uncertainty and the emotional trauma that they witnessed with past deaths in their families. Therefore, the participants' justification for making ADs was to relieve their families of the burden of uncertainty in decision making. I would also conclude that the past experiences of some of the participants – in particular, Anna and William – 'watching' and 'waiting' for a prolonged dying process to end, and the emotional trauma suffered by those experiences, was another reason why the participants did not want their families 'hanging around' seeing them die in a similar way. I would argue the notion of not wanting their families thinking ill of them for 'hanging on' dying, of which the participants would have no control, is another reason for the participants taking the lead and trusting that in advance of losing the capacity to make their own choices at the end of life, their wishes in their ADs will be respected. All the participants believed that if there were no hope of recovery they would consent to withdrawing life-sustaining measures.

## ***Conclusion***

In conclusion, I have demonstrated my understanding of the data analysis with examples taken from the transcripts to illustrate the emergence of the three dominant interpretative repertoires and the three corresponding subject positions. To speak the repertoires is to speak from subject positions (Potter & Wetherell, 1987). A detailed

discussion exploring the emerging themes from each repertoire was included, along with relevant literature to support the discussion.

## Chapter 5: Discussion

### *Introduction*

Care near the end of life is increasingly recognised as a family matter and, end-of-life decision making is not necessarily individualistic in its focus (Haley et al., 2002). Although the participants in this study spoke from subject positions of being strong, self-determining, and autonomous decision makers and judges of a dignified way to die, one of their major concerns depicted in the third interpretative repertoire was the disturbing effect that end-of-life decision making could have on their families. The participants claimed that if the families were left with this surrogate decision making, choosing between withdrawing life-sustaining treatments or continuing with life-prolonging treatments for their dying parents, this could lead to unnecessary feelings of guilt and an overwhelming sense of burden. The participants' main wishes were to relieve their families of uncertainty around surrogate decision making, hence their justifications for making their advance wishes known in ADs.

**Figure 1. Identified interpretative repertoires (left) and the corresponding subject positions (right).**

<i>Interpretative Repertoires</i>	<i>Subject Positions</i>
Readiness to make an informed decision after witnessing an undesirable prolonged death	The strong, self-determining decision maker
Desiring to determine the appropriate and inappropriate treatments at the end of life	The judge of a dignified way to die
Relieving the family of uncertainty	The concerned parent

The purpose of this chapter is to initially review some of the underlying apprehensions that appeared to relate to these family matters. One of these notions was

the participants' accounts of being past witnesses to dying relatives who were given life-sustaining treatments which resulted in the artificial prolongation of the inevitable deaths. The participants' descriptions of being 'ready' to make ADs and the underlying sequence of events that led to this readiness will also be examined. This discussion will be followed by an exploration of the implications of the findings for nursing. The chapter will conclude with comments on the limitations of the research study in general.

As previously mentioned, the participants' major concern was to relieve their families of the burdens which they had encountered in the past when witnessing events of dying family members. Interestingly, the overall justifications for making ADs were influenced by these past events of witnessing (what was often referred by the participants as) the unnecessary, artificial prolongation of life when death was inevitable. Being present during a prolonged dying process had a profound impact on the participants, with the result that they in turn would not wish this to happen to their families in the future.

Closely aligned with the notion of 'witnessing' is the construct of 'watching and waiting' that the participants claimed occurred as they witnessed a prolonged dying. All the participants stated that from their past experiences, the burden on the family 'watching and waiting' for the death to occur is not something they would want their families to experience. If the 'watching and waiting' timeframe was prolonged by medical intervention, this appeared unacceptable to most of the participants and was evaluated as a loss of dignity for the dying person.

### *'Watching and Waiting'*

It is possible that this apprehension of family members 'watching and waiting' is what Glaser and Strauss (1964) referred to when they describe the stages of grieving that families may go through as they prepare to wait and watch when a lingering death

is happening. It is also possible that the participants' recall of the grieving for their family members may have been attributed to the stress and discomfort that, despite having gone through their grieving process, their dying family member was still lingering. It is understandable, therefore, that the participants would not want their families in turn to grieve over them and then feel regretful that their parents' dying was lingering.

The participants appeared to apportion some of the blame on doctors for a lingering death by the giving of futile, life-sustaining treatments thereby delaying the inevitable death and causing the witnessing family to grieve unnecessarily. One outcome of this situation is that families were then left with the burden to make the final decisions to withdraw life-prolonging treatments. Azoulay and Sprung (2004) challenge such burdens by stating:

Family members should not be left to make end-of-life decisions alone. People in general, and patients with chronic disease, should discuss their values and preferences at home so that their loved ones can act as surrogates, if they wish to, secure in the knowledge that they can help the patient realize his or her wishes. (p. 2327)

Kaplan and Schneider (2000) attempt, from a different perspective, to address the dilemma that exists for doctors in that the doctors see their professional duties as requiring them to employ whatever technologies are available to prolong life even if the chances for success are negligible. Ironically, it might be argued that a doctor, who offers life prolonging treatments in the contexts described above, could be seen to be failing to communicate clearly with the family members and is possibly misleading them and offering false hope. Although a doctor is committed to relieving pain and caring for a dying patient in an empathetic way, the application of futile treatments may cause the family undue stress and upset (Glaser & Strauss, 1965, Zimbelman, 1994).

### *‘Witnessing’*

The participants evaluated the concept of ‘witnessing’ as a traumatising event for families and that this past traumatic experience had led some of them to seek information from their lawyers about making ADs. This was to prevent their families from going through a potentially traumatising experience in the future. The participants thought that the result of their families knowing the instructions in the ADs, they would be more informed to make surrogate decisions. This concurs with a study by Boyd (2001), which indicated that family members experienced increased stress following a decision to terminate end-of-life care, but that in cases where there was no verbal or written AD, the stress was higher and lasted longer.

Tilden, Tolle, Nelson, and Fields (2001) also maintain that family stress associated with the decision to withdraw treatment was high immediately following the death, especially if there was no past direction of what the dying family member would have wanted. Although this stress decreased over time following the death, the authors’ claim is that it remained high half a year later.

One participant, Charles, recalled his experience of having to make a decision to turn off life support for his sister-in-law, for whom he held enduring power of attorney. Even though he conferred with relatives, he felt troubled with this decision even after five years, and still questioned whether his actions were right. Charles was adamant that he did not want his family to go through this burden in decision making. He wanted his son, who holds his EPA, and the rest of his children, to know that if a similar decision was to be made for him in the same situation as his sister-in-law, then they would be knowledgeable about his wishes in advance.

By constructing stories of themselves as witnesses of others’ prolonged deaths, the participants were justifying their decisions to make ADs with the intent that their

families would not be burdened by witnessing their potential lingering deaths in the future.

### *Medical Management*

Another underlying theme of the participants' accounts of the consequences of witnessing a prolonged family death was their rejection of the social practice of how they perceived doctors managed death and dying in New Zealand hospitals. The social practice of medical decision making was evaluated as being 'over the top care' and 'lots of treatment being forced on people'. All the participants spoke of their suspicion of the power of medical decision making at the end of life. By making ADs, the participants anticipated that this was one means of addressing the potential overarching power of doctors' decision making. The participants hoped that their advance written statements would be considered by the doctors at end of their lives. Indeed, the purpose of ADs is to elaborate, clarify, express, and provide convincing evidence of the patients' wishes so that doctors and families would comply with those preferences.

Doctors and other healthcare professionals, including family members, have a moral obligation to consider the preferences of the patient. Zimbleman (1994) argues from a moral viewpoint by stating:

Individuals [families and doctors] trusted with the treatment or care of patients, are morally required in a serious way, to take account of the patients' desire and wishes. Respect for patient autonomy and the patients' right to decide *which* considerations ought to be factored into treatment decisions and *how* they ought to be weighed means that caregivers and, in appropriate situations, proxy decision makers are morally required to give serious consideration to factors, consideration, and perspectives with which they may not agree or have affinity. (p. 24)

### *Justifications for Making Advance Directives*

The participants' overall justification for making ADs was constructed as a written means or as a guiding tool that would help families and doctors to make end of life treatment decisions knowing in advance their values and choices and respecting their reasons for making ADs.

Some of the participants – namely Molly, William, and Penny – appeared to reason that by making an AD there was some hope that doctors would not be in a position to ignore the power of the legally signed document. The legal document was attributed with a position of power and influence if the participants' end of life wishes were being questioned. However, all the participants were positive about making their ADs, but paradoxically; they also expressed their doubts about whether ADs would have much sway with doctors. This uncertainty of whether the AD would have an effect on decision making appeared to trouble the participants.

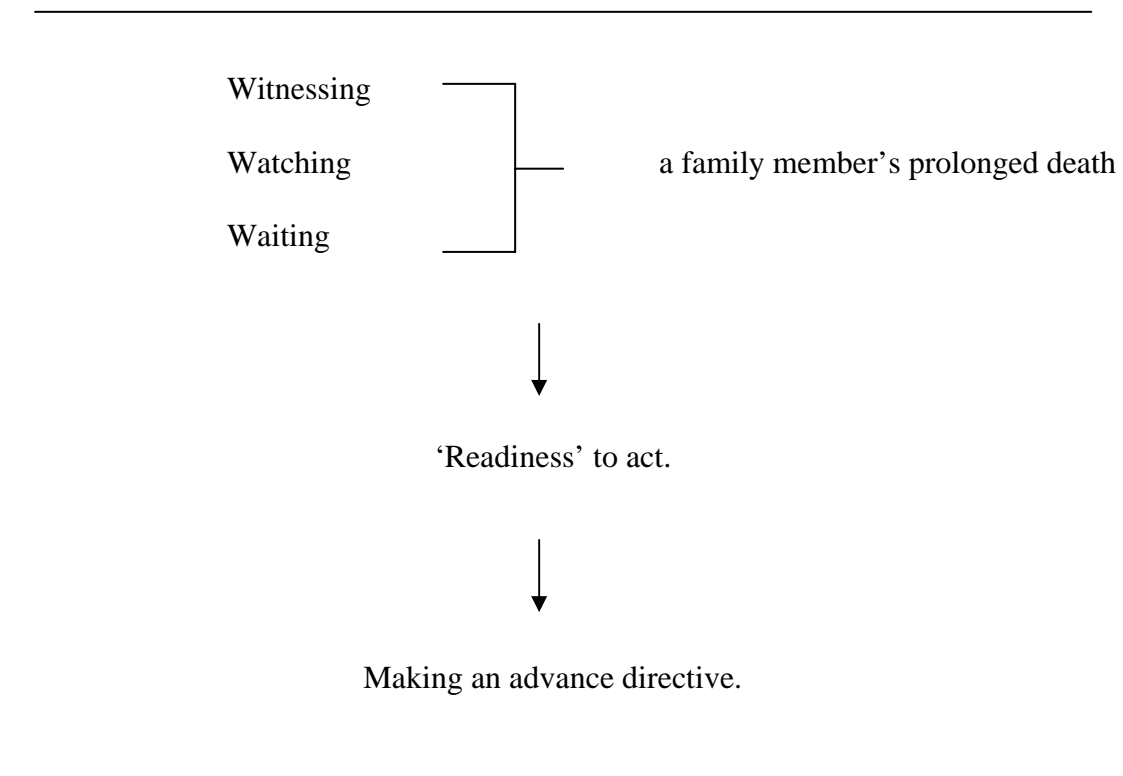
### *'Readiness'*

In discourse analysis, Redwood (1999) raises the possibility that closer examination might reveal some of the repertoires are less overt than others. A less overt repertoire constructed by the participants within this study was the notion of 'readiness'. The concept of 'readiness' was constructed by Penny to clarify when she believed it felt right for her to see her lawyer and make her AD.

Penny constructed a sequence of events that led up to her 'readiness'. Firstly, she claimed that she witnessed many undesirable deaths in her family, and then she stated that she came to conclusions about how the consequences of such deaths happening to her in the same way in the future could potentially affect her family. To protect her family from these consequences she needed to act and therefore, she was ready to make an AD through her lawyer.



**Figure 2. Sequence of events to making an Advance Directive.**



### *Comfort Care at the End of Life*

By making ADs, the participants were adamant that they did not want their wishes to be interpreted as the withdrawal of basic nursing care. Some of the participants believed it to be a necessity to be given basic care such as comfort and pain relief at the end of life. For example, one of the participants, George recalled his daughter stating, “we will all be there to look after you and make sure you are comfortable”. George further added, “I’d expect the best of care and I think they [the family] would be sure that I got that”. The BMA (1995) clearly states in its own guidelines that where there is a directive refusing basic care and maintenance of the non-competent patient, this should not be binding on the carers. Kendrick and Robinson (2002) support this position stating:

However, while the consent of the patient remains critical, any refusal [of basic care] should be set aside in the exceptional circumstances that

this causes harm to others or places an intolerable burden on the carers. In the first of these it may be that lack of attention to the care and hygiene of the patient could lead to infection that could affect others. In the second category, if the patient is not made comfortable or free of pain this could make things difficult to bear for the family and medical staff. (p. 59)

### *Valuing the Legal Encounter*

In contrast to their suspicions of medical power in decision making at the end of life, the participants assigned credibility and power to lawyers when making ADs. Lawyers were positioned as having the correct knowledge and information to interpret the participants' wishes on a legal document. The participants constructed the positions of lawyers and the 'legal space' as one of trust and neutrality. In contrast, the doctors were positioned by the participants as being potentially paternalistic and untrustworthy, and needing to be challenged when making end-of-life decisions. As a consequence, the participants trusted their families to have effective advocacy skills to engage with doctors to ensure their dying wishes would be respected at the end.

### *Power Base*

Throughout this study there is an underlying concern of the power of the patient and the family. There is a sense that when people encounter a health system, there is the ever-present potential for them to become disempowered (Illich, 1976; Lupton, 1997a). Lupton (1997b) conducted interviews with service users and found that many commented that it was important to be treated as "*real people* with feelings as individuals, rather than as a mass of anonymous patients" by their doctors (p. 373). The perception of being treated as anonymous patients may contribute to this notion of disempowerment during the doctor-patient encounter. Whilst it is beyond the scope of this study to address such power issues formally, it is acknowledged that this theme was frequently noted in the responses of the participants.

The lack of confidence in, and the questioning of, doctors' intentions to make the right decisions in the best interests of dying patients are possibly based on the participants' past experiences as witnesses to dying family members receiving medical care. Interestingly, Tulsky (2005) contends that a trusting relationship between the doctor, family, and patient influences the confidence that healthcare professionals are acting unfailingly in the patient's interest and that this confidence is fundamental to effective medical care at the end of life. However, another reason for this lack of confidence in medical decision making is reported by Moore and Sherman (1999) who claim that the respondents in their study reported a fear of having life-support terminated too soon when a chance of recovery may be possible.

Because of the sensitive nature of end-of-life decisions in ADs, confidence in doctors' decision making results from a process requiring extended dialogue between health professionals, families, and patients. The American Geriatric Society's recommendations for improving end of life care affirm the importance of this trusting relationship when it states, "only with enduring relationships with professional caregivers can patient and family develop trust, communicate effectively, and develop reliable plans" (1997, p. 526).

### ***The Implications for Nursing***

The participants did not construct a nursing position during the interviews, nor were they explicitly asked about their views of the role of nursing in relation to ADs. Two of the participants mentioned that they had daughters who were registered nurses. They portrayed these daughters as having the necessary skills to confidently challenge the doctors' medical decisions if they were contrary to their wishes in the ADs. Possible implications for nursing arising from the three dominant repertoires deserve brief discussion.

### Nursing dialogue

Literature suggests that an AD is potentially a focus of dialogue and narrative for nursing care (Castledine, 2003; Jezewski, Meeker & Schrader, 2003; Maxfield, Pohl & Colling, 2003; Meyer, 1993). Acknowledging that the AD may have been made in the past, the nurse-patient encounter becomes a dialogue around a revisiting of values and beliefs; a justification about the relevancy of the decision making in the present and for the future; how death is viewed; and how decision making about death and dying will be approached. Statements in the AD can assist the process of dialogue but it is not substitute for it (Emanuel, Danis, Pearlman & Singer 1995; Kendrick & Robinson, 2002).

### Respecting autonomy

An AD gives attention to the key concept of respecting the autonomous wishes of an individual as well as an awareness of the chronological significance of a person's values and beliefs taking into account a person's past life and present situation. Kendrick and Robinson (2002) maintain that the AD is a vital part of this communication process between a nurse, patient, and the family and/or surrogate decision maker such as the EPA. Examining the implications for nursing in end of life care encompasses discussions on the attributes and role of the nurse, the ethical relationship a nurse may have as a patient advocate and the leadership skills involved working collaboratively with patients, families, and other health team members involved with planning end of life care (Martin, Emanuel & Singer, 2000). A nurse is a key health professional and can aptly facilitate these key concepts to end of life care (Blondeau, Lavoie, Valois, et al. 2000; Enes & de Vries, 2004; Johns, 1996; Tyree, Long & Greenberg, 2005).

### *The pivotal role of nurses*

Helping the person to understand and to execute an AD as well as periodically review their previous decisions, was recommended in a nursing focused study that claimed nurses have a pivotal role in educating and improving end of life care planning with adults (Mezey, Bottrell & Ramsey, 1996). However, nurses need to be mindful that not everyone may be 'ready' to talk about end of life issues and to pressure a person into speaking about their future death may be, at best, insensitive and, at worst, traumatising. Holland (2003) claims that there may be a popular misconception that every adult, and especially the elderly, are ready to discuss and make ADs.

Inman's (2002) concern was that nurses needed to initiate discussions or provide information about ADs when individuals were well, not when they were ill or suffering mental deterioration. Her recommendation was that such discussion ought to take place on an outpatient basis. Inman's other recommendation was for nurses to educate lawyers about the benefits of preparing ADs and appointing surrogate or enduring power of attorney for personal care and welfare when clients are mentally competent to arrange their estate wills. Similarly, Johnson (2004) states, "nowadays, there is some encouragement to all people to grant an enduring power of attorney well before there is any sign of incapacity" (p. 123). Nurses in New Zealand, particularly Practice Nurses, may be well placed as patient advocates to educate and initiate discussions with patients as to the benefits of appointing an enduring power of attorney of personal care and welfare as well as considering making an AD.

There is clear evidence of the positive outcomes for patients and families when nurses become more involved and take an active role as a patient advocate (Canadian Nurses Association, 1998; Milton, 2001). Although nurses claimed to have little or no influence on the development of end of life care plans, Kennard, Speroff, Puopolo,

Follen, Mallatratt, Phillips, Desbiens, Califf, and Connors (1996) disclaimed this and found evidence of a different picture when they separately interviewed patients and surrogates regarding their perception of the nurse's influence on their plan of care. More than 50% of the interviewees believed that the information provided by nurses helped them make end of life healthcare decisions.

One conclusion that could be drawn from this study is that nurses need to value their contribution of giving and clarifying information, and appreciate how much trust people instill in nurses to support them when end of life treatment options are sought. There appears to be no published nursing research in New Zealand to make comparisons with the results of Kennard et al.'s 1996 study regarding nurses' roles in end of life care in New Zealand. However, one published New Zealand study alluded to the cultural changes required for nurses to become more active in their advocacy role in 'Not for Resuscitation' (NFR) orders (Bickley-Asher, 2003).

Hollows (1995) conducted a phenomenological study in Dunedin hospital to capture the lived experience of registered nurses involved in the withdrawal of nutrition and hydration in a persistent vegetative state (PVS) patient. One of her discussion points was that nurses have unique roles as primary care givers where they are able to foster trust and communication with families and significant others so that shared decision making can occur. The nurses are able to empower the family by providing understandable explanations of medical jargon and consistent explanations in an open and informal way. It was recommended that if the nurses in the study believed that they ought to be more involved in the end of life decision making process with the other health professionals, they need to be able to talk through the issues in a supportive peer environment and have a sound knowledge of the patients' conditions. As a consequence of this knowledge, nurses can think through the issues in an informed way when

families require clarification. These recommendations could serve to enable nurses to gain confidence as a valued collaborative team member and most of all to provide valuable insights as patient advocates (Hollows, 1995).

#### Advance care planning

An additional and related element of the quality of end of life care is the concept of advance care planning (ACP). The BMA (1995) proposed that ACP was a process of communication among patients, their health-care providers, families, and significant others regarding the kind of care that would be considered appropriate when the patient became incapacitated and unable to make decisions. ACP may, and generally does, include written AD forms (Singer, Martin, Lavery, Thiel, Kelner & Mendelssohn, 1998; Teno & Lynn, 1996; Teno, Lynn, Phillips, Murphy, Younger & Bellamy, 1994).

ACP is conceptualised as an event whereby a set of decisions and an AD form may be developed and made. However, the process importantly hinges on effective communication among all involved (Martin, Emanuel & Singer, 2000). These authors claim that the AD forms can give structure and clarity to discussions and guidance where people are able to articulate their values, goals, and preferences, and can provide a framework to facilitate discussions with others as people work through their treatment preferences.

#### Values history

Communicating a person's wishes in a values history is a less contentious way for a nurse to communicate with the patient and record their wishes in an ACP (Kendrick & Robinson, 2002). Values-based directives can help clarify values that underlie healthcare preferences and address the concern that people cannot anticipate all situations that may be encountered at the end of life. The values history record focuses

on autonomy of the person's preferences and values and enables the person to clarify values and principles which become part of the decision making process.

A positive outcome of this values history process being part of the formulation of an AD is that the broader view of the person and values is more important than any specific medical directive. Another positive factor of a value-based AD is that it may offer more assistance to surrogate decision makers who may be called upon to make specific decisions in situations that were not anticipated. A nurse can easily raise the idea of values orientated AD in a positive way that can inform the patient's treatment preferences thus providing an important focus for dialogue about ACP among the family and with healthcare professionals (Fischer, Alpert, Stoeckle & Emanuel, 1997; Kendrick & Robinson, 2002; Martin, Emanuel & Singer, 2000). However, I am mindful that from a poststructural perspective of subjectivity as fluid and contradictory, ADs, ACP, and values-based directives are problematic in that all of them assume the patients' views and values remain fixed throughout time.

Briggs and Colvin (2002) claim that when multiple healthcare professionals embrace ACP, a shared responsibility in assisting individuals and their families through health changes and stages is necessary. The team approach requires commitment to learning new skills and to developing collaboration and partnership amongst the health professionals. However White, Coyne, and Patel (2001) questioned whether nurses were adequately prepared and confident to act in an advocacy role within a multiple healthcare professional team.

In contrast, Thompson, Barbour, and Schwartz (2003b) claim that nurses are, however, more likely to assume the role of patient advocate, whereas physicians are more often placed in the role of decision maker. If, however, the power base in the



decision making is not collaborative between the health professionals this can lead nurses to relinquishing their advocacy role.

### *Cultural change and participation*

Briggs and Colvin (2002) recommend that nurses need to be actively involved in cultural changes in the healthcare setting to promote patient autonomy and improve the experience of, and satisfaction with, end of life care.

Arguably, in order to achieve this 'cultural' change, nurses initially need to gain the necessary competence to collaborate with other health professionals on an equal footing when involved with the patient and the family in end of life decision making (Briggs, 2002). Ramsden, (1993) claimed the need for nurses in New Zealand to act as 'bearers of culture' by first examining their own cultural beliefs, attitudes, and behaviour, and then to consider how their 'culture' impacts on others in healthcare, including interdisciplinary processes.

Castledine (2003) compares the different approaches between doctors and nurses in the UK. His claim is that doctors have been slow to encourage patients to participate in their own medical care, with the result that people are often suspicious of how doctors intend to treat them. According to Castledine, (2003) nurses have been quicker to encourage patient participation because the very nature of nursing is to endorse patient autonomy. In New Zealand, Bickley-Asher (2003), states that nurses have a key role in mediating between doctors and patients but they must be prepared to be involved in developing policies concerning end of life care, and in particular do not resuscitate (DNR) policies, if the significance of their advocacy role is to valued in the New Zealand health arena.

Nurses have, then, an opportunity to take a leadership role in establishing an appropriate plan of care in negotiation with the patient and the surrogate in advance of a

patient's deteriorating illness and incapacity. Such a plan must include the patient's wishes, values, and beliefs related to end of life care and should include clear information on the appropriateness of treatments such as CPR, given the patient's prognosis (Diem, Lantos & Tulsky, 1996; Schultz, 1997; Weil & Weil, 2000).

Advance care planning guidelines for the New South Wales Department of Health (NSWDH) were released on March 3<sup>rd</sup>, in 2005. One feature of the new end of life guidelines is the focus on building consensus, in particular where patients do not have the capacity to decide on life-sustaining treatment for themselves.

The recommendation from the NSWDH guidelines is that early, proactive, and sensitive communication is important to clarify the goals of treatment, possible outcomes, and the patient's values and wishes. The document claims that one of the best practice recommendations is that the most appropriate health professional to conduct discussions about end of life care is the one who is identified as significantly involved in the active care of the person. Therefore, the recommendation suggests that a multidisciplinary approach to ACP is appropriate (NSWDH, 2004).

#### *The community nurse role*

I would assert that the role and scope of the community nurse in the primary healthcare setting in New Zealand, for example, the Practice Nurse, is well situated to facilitate the initial discussions preparing for the end of life phase. As the number of Nurse Practitioners working in the Older Adult Care setting increases in New Zealand, they need to be better equipped to play a role in discussions, planning, and co-ordinating end of life care including making ADs for patients and families in the community.

A nurse is able to develop trusting relationships with the patients and their families and assist with the complex decision making at the end of life. However such a

nursing role requires professional preparation as an advocate and a confidence not only to be able to facilitate discussions with the patient and their family, but also to mediate with other health professionals caring for the patient. Furthermore, the environment and culture where the nurse works needs to acknowledge the nursing role and positively affirm the contribution that the nursing role plays in ACP.

### Summary

In summary, an AD is a narrative that fosters freedom of choice and creates an openness of purpose and gives a voice to future treatment decision making. The nurse's unique role here is to smooth the progress so that the voice of the patient is heard at their end of life when his or her voice can no longer actually speak (Wareham, McCallin & Diesfeld, 2004).

So far, this chapter has reviewed the underlying apprehensions that the participants alluded to during the interviews: the witnessing of a relative's prolonged death and the concerns that they have for their families as potential surrogate decision makers when, as parents, they may lose capacity to make their own decisions at the end of life; the notions of 'watching and waiting' for a prolonged death to occur, which contributed to a sense of 'readiness' to approach their lawyers to make an AD; and the sense of disempowerment when encountering doctors in the health system. Discussion about the implications for nursing suggested that nurses have a pivotal role in planning end-of-life care and obtaining a values history in advance; this would contribute to understanding the person's general values. Nurses who work with well adults in the community are best placed to be able to initiate end-of-life discussions and act as advocates for people who have made ADs.

### ***Limitations of the Study***

This study has provided insight into how individuals within a small participant group of New Zealanders justify making ADs. As with all research, the study had limitations.

One of the initial limitations to emerge was the use of term ‘advance directive’ when I was recruiting participants. The term was unfamiliar to people in relation to end of life wishes, whereas the term ‘living will’ appeared more easily recognisable among people in general. It became apparent that I needed to add the term ‘living will’ to the flyer calling for participants who had made an AD, and to include the term on the Information Sheet to explain and clarify the aim of the study. I was under the misapprehension that an AD was a generally understood concept because it was in the Code of Health and Disability Services Consumers’ Rights (1996) as a consumer right (Right 7[5]) and therefore would be a known Right.

Another limitation that I identified was that the findings related to a small group of six European New Zealanders over the age of 50 years. However, there has been no attempt to generalise the findings to all New Zealanders who have made ADs pertaining to the end of life. My aim was explore how these six participants justified making ADs and what subject positions they formed so as to utter their insights into how they justified their actions. Consistent with Potter and Wetherell’s approach to discourse analysis (1987), my aim was also to identify any commonalities that arose from the six interviews that gave insight into the contradictory and inconsistent organisation of the broader interpretative resources these six people were actively working over as they tried to justify their positions for making ADs. While this research method claims that the rules of discursive formation emerge from within the general social, cultural, and historical contexts that surround the participants, New Zealand is a multicultural

country and the study was clearly not representative of the many ‘cultural voices’ of New Zealand consumers of healthcare. While the findings were narrow in focus, they represented the truths of six people. To broaden the focus further, I would suggest that there is a need for future study into the different cultures that make ADs, particularly when noting that the Code of Health and Disability Services Consumers’ Rights applies to all citizens of this country. There appears to be no published New Zealand research related to different cultures making ADs. Another focus for future research would be to hear the voices of younger citizens who make ADs or living wills.

The participants’ discourses were closely intertwined with the positions they attributed to their families and their roles of surrogate decision making at the end of the participants’ lives. This study was limited to analysing the construction of reality for the participants and the study did not include family members. In the interest of furthering the study of ADs in New Zealand, the focus of the individual within a family network requires further exploration. One purpose for studying the family view would be to illuminate the potential tensions between health professionals and families when the dying patients lose capacity to make decisions, and they then rely on their families to make the right decisions as stated in the ADs.

### ***Personal Tensions***

In this study, discourse analysis proceeds on the basis of the researcher’s interaction with the interview texts. I found my interaction with the detailed six interviews challenging in that I was constantly reminded of the recommendation of Potter and Wetherell (1987) to continually question: “why am I reading this passage in this way?” and “what features of the text were producing my interpretation of the texts?” (p. 168).

To be faithful to Potter and Wetherell's approach, I was required to pay close attention to the constructive and functional dimensions of discourse in the data analysis. I needed to explore the context, variability, and construction of the participants' accounts of making ADs in order to facilitate a systematic and sustained exploration of these three dimensions. It was necessary to look at how the texts in the interviews constructed its objects and subjects in the 'talk', how such constructions vary across discursive contexts, and with what consequences they may be deployed (Willig, 2001). I needed to pay attention to the terminology used and the stylistic and grammatical features, such as the preferred metaphors, employed. Potter and Wetherell (1987) refer to such systems of terms, or features, as 'interpretative repertoires'.

In hindsight, I found this approach demanding in that different repertoires are used to construct different version of events and of the truth by the same speaker at different times in the interviews. I was often tempted to go beyond the repertoires to explore a deeper meaning but that is not the purpose of Potter and Wetherell's approach. The analytical focus is upon variability across contexts and the action orientation of talk, not the embedded meaning beyond the texts, which I was (at times, unwittingly) tempted to do. As a novice researcher, I initially found it difficult to identify the tensions and contradictions among the interpretative repertoires that are indicative of the speakers, as the discursive resources that they draw on are inherently dilemmatic (Billig, 1991).

Crucially, by examining naturally occurring discourse in detail, the distinction between 'object of thought' and the position of a 'dimension of judgment' is at times, I believe, impossible to make (Potter & Wetherell, 1987). Different respondents will understand and formulate the object of thought in different ways, therefore sameness of wording does not necessarily indicate the same meaning, nor may it mean the same

thing to the same respondent in different contexts. This meant constant checking and rechecking of the interview tapes while reading the transcribed texts for clues of the presence of interpretative repertoires. Whilst I used Potter and Wetherell's approach, I am aware that such an approach has been critiqued for its limitations (Parker, 2004; Willig, 1999). This approach makes a significant and specific contribution to understanding the role of language and language use. However, the contribution of the critical social and political analyses and the inclusion of dominance and inequality discourses in the analysis of this study would have added an in-depth discussion of the findings. That is to say, for example, that when analysing an interpretative repertoire, I would have considered identifying what conflicting influences were impacting on the participants' subject positions as they 'spoke' the repertoire. As a consequence, close attention would have been paid to the social context of language and to its function in or relation to structure of power (Powers, 1996).

### ***Positive Outcomes from the Study***

Although I have identified some of the limitations of the topic and research approach to analysing the question of making ADs in New Zealand, there were also some positive outcomes from the study. Primarily, I am so grateful to the participants, not only for their honesty and willingness to engage with me on the topic, but also for the extra time they gave when I re-contacted some of them to verify my understanding of their versions of making ADs. For some of the participants, involvement in this study reminded them to re-open discussions with their families and to let their doctors know of the existence of their ADs. One of the participants, Penny, stated that she had visited her lawyer since the interview to update her AD. Without the opportunity to discuss the topic in an interview, she claimed that she doubted that she would have realised the need to update her end of life wishes as well as to consent to being an organ donor.

## ***Conclusion***

In conclusion, the participants' major expectations in making ADs were that their wishes would be honoured by the doctors and their families at a time when they anticipated that they could lose competence to give informed consent and participate in end of life treatment decisions. Equally, the participants justified that ADs were made from positions as concerned parents who wanted to lessen the burden of their families making surrogate end of life decisions. The traumatic and stressful experiences of being a witness, of watching and waiting on a lingering death, and acting as surrogate decision makers in the context of past family deaths, appeared to have a major influence on the participants being ready to act and to make ADs with their lawyers. To live indefinitely as a 'vegetable' or to have a lingering death due to futile life-sustaining treatments when quality of life had gone, was constructed by the participants as an affront to their personhood. The participants wanted to die in a dignified way and have their end-of-life wishes honoured, not only by health professionals, but also by their families.

This chapter also identified the key role nurses play in helping people construct a values history and formulate end-of-life advance care plans. My conclusion is that more research needs to occur with nurses in the primary healthcare sector. The major reason for this conclusion is that primary healthcare nurses are best placed to assess well patients' values and to explore with them and their families their end-of-life wishes. Primary healthcare nurses are often familiar with the patients' backgrounds and medical histories and have often developed a trusting relationship with the patients if they have known them over a prolonged time. Despite the multiple obstacles nurses may face in assuming more active roles as patient advocates in decision making, the literature discussed in this chapter produced clear evidence supporting such



involvement. The positive outcomes for patients and families when nurses become involved with advance care planning may include helping patients to clarify and formulate their end-of-life wishes in ADs. I also identified the limitations of the study and proposed areas for further research.

The aim of this study was to explore how people justify making ADs in New Zealand using a discursive approach after Potter and Wetherell's (1987) method to analyse the data. There were three dominant repertoires identified in the findings; readiness to make an informed choice after witnessing an undesirable prolonged death, the appropriate and inappropriate treatments at the end of life, and relieving the family of uncertainty. These repertoires were spoken from three corresponding subject positions; the strong, self-determining decision maker; the judge of a dignified way to die; and the concerned parent taking the lead in decision making to relieve the family of any future burden they may encounter as surrogate decision makers. The purpose of making ADs is captured by Sommerville (1996) who states:

Advance directives or 'living wills' attempt to deal with medicalisation and marginalisation. They aim to permit individuals to have voice in situations where they are otherwise unable to control what is done to them. Their purpose is to empower the individual to make future choices using present mental capacity and knowledge. The effectiveness of the advance directive depends ultimately upon wide recognition that individual views, rather than clinical opinion alone, must dictate treatment. (p. 31)

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## Appendix A: Flyer advertising for participants



*Hello*

my name is

**Pauline Wareham.**

**I am a student enrolled in the Master of Health  
Science (Nursing) at AUT.**

**I am wanting to speak to people who have made an  
*Advance Directive* also known as a *Living Will*.**

**If you have completed an Advance Directive with  
your Doctor, Lawyer or with the Public Trust Office,  
I would like to hear from you.**

*Thank you*

**My contact details are:**

**Pauline Wareham**

**Lecturer - School of Nursing**

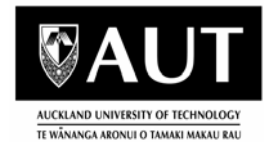
**Auckland University of Technology**

**Private Bag 92006**

**Phone: (09) 9179999 ext. 7166**

**Email: [pauline.wareham@aut.ac.nz](mailto:pauline.wareham@aut.ac.nz)**

## **Appendix B: Participant Information Sheet**



**Project Title:** New Zealanders making advance directives:  
a discourse analysis.

### **What is the purpose of the study?**

Very little has been published or appears to be known about making advance directives (also known as a living will) in New Zealand.

As you have made an advance directive, I will be asking you how you became aware of advance directives, what led you to do this, why you consider this to be an important thing to do and what expectations you believe are derived from doing this.

### **How are people chosen to be asked to be part of the study?**

I am inviting people who have made an advance directive to participate in my masterate thesis.

### **What happens in the study?**

You will have received this Participant Information Sheet in response to me contacting you by phone and confirming your continued willingness to participate in this research.

In two weeks time I will make contact with you to see if you are interested in participating in my study. If you are, I will organise a date and time of your choice to interview you.

The interview will be like an informal conversation and would last about 60 – 90 minutes. The interview will be audio taped, and then transcribed.

The transcripts will be returned to you, to enable you to make any changes or to request withdrawal of information that you do not wish to be made public.

### **What are the discomforts and risks?**

It is possible that our discussions concerning making an advance directive may raise issues for you. I will stop the interview and turn off the tape. If you choose we can continue or discontinue the interview, or continue at another time convenient for you.

### **What are the benefits?**

There may be no benefits for you participating in this masterate thesis.

Your experiences may inform health professionals, in particular nursing colleagues, as I intend to publish the results of the study.

### **How will my privacy be protected?**

To ensure your privacy and confidentiality, the data will be coded and no identifying names of participants, institutions or third parties will be used. I will ask you to choose a pseudonym that you will be known by. Only you and I will know your true identity. The consent form that you sign will be kept secure in a locked safe throughout, and following the study. The information I gather will be confidential and the only other people who will have access to it will be my thesis supervisor, Dr Debbie Payne, and a transcriber who will have signed a confidentiality form. All the study data collected will be kept in a locked safe in a secure place at AUT. The audiotapes will be returned to you immediately or alternatively destroyed once the work is completed. All the data will be destroyed after six years.

### **What are the costs of participating in the project? (including time)**

The only cost to participate in this research will be the 1 to 1½ hours of your time for the interview at a place of your choosing.

### **Opportunity to reconsider invitation**

When you receive this Participant Information Sheet, I will contact you after two weeks so that you have time to consider this invitation and feel free to participate in the study. You will be asked to sign the attached Consent Form that I will discuss and collect from you before the interview takes place. It is important that you feel comfortable with the research process. You are not obliged to provide any information that you do not feel comfortable with providing. If there are any questions that you are asked that you are not comfortable with, then you are not obliged to answer them.

You may withdraw from the study at any time up until I have completed the data collection. Also you have the right to turn off the tape recorder at any time.

### **What will happen with the thesis?**

This thesis will be submitted to Auckland University of Technology School of Nursing for evaluation. The findings of the research project will be submitted for publication in professional journals.

### **Opportunity to receive feedback on results of research**

A summary of findings will be made available to you on request.

### **Participant concerns**

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

Project Supervisor:  
Dr. Debbie Payne  
School of Nursing  
Postgraduate Studies  
Auckland University of Technology  
Private Bag 92006  
Auckland  
Phone (09) 9179999 ext. 7112  
Email: DPAYNE@aut.ac.nz

Concerns regarding the conduct of the research should be notified to the Executive Secretary, AUTEK, Madeline Banda, [madeline.banda@aut.ac.nz](mailto:madeline.banda@aut.ac.nz), 917 9999 ext 8044.

### **Researcher Contact Details:**

Pauline Wareham  
School of Nursing  
Auckland University of Technology  
Private Bag 92006  
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**Approved by the Auckland University of Technology Ethics Committee on 14/06/04.**  
**AUTEK Reference number 04/106.**

**Date Information Sheet Produced: 13/5/04**

## Appendix C: Consent to Participation in Research

**Title of Project:** 'New Zealanders making advance directives:  
a discourse analysis'.

**Project Supervisor:** Dr. Debbie Payne

**Researcher:** Pauline Wareham

- 
- I have read and understood the information provided about this research project (Information Sheet dated 13 May 2004)
  - I have had an opportunity to ask questions and to have them answered.
  - I understand that the interview will be audio taped and transcribed.
  - I understand that I may withdraw myself or any information that I have provided for this project at any time prior to completion of data collection, without being disadvantaged in any way.
  - If I withdraw, I understand that all relevant tapes and transcripts, or parts thereof, will be destroyed.
  - I agree to take part in this research.
  - I wish to receive a copy of the report from the research.

Participant signature: .....

Participant name: .....

Participant Contact Details (if appropriate):

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

Date: .....

<b>Approved by the Auckland University of Technology Ethics Committee on</b> 14/06/04 <b>AUTEC Reference number: 04/106</b>
---

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

## Appendix D: Transcriber Confidentiality Agreement

I .....

Of .....

Agree that I will maintain confidentiality with the tapes and transcripts that I work with in this study.

The only person with whom I may discuss any of the material is the researcher.

Once the transcripts are completed, they will be returned to the researcher along with the audiotapes.

Signed.....

Date.....

Witness.....

## Appendix E: Ethics Committee Approval

### MEMORANDUM

Student Services Group - Academic Services



To: Deborah Payne  
From: **Madeline Banda**  
Date: 20 July 2004  
Subject: 04/106 New Zealanders making advance directives: A discourse analysis

Dear Deborah

Thank you for providing clarification and/or amendment of your ethics application as requested by AUTEK.

Your application is approved for a period of two years until 20 July 2006.

You are required to submit the following to AUTEK:

- A brief annual progress report indicating compliance with the ethical approval given.
- A brief statement on the status of the project at the end of the period of approval or on completion of the project, whichever comes sooner.
- A request for renewal of approval if the project has not been completed by the end of the period of approval.

Please note that the Committee grants ethical approval only. If management approval from an institution/organisation is required, it is your responsibility to obtain this.

The Committee wishes you well with your research.

Please include the application number and study title in all correspondence and telephone queries.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Madeline Banda'.

Madeline Banda  
**Executive Secretary**  
AUTEK  
Cc: 0310004 Pauline Warcham

From the desk of ...  
Madeline Banda  
Academic Services  
Student Services

Private Bag 92006, Auckland 1020  
New Zealand  
E-mail: madeline.banda@aut.ac.nz

Tel: 64 9 917 9999  
ext 8044  
Fax: 64 9 917 9812

## Appendix F: NZMA Sample Advance Directive Form

I, .....

of .....

advise that in any circumstance that I am not competent to make a choice about a future healthcare procedure, should the following situation arise:

.....

.....

.....

that I accept/decline/withdraw (delete those which are not applicable) the following treatment/s:

.....

.....

.....

I confirm that information about the risks, consequences and treatment options of my decision were given (summarise below):

.....

.....

.....

Name of Doctor (or Medical Practitioner with the closest relationship with the patient): .....

Signed: ..... (Patient)

Signed: ..... (Doctor)

Witnessed: ..... (Contact person)

Date: .....

Updated/reconsidered/endorsed on .....

Updated/reconsidered/endorsed on .....

Updated/reconsidered/endorsed on .....

Another NZMA service.

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## **Appendix G: A Completed Patient Advance Directive**

TO: MY FAMILY, MY DOCTOR, MY SOLICITOR, MY CLERGYMAN  
TO: ANY MEDICAL FACILITY IN WHOSE CARE I HAPPEN TO BE  
TO: ANY INDIVIDUAL WHO MAY BECOME RESPONSIBLE FOR MY  
HEALTH, WELFARE OR AFFAIRS

Death is as much a reality as birth, growth, maturity and old age – it is the one certainty of life.

If the time comes when (identified name deleted) am no longer take part in decisions for my own future, let this statement stand as an expression of my wishes, while I am still of sound mind.

If the situation should arise in which there is no reasonable expectation of my recovery from physical or mental disability, I request that I be allowed to die and not be kept alive by artificial means or “heroic measures”. I do not fear death itself as much as the indignities of deterioration, dependence and hopeless pain. I therefore ask particularly that any hospital or doctor caring for me should be careful not to artificially prolong my life but that such professional be prepared to allow me to die at an appropriate time.

This request is made after careful consideration. I hope you who care for me will feel morally bound to follow its mandate. I recognize that this appears to place a heavy responsibility upon you, but it is with the intention of relieving you of such responsibility and of placing it upon myself in accordance with my strong convictions, that this statement is made.

Postscript:

This person died October 2005 and the wishes in this AD were honoured by the nursing staff in his care.