UNIVERSITY OF ADELAIDE LIBRARY 16/8/06

The Do-Not-Resuscitate Decision: A Discursive Analysis Of Cancer Patients' Talk

Jaklin A. Eliott BA (Hons)

Thesis submitted for the degree of

Doctor of Philosophy

Department of Medicine

Faculty of Health Sciences

The University of Adelaide

March 2006

Table of Contents

Table of Contents ii
List of Tables vi
List of Figures vii
List of Appendices viii
Abstract ix
Declaration xi
Acknowledgement of contributions of others on published articles xii
Acknowledgements xiii

Chapter 1. Introduction: What's it all about? 1
Chapter 2. Background: What has gone before? 4
2.1 The development of DNR orders 4
2.2 Representations of DNR orders within the medical literature 6
2.2.1 Medical 7
2.2.2 Personal 8
2.2.3 Economic 8
2.2.4 Legal 9
2.2.5 Social (and interpersonal) 9
2.2.6 Bioethical 10
2.3 DNR orders are personal: Autonomy, patient decision-making, and surrogacy 11
2.3.1 Autonomy 11
2.3.2 Patient autonomy and decision-making 13
2.3.2.1 Criticisms of dominant concepts of decision-making 14
2.3.2.2 Surrogacy 19
2.4 DNR orders in Australia and within the research site 24
2.5 The current research 27
2.5.1 What does it address? 27
2.5.2 What are the research questions? 28
Chapter 3. Method: Describing the approach, the process, and the participants 30
3.1 Approach 30
3.1.1 Social constructionism, qualitative research, and discourse analysis 31
3.1.2 Semi-structured interviews 35
3.1.3 Sampling the population 40
3.1.4 Recording and transcription 41

3.1.5 Ethics 44
3.2 The process (procedure and participants) 46
3.2.1 Details of the analytical process: N6 and beyond 52
3.3 Evaluating this research 60
Chapter 4. Study 1. Constructing DNR orders 64
4.1. Defining DNR orders 64
4.2. Legitimating implementation of DNR orders 66
4.2.1 Positive construal of DNR orders 66
4.2.2 Negative construal of CPR 69
4.3 Conclusion 72
Chapter 5. Study 1. Patients, others, and decision-making 74
5.1 The patient as decision-maker 79
5.1.1 Timing the DNR discussion 80
5.1.2 The paradox of autonomy 93
5.1.2.1 Deciding not to decide 93
5.1.2.2 Doctors determine timing of DNR discussions 94
5.1.2.3 Patients' familial obligations 96
5.2 The Family as surrogate decision-makers 97
5.3 Resolution of the modernist and romanticist repertoires 102
5.4 Conclusion 103
Chapter 6. Study 1. The discursive properties of hope in cancer patients' talk 106
6.1 The medical literature on hope 106
6.2 Finding hope within the speech of patients with cancer 110
6.2.1 Hope-as-a-noun 111
6.2.1.1 Hope exists independently 112
6.2.1.2 Hope can vary in degree and resilience 113
6.2.1.3 "Unrealistic" (or "false") hope 117
6.2.2 Hope-as-a-verb 118
6.2.2.1 Hope is the active desiring of a possible positive future outcome 118
6.3 The consequences of (multiple versions of) hope 119
6.3.1 Hope and the progression of cancer: the discourse of will 120
6.4 Conclusion 122
Chapter 7. Study 2. Constructing DNR orders 123
7.1 The medical definition 123
7.2 Medical intervention, and a natural death 124
7.3 Treatment refusal 128

7.4 Euthanasia 128
7.5 Documentation 130
7.6 Unfamiliarity with DNR orders 130
7.6.1 It's not for me to decide because doctors should decide 131
7.6.2 It's not for me to decide because I'm not ready 133
7.7 The choice of life and death 136
7.8 Conclusion 138
Chapter 8. Study 2. Justifying DNR orders 139
8.1 Person-centred (personal) arguments 139
8.1.1 Patients' pain and suffering before an arrest occurs 140
8.1.1.1 When you get to that stage … you've had enough 141
8.1.2 Quality of life before an arrest occurs 142
8.1.3 Quality of life after CPR is performed 145
8.1.3.1 Being less than human 146
8.1.4 Preparation for death 146
8.2 Other-centred (social) arguments 147
8.2.1 Avoid or end others' suffering 148
8.2.2 Avoid burdening others 152
8.2.3 Don't take up useful beds 153
8.3 Fatalistic (philosophical) arguments 156
8.3.1 Death's inevitable … 156
8.3.1.1 … because I've got (non-curable) cancer 156
8.3.1.2 … because resuscitation just prolongs things 157
8.3.1.3 … because humans die 158
8.3.1.4 … therefore resuscitation is pointless 159
8.3.2 The significance of cardiac arrest 160
8.3.2.1 When my heart stops, I'm dead 160
8.3.2.2 It's God's call 161
8.4 The DNR category 162
8.5 Justifying not establishing DNR orders: Deviant case analysis 162
8.5.1 I'm not in the DNR category 162
8.5.2 I want them to try to keep me alive 167
8.5.3 I do, and I don't want resuscitation 169
8.6 Conclusion 174

Chapter 9. Study 2. Patients, others, and decision-making 176
9.1 The patient should make the decision 176
9.1.1 Challenges to patient decision-making 180
9.1.1.1 Excluding the patient 181
9.1.1.2 Patients deciding not to decide 182
9.1.1.3 Patients making the wrong decision 186
9.1.1.4 Decisions at the moment of crisis preclude patient participation 187
9.2 Doctors and the DNR decision 188
9.2.1 DNR orders as medical: Doctors know the medical facts 189
9.2.2 DNR orders as personal: Doctors know the patient 192
9.2.3 Challenges to doctor decision-making 196
9.3 Family and the DNR decision 199
9.3.1 DNR orders as personal: Family as support 200
9.3.2 DNR orders as social: Family with a stake in the outcome 203
9.3.3 Challenges to family decision-making 207
9.4 Conclusion 212
Chapter 10. Study 2. The discursive properties of hope in talk by dying patients 215
10.1 Hope-as-a-noun 215
10.1.1 Objective characteristic of the situation 216
10.1.2 Subjective possession of the patient 220
10.2 Hope-as-a-verb 228
10.3 Conclusion 238
Chapter 11. Conclusion: What does it all mean? 244
Appendices 257
References 290

List of Tables

Table **Page**

1. Concepts shaping DNR questions asked during interviews, with examples of prototypical questions addressing these, and probe questions to follow 38

2. Details of interview-based characteristics of participants 48

3. At-interview demographic and disease-related status of participants 50

4. Details of time interval between interview and death of participants 51

5. Details of DNR status on file and independent relevant documentation made by participants 51

6. Details of DNR status and patients' preferences expressed at interview (Study 2 only) 52

7. Characteristics of tests for rationality in decision-making 76

8. Selected review of published papers delineating elements of hope 108

9. DNR status of patients who (during interview) indicated a preference for CPR (Study 2 only) 163

10. Summary of differences in functions and consequences of patients' use of hope as a noun or verb 240

11. Selected summary of potential dualistic constructs constituting hope as spontaneously used in the speech of patients 241

List of Figures

Figure **Page**

1. Detail of the hierarchical tree structure within N6 showing examples of demographic level of coding 54

2. Detail of the hierarchical tree structure within N6 showing examples of interview-based level of coding 55

3. Detail of the hierarchical tree structure showing initial coding within N6 of Question 4 56

4. Detail of the hierarchical tree structure showing developed coding within N6 of Questions 3 and 4 56

5. Detail of the hierarchical tree structure within N6 showing developed coding structure regarding patient's expressed views on CPR or DNR orders (Study 2 only) 57

6. The reciprocal relationship between doctor and patient construals of the DNR discussion which operate to maintain the negative construction of the DNR discussion, and to justify its deferral 83

7. Detail of hierarchical tree structure showing how hope was coded in N6 111

8. Reciprocal relationship between three specific versions of hope and patient health: Poor prognosis 120

9. Reciprocal relationship between three specific versions of hope and patient health: Good prognosis 121

10. Relationships between patient's and observer's suffering 150

List of Appendices

Appendix **Page**

A. The Royal Adelaide Hospital Medical Policies and Procedures Manual detailing policy effective during data collection for the presented research 257

B. An examination of South Australian legislation and policies in effect at The Royal Adelaide Hospital during data collection for the presented research 261

C. Study 1: Interview schedule 272

D. Study 2: Interview schedule, version 1 273

E. Study 2: Interview schedule, final version 274

F. Study 2: Form for recording demographic and treatment details of participants 276

G. Study 1: Form for recording demographic and treatment details of participants 277

H. Study 1: Information form for participants 279

I. Study 2: Information form for participants, version 1 280

J. Study 2: Information form for participants, version 2 281

K. Study 1: Consent form for participants 282

L. Study 2: Consent form for participants, version 1 283

M. Study 2: Consent form for participants, version 2 284

N. Summary of alternative construals of issues surrounding DNR decisions and decision-making re-presented in participants' talk 285

O. The Royal Adelaide Hospital Resuscitation Plan being developed by the end of the presented research 287

Abstract

This thesis is a qualitative examination of how patients with cancer talk about a decision at the end of life: the decision to forego cardiopulmonary resuscitation (CPR) following cardiac arrest—otherwise known as the 'do-not-resuscitate' (or DNR) decision. Within medical discourse, responsibility for this decision remains a contested issue, notwithstanding the dominant construal of it as a matter of patient autonomy. This construal contains various assumptions regarding patient decision-making, typically drawing upon a rational, individualistic model that constitutes the patient as independently and methodically gathering and assessing medical information prior to articulating a consistent preference. Although these assumptions have been challenged, there is little examination of how patients talk about or represent DNR decision-making and DNR orders (documentation of the decision within case-notes), nor of how they construe patients and others in the process. This omission is here addressed.

Qualitative data were obtained through two groups of interviews with patients with cancer. The first group of 23 (14 male) participants, although facing a serious illness, were considered not in a position where DNR orders were an immediately relevant issue. They were questioned about who should be responsible for making the DNR decision, when discussions regarding DNR orders should take place, and what factors were important to consider when making decisions. The second study was similarly designed, but the 28 (15 male) participants were terminally ill, and considered to be within weeks of their death.

The taped interviews were transcribed, and analysed according to discursive analytic principles—thus similarities in content, and variation within and between interviews were noted. Analysis focused upon how DNR orders were construed by participants, who constituted an appropriate decision-maker, what systems of meanings were drawn upon to justify different positions espoused, and potential implications of their talk for patients, their clinicians, and policy makers. In addition, the assumptions inherent in participants' speech were compared with those implicit within medical practice and policy.

Data and analyses are presented to argue that patients' assumptions regarding DNR orders and decision-making are not necessarily congruent with dominant assumptions within medical discourse and practice, including those inherent within dominant models of decision-making. Although autonomy was prioritised by these participants, it was differentially interpreted, and the patient's right to make the DNR decision was problematised through invocation of medical, social, economic, and moral issues. The

presence of emotion was also deemed to excuse individuals from decision-making. Participants' speech exhibited various assumptions regarding medical practice (including the provision of CPR and institution of DNR orders) that were sometimes contradictory, sometimes incorrect. A further area arising as significant within participants' speech was that of hope. Patients' variable use of hope (specifically noun or verb use) was analysed and compared to dominant representations in the medical literature—this comprising a major component of this dissertation.

In summary, participants' construals of DNR orders and decision-making, of autonomy and hope, varied. The diversity of potentially justifiable views available to (and here accessed by) patients suggests that policies and practices attempting to accommodate these must be maximally flexible.

Declaration

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text.

I give consent to this copy of my thesis being made available in the University of Adelaide Library.

I acknowledge that copyright of published material arising from this thesis (as listed below) resides with the copyright holder/s of those works.

Eliott, J. A. & Olver, I. N. The discursive properties of "hope": A qualitative analysis of cancer patients' speech. *Qual Health Research* **12**, 173-93 (2002).

Eliott, J. A. & Olver, I. N. Legitimating do-not-resuscitate orders: a discursive study of cancer patients' speech. *J Palliat Care* **6**, 59-68 (2003).

Eliott, J. A. & Olver, I. N. End-of-life decision making is more than rational. *Communication in Medicine* **2**, 21-34 (2005).

Eliott, J. A. & Olver, I. N. Hope and hoping in the talk of dying cancer patients. *Soc Sci Med* (in press).

Olver, I. N., Eliott, J. A. & Blake-Mortimer, J. Cancer patients' perceptions of Do Not Resuscitate Orders. *Psychooncology* **11**, 181-7 (2002).

Jaklin A. Eliott

March 2006

Acknowledgement of contributions of others on published articles

The following persons were named authors on published articles arising from research comprising part of this thesis.

1. Professor Ian N. Olver: Not only my primary supervisor, Professor Olver designed and initiated the first phase of current project. He also read and commented upon several drafts of papers arising, and this dissertation.
2. Dr Jane Blake-Mortimer was responsible for conducting the interviews for the first of the two studies herein analysed.

Acknowledgements

During my PhD candidature, I consider myself fortunate to have had two learned, wise, and endearing supervisors: the two Ians—Olver, and John! I want to extend copious thanks to Professor Ian Olver, not only for the opportunity to undertake this PhD research, but also for his ongoing support and guidance over the period of my candidature. Throughout, he has been encouraging and accessible, giving guidance where needed, but always allowing me to explore data and themes as I chose. His comments upon various draft stages of writing were typically instructive and incisive—and often humorous! Above all, he kept me focused upon what it all meant for the patient, but also, for their carers.

I also wish to thank Professor Ian John, for sharing his extensive breadth of knowledge, and helping me coalesce vague musings into meaningful conclusions. I also benefited from his unerring eye for poor grammatical choices!

My further thanks go to members of the Discourse and Rhetoric Unit (DARU), for opportunities to present preliminary conclusions to a group of like-minded colleagues, and for the lively and enlivening debates over the exigencies of (versions of) discourse analysis. And to members of TSG (aka Thesis Support Group, or Terrific Sexy/Serious/Scintillating Girls!)—Shona Crabb, Victoria Dennington, Danielle Every, and Katherine Hodgetts—for sharing the whole ordeal, tossing over ideas, remembering those obscure references, supporting through the confusing moments in analysis and the immensity of the writing endeavour, and most of all, sharing the joy at mile-stones reached: Thanks for your collective wisdom and the sheer good times.

I am also indebted to the University of Adelaide and the Cancer Council of South Australia for partial funding of this research.

In addition, I have been and am blessed with my family. I give thanks to and for Alan, for love, patience, and support (emotional and tangible—my very own computer whiz!) as this project took over aspects of our lives. Ditto for my children, Glyn and Cera, whose arrival interrupted the progress of my thesis, and helped me to keep it in perspective—my commitment to it, though great, pales by comparison to my commitment to my family (as do the challenges and potential rewards! And that's the way it should be.)

And finally, I thank the patients (and their families) who shared their time and thoughts, some when they had little time to share. I hope I have re-presented them well.

Chapter 1. Introduction: What's it all about?

This thesis presents a qualitative examination of the ways that patients with cancer talk about the decision not to resuscitate a patient following cardiac arrest, often referred to as the *do-not-resuscitate* (DNR) decision. The primary aim was not to determine *the* decision of an individual patient (i.e., to record what they might have decided), but to examine the ways in which patients—not doctors, not psychologists, not lawyers, not bioethicists—represented or construed these decisions. The hope was that this might provide useful information for hospital policy makers and medical practitioners developing or implementing DNR policy.

It began with several questions: Did patients even know what DNR decisions were? If they did, how were these decisions evaluated? If there was a decision to be made, who was held responsible for making it? How did patients justify their conclusions about DNR decisions? What factors were deemed relevant? What issues formed a background for or arose from what they said? What were the implications of the ways that they talked about DNR decisions, both for patients, and for those responsible for their care at the end of life? Did patient and medical representations of DNR decisions and associated practices concur? In attempting to answer these questions, I analysed two sets of interviews with a total of 51 patients (and incidentally 21 attending family or friends), employing discursive analytic techniques to consider the functions and consequences of the ways that they talked about the people and processes associated with the DNR decision.

In Chapter 2 I review the medical literature on the DNR decision and practices associated with it. I begin with a brief account of their historical development, then examine the different ways that the DNR decision is represented, arguing that these differences underpin much of the controversy about who should have authority over the decision to forgo resuscitation. I narrow my focus to consideration and critique of the dominant representation of DNR orders as representing patient autonomy, of the dominant model of patient decision-making associated with this, and the associated practice of surrogacy. Recognising that most of the DNR literature originates from the United States (US), I then refer to the Australian and local institutional context for this research. The chapter finishes with the presentation of, and rationale for the research questions herein addressed.

In Chapter 3 I explain and justify the research methodology employed, discussing both the theoretical underpinnings and specific analytic approach of this research. I also describe

the process of data collection, as well as the participants in the two sets of interviews conducted, drawing attention to differences between the two studies.

In the following 7 chapters I analyse and discuss the data obtained during interviews. Chapters 3-6 refer to the first study, Chapters 7-10 to the second.

Chapter 3 begins with an examination of the variable ways that patients with cancer defined DNR orders, and how they rendered these legitimate. I conclude that DNR orders were primarily deemed a matter of personal choice. In the next chapter I further examine how participants justified assignation of responsibility for the DNR order. I also consider the implications of this with regard to issues of timing when DNR orders should be appropriately addressed or instantiated. In so doing I note the emphasis on both rationality and emotion within patients' accounts of DNR decision-making, and draw attention to some limitations of the dominant medical model of patient decision-making. Chapter 6 presents a discursive examination of hope as it emerged spontaneously during interviews. Hope was not a topic originally targeted for investigation, but featured often, and moreover, proved to have implications for patients and their carers. I review the medical literature on hope, and compare and contrast this with patients' construction of hope, specifically focusing on differences between noun and verb use.

Chapters 7 to 10 examines the speech of dying patients (and in many instances their family) regarding the DNR decision. I note the presence and effect of different construals of DNR decisions and cardiopulmonary resuscitation (CPR), as well as discrepancies between patient and physician positions on these—possible because many patients recounted how they had made a decision, and many had DNR orders documented in case-notes. In Chapter 7 I examine the different ways that DNR orders were constructed within participants' speech, and consider the implications of these, both for patients and for medical practice. Chapter 8 begins with examination of how participants justified the decision to forgo CPR. I argue that participants effectively constructed a category of persons for whom DNR orders were appropriately instantiated, and conclude with examination of how individual patients justified their exclusion from this category. The following chapter examines how patients (and their families) negotiated issues of responsibility for these orders. I argue that patient autonomy was prioritised by patients but was differentially interpreted, leading to justification for a range of not always congruent conclusions. I further demonstrate how patients, their families, and their doctors were variously deemed appropriate and inappropriate decision-makers, and examine the relationships between and effects of juxtaposition of different construals of the decision.

The final chapter of analysis and discussion examines hope as used spontaneously during these interviews with dying patients. I further explore differences between noun and verb use, focusing on how hope functions in an interpersonal (and specifically in the medical) context. I conclude this chapter by discussing implications of patients' variable use of hope (as evident in both studies), and of differences between these and dominant representations of hope in the medical literature.

In the final chapter, I present my summary of and conclusions from the preceding analytical chapters. I draw attention to the implications of participants' constructions of DNR orders and associated practices, pointing out where patient and professional (practitioners and policy makers) positions might diverge. I further note some limitations of this research, and some research possibilities arising. I observe that this analysis of participants' talk of DNR orders and decision-making as well as their constructions of autonomy reveals a diversity of potentially conflicting, but equally justifiable views. I conclude that medical policies and practices addressing these issues should be capable of accommodating this diversity, recommending and describing what they might incorporate.

Chapter 2. Background: What has gone before?

According to Burns and colleagues,[1] "few initials in medicine today evoke as much symbolism or controversy as the DNR (do-not-resuscitate) order" (p. 1543). There is a voluminous literature (medical, legal, and bioethical) exploring, debating, and defining issues surrounding DNR orders. In this chapter, I review some of this literature, with the specific aim of providing the background and rationale for this study. I address four substantive areas, moving from the macro to the micro context. First, I discuss the development of DNR orders themselves; then, illustrating that DNR orders are a contested and complex construct, I consider the various different ways they are construed within the medical literature; next, I zero in on what has been asserted as the dominant construal and the principles and practices that inform or are derived from this; finally, I set out the Australian research and current policies at the site for this research. I then note limitations with the DNR literature, and present the research questions that directed this thesis.

2.1 The development of DNR orders

A DNR order is the written documentation of a decision not to undertake cardio-pulmonary resuscitation (CPR) upon a specific patient within a medical setting.[2-4] According to Ebell,[2] it explicitly "instructs the patient's health care provider to forego CPR should the patient undergo cardiac or respiratory arrest" (p. 255). DNR orders are a modern and unique phenomenon, emerging within hospitals in the last quarter of the twentieth century.[1, 5, 6] They are about foregoing action, reversing society's standing order that physicians preserve life against death, and challenging the protocol that authority must be granted to touch, rather than not to touch.[1, 7] The development of DNR orders is consequential upon that of CPR, now briefly discussed.

Niemann[8] stated that, following cardiopulmonary arrest, CPR is initiated with the aim of providing "artificial ventilation and circulation until advanced cardiac life support can be provided and spontaneous cardiopulmonary function restored" (p. 1075). Prior to the development of resuscitative techniques, the patient who arrested in a hospital ward (or indeed, anywhere else) would die, with the medical profession unable to take any action to prevent or reverse this occurrence.[9] But in 1960, Kouwenhoven, Jude, and Knickerbocker[10] published "Closed-chest cardiac massage" detailing their version of CPR, a relatively simple, easily learnt method, requiring neither specialised skills nor equipment. As noted by Elam,[11] it was "enthusiastically accepted" as applicable to "all victims of sudden respiratory or cardiac collapse" (p. 12). However, because part of the dying process is the

cessation of both heart and lung function, CPR is potentially applicable to all persons who are dying.[5, 12, 13] Giving the appearance of staving off death, CPR rapidly became the default option for all 'victims' of cardio-pulmonary collapse within a hospital, regardless of any underlying pathology.[5, 7, 14] It remains the standard immediate and default medical response to cardiac or respiratory failure.[5, 13, 15-17]

However, CPR was originally intended to reverse unexpected cardiac failure in otherwise healthy individuals: As such it was highly successful.[5, 11] In patients with chronic illnesses approaching death, specifically those with advanced (or metastatic) cancer, CPR is less efficacious as survival-to-discharge rates are extremely low to non-existent (varying between 0-2.4%).[18-23] CPR is moreover a highly intrusive and violent technique that may result in significant injury, particularly in the frail and dying.[14, 24, 25] Thus some patients might be successfully resuscitated only to live for a short time and die in great discomfort, or be subjected to repeated resuscitation attempts.[14, 22, 26-28] Within medical practice, application of CPR in the terminally ill has been denounced as prolonging the dying process, rather than restoring life.[5, 27-32]

Somewhat understandably then, following the routinisation of CPR within hospitals, health professionals (including doctors and nurses), became reluctant to commence CPR upon terminally ill patients, and developed systems of subverting the process through, for example, 'slow code' maneouvres, delaying the application of CPR.[1, 6] Baker[33] noted that different hospitals developed idiosyncratic and covert methods of communicating the decision by medical staff that patients should not receive CPR, including attaching dots to their file, writing obscure and cryptic initials within case-notes, or just verbally relaying the decision from shift to shift. Such practices, though well meant, were deemed to be of questionable ethical status, leaving medical staff potentially vulnerable to legal and moral recrimination, and leading to calls for the development of policies regarding decisions not to resuscitate—allowing for transparency of process, and accountability of involved parties.[6, 34] Precisely because CPR was established as the default option, decisions to forgo it (i.e., the establishment of DNR orders) require authorisation.[7]

Although these first decisions not to invoke CPR were made by clinicians, and entered in patients' files with neither patient knowledge nor consent,[6] the call for codified DNR policies coincided with the ascendance of bioethics in providing the framework for considering end-of-life decision-making, itself emerging at a time when increasingly patients' rights were seen as fundamental, taking priority over other ethical principles valued within medical practice.[1, 35, 36] Medicine was shifting from a paternalistic practice

wherein doctors made decisions and patients acquiesced, to one where patients made the decisions and doctors acquiesced—patient autonomy prevailed.[36, 37] Where hitherto a doctor-initiated DNR order might have passed unnoted, at the time when DNR orders emerged this was no longer the case.[38] By the early 1970s, policies that asserted the primacy of autonomy, and the right of the patient in determining DNR orders began to emerge in the US,[1, 39] and by 1988 such policies were mandatory for all US acute and chronic care hospitals.[40]

In an oft-cited paper, Tomlinson and Brody[41] nominated three circumstances as appropriate grounds for making a decision not to resuscitate (making the DNR decision). These were: first, that the pre-arrest quality of life is unacceptable to the patient (or carers if the patient is incompetent); second, that the anticipated quality of life after successful resuscitation would be unacceptable even if survival was prolonged; and third, that the medical team believes that resuscitation almost certainly would fail, and thus would provide no benefit to the patient. The first positions the patient as central, requiring them to have and to state their preferences, and theoretically need not involve medical staff in the making of the decision: Thus if it is known that the patient has completed an advance directive (i.e., has proactively documented their preference regarding end-of-life treatment and refused CPR,)[42, 43] this is considered sufficient grounds to instantiate DNR orders.[44] Although the second similarly positions the patient as decisive, it requires that they have medical advice regarding the probable outcome of CPR. Conversely, the last implies a medical judgment by the physician based upon medical knowledge of the patient and their prognosis, and may be made by the physician, theoretically without any patient input. There are a number of potential discrepancies within Tomlinson and Brody's guidelines, particularly regarding the relative contribution of patient and doctor to the DNR decision, and these underpin an on-going debate regarding authorisation of DNR orders.

2.2 Representations of DNR orders within the medical literature

It is generally agreed that the senior consultant on a case is in charge of documenting the DNR decision within the patient's case-notes.[44-47] Without such documentation, attending clinical staff (primarily nurses) are legally obliged to commence CPR, regardless of its predicted efficacy—a possibly morally untenable and personally distressing situation for these carers.[38, 48-50] Not surprisingly, nurses are often instrumental in calling for clarification in DNR status of a patient,[13, 50] and are known to act independently (albeit illegally) to affect the outcome should appropriate documentation be lacking.[32, 51-53]

Regardless, and notwithstanding the affirmation of patient autonomy, who authorises the DNR decision not to commence resuscitation—who is actually responsible for *making* the DNR decision then documented—is still contested within medical discourse.[21, 32, 54-56] Debate is contingent in part on how DNR orders are construed, to which I now turn. My intent is not to extensively critique the following representations of DNR orders, rather, to demonstrate that they exist and collectively constitute DNR orders as a multi-faceted, complex, and contested construct.

2.2.1 Medical

Some have construed the DNR decision as a *medical* decision—as reflecting the considered judgment of the physician that the provision of CPR would not benefit the patient. Invoking the notion of medical futility, they have concluded that, when CPR is deemed likely to fail, just as the physician is under no obligation to offer or provide non-beneficial treatments to the patient, so they need neither offer nor discuss CPR, nor obtain patient consent for recording a DNR order.[14, 17, 30, 32, 57, 58] Proponents of this view have also asserted that patient autonomy does not include the right to demand CPR against a medical recommendation.[58-60] Others have framed the decision as primarily medical, but with *moral* aspects, suggesting that, although the ultimate decision remains a clinical one, doctors should (i.e., have a moral obligation to) discuss their decision with the patient or family and articulate the clinical basis for the decision.[21, 61]

The legitimacy of unilateral DNR decision-making by doctors may be challenged. First, inherent within it is the presumption that doctors will only consider information pertaining to the medical condition of the patient. By contrast, several studies have reported that doctors' decisions about a patient at the end of that patient's life (including the DNR decision) are influenced by non-medical factors, including physician's fear of prosecution, specialty, length of time in practice, and religion, as well as particular institutional forces, interpersonal issues between doctor and patients, and doctors' assessments about patient quality of life, social status, and psychiatric functioning.[4, 62-70] Furthermore, physicians' decisions about DNR orders have been found to differ by diagnosis, even when prognoses were identical, with rates varying according to physician specialty.[63-65, 69] In addition, one study found variation (independent of medical factors, e.g., patient sickness at admission and functional impairment) in rates of DNR orders according to patient age, race, gender, insurance status, and rural location (although who initiated these orders was not noted).[71] Others have concluded that a variety of cultural and professional values influence end-of-

life medical decision-making, including doctors' own comfort with discussing death, and both implicit and explicit hospital policy.[72]

Second, although the construal of the decision as medical would seem to require that doctors know and consider the probable success of CPR, doctors tend to overestimate the efficacy of CPR.[73, 74] In addition, doctors' definitions of DNR orders have been found to vary, with some, but not consistent association with restrictions in treatments other than CPR.[75-79] These observations challenge the credibility of unilateral decision-making by doctors. As a final point, it has been noted that the benefit or futility of any proposed intervention is comprised of both a quantitative component (the probability of achieving a desired physiological effect) and a qualitative one (the resulting benefit to the patient).[80, 81] Although the first may be (objectively) assessable by the doctor, the second can only be (subjectively) established by the patient.[46]

2.2.2 Personal

Accordingly, it is suggested by an alternative faction that a medical assessment of physiologic inefficacy should not supercede patient preferences, and that the decision is fundamentally a *personal* (sometimes termed *moral*) decision.[1, 7, 48, 82, 83] In this construal, determining and complying with patient preference champions autonomy as curtailing the perils of paternalism.[46, 84] In practice, this requires that patients have, are able to, and do state their preferences, often through completing advance directives. Indeed, Burns et al.[1] noted that DNR orders and advance directives are increasingly conflated. As this version of DNR orders is currently dominant within medical practice[85] I shall discuss arguments for and against it in further detail in 2.3.

These two construals—medical and personal—are the dominant representations of DNR orders within the medical literature. There are, however, others.

2.2.3 Economic

Some writers have noted the economic impact of providing CPR as a routine practice, particularly given limited funding for an ever-expanding array of medical services designed to sustain life.[7, 44, 58, 61] There are moreover a number of studies estimating (though not always agreeing about) the high cost of interventions at the end of life, usually in the guise of assessing whether or not advance directives reduce the use of hospital resources,[86-88] with some promoting them as curbing costs.[89] Others have examined cost differences associated with differences in timing of the establishment of DNR orders.[90, 91]

In addressing issues of cost, these writers construe DNR orders as *economic* issues. However, arguments concerning distribution of resources typically centre around notions of (distributive) justice,[92-95] and thereby work to construe DNR orders as having *moral* connotations.

2.2.4 Legal

DNR orders have been, in various ways, located within the legal domain. For example, Mello and Jenkinson[61] observed that the development of hospital policies and legislation about DNR orders has not only established the legal status of these orders, but effectively codified CPR as a default measure. Fear of litigation, and concern regarding legal consequences of their actions and the legal standing of DNR orders have been cited as influencing physicians' decisions.[3, 32, 61, 62, 96-98] Some have noted that the legal status of withholding treatment remains ambiguous,[97] others calling for clarification over what constitutes a legally appropriate policy.[44] In contrast, some have argued that DNR orders have led clinical staff to an inappropriately legalistic view of their responsibilities to dying patients,[67, 99] and others suggested that increased legal involvement in medical decision-making at the end of life leads to increased probability of aggressive intervention, including CPR.[100, 101] Finally, a number of writers have focused on the development and implementation of (including documentation), and compliance with DNR policies in medical institutions (ranging from acute, intensive, and long-term care settings).[17, 102-109] Regardless of the focus of these writers, they collectively construe DNR orders as not just medical, but *legal* constructs. In addition, by presuming a society that pre-exists, shapes, and is shaped by these legal parameters, DNR orders are simultaneously construed as being intrinsically *social*. This point is applicable to economic-based arguments. However, as legal debate centres on the right of the individual to dictate their healthcare, again, the *personal* construal of the issue is brought to the fore.

2.2.5 Social (and interpersonal)

The social aspect of DNR orders is also discernable in arguments concerning the family. Family are typically implicated in discussions of patient decision-making and often represented as supporting patient autonomy,[95, 110-113] although many models of decision-making presume them a threat to same.[114] Regardless, family are regularly identified as the most appropriate or customary decision-makers for the incompetent patient—that is, as appropriate or acting surrogates.[111, 112, 115, 116] I shall discuss both surrogacy and family, specifically in relation to patient autonomy, in further detail at 2.3.2.2. Finally, some writers have argued that family are significantly affected by the consequences of the

decision and the decision-making process,[111, 113, 116, 117] with reports that patients consider this in their own decision-making.[95] Considerations such as these have led some to assert that family's needs and views should be weighed against those of the patient, [118] though this is rebutted by others.[111] Notwithstanding the differences in how family are construed, their nomination within the DNR literature sees DNR orders as simultaneously *interpersonal*, *social*, and *moral*.

2.2.6 Bioethical

Finally, DNR orders and CPR are staples of discussion and empirical research within bioethics.[55] Indeed, much of the controversy around DNR orders is embedded within and debated in *bioethical* concepts.[61, 78, 119] Bioethics has established authority in medical practice,[37, 120] guiding the provision of care at the end of life.[121] Accordingly, it is not surprising that ethical aspects of DNR orders emerge within several of the aforementioned construals: For example, in promoting the decision as medical, writers have typically pitted the bioethical principles of non-maleficence and beneficence over that of autonomy; both economic and legal arguments have drawn upon notions of justice, the latter further championing autonomy, also prioritised within the construal of the decision as personal.

These four bioethical principles—autonomy, beneficence, non-maleficence, and justice—defined by Beauchamp and Childress[122] are widely cited within the field of bioethics, guiding appropriate behaviour for clinicians and researchers interacting with patients. Although Beauchamp and Childress argued that all four principles had relevance to medical practice, autonomy has been elevated above the others, and as noted earlier, currently prevails.[35, 37, 123-125] Several reasons why this should be so have been suggested: As previously observed, the emergence of bioethics as a discipline (specifically within Western society) coincided with the ascendance of individual rights, but also with the questioning of traditional authority that included calls for accountability in the medical profession and rejection of paternalism,[37, 121, 126] and the advent of the consumerist society which redefined patient-doctor roles to that of consumer-service provider.[35, 84, 123, 125] Autonomy resonated with the ethos of the day.[121] In addition, unlike the other principles, autonomy is easily codified into a set of rules and procedures that can be quickly and consistently applied in practice.[121, 125] As a consequence, within bioethics (and consequently, medical practice informed by bioethics) autonomy is the dominant concept informing decisions about a patient (including those at the end of life).[35, 123, 127] The dominant construal of the DNR decision is that it is *personal*.

To summarise, the medical literature construes DNR orders and DNR decision-making in several different ways. I have here delineated six—medical, personal, economic, legal, social, and bioethical versions. I acknowledge that this list is not exhaustive. For example, Burns et al.[1] identified DNR orders as (at least potentially) having religious connotations. In addition, the presence of protocols, policies, and documentation pertaining to these orders has implications for bureaucratic or administrative agencies. However, concerns relevant to the latter may be readily subsumed with the medical or legal representations. Furthermore, although different religious traditions have differing perspectives upon treatment withdrawal at the end of life,[128] few have specifically commented upon DNR orders.[1] Therefore I have limited my discussion to the six listed, further arguing that, due to the pre-eminence accorded autonomy, the DNR decision is deemed primarily a matter of personal choice.

2.3 DNR orders are personal: Autonomy, patient decision-making, and surrogacy

Given that medical discourse treats the concept of autonomy as paramount in determining DNR orders, I deem it useful to explore how autonomy is articulated—in theory and in practice. Following this, I attend to criticisms derived from theoretical and empirical observations, and finish with a similar treatment of the practice of surrogacy, typically construed as deriving legitimacy from its relationship with autonomy.

2.3.1 Autonomy

Although there is consensus within the medical and bioethical literature regarding the ascendance of autonomy, there is little about what it means, or when it can be legitimately employed.[129] Hill[130] has observed that the concept is complex, meaning different things to different persons: Thus there is a plurality of autonomies which may be invoked to different effect,[114, 130] fostering confusion within debates over the merits and effects of autonomy in practice.[129] A comprehensive examination of autonomy is beyond the scope of this dissertation, but the following different definitions attest to difficulties in presuming unanimity of meaning.

Mackenzie and Stoljar[129] observed that theories of autonomy may be divided into procedural and substantive accounts. *Procedural* accounts are content-neutral, prioritising a process of critical reflection, and deeming irrelevant what prefigures the autonomous decision (e.g., desire, emotional attitude, beliefs, and values). The pivotal idea within *substantive* theories of autonomy is that of normative competence: Autonomy is equated

with reason and the capacity for rational self-government. Both accounts were criticised by these writers: procedural, for ignoring the development of standards used to critically reflect (a point I note as relevant to both accounts); and structural, for being stringently normative and conflating autonomy with moral responsibility.

Meyers[131] has defined the concept of autonomy *competency*, positing that autonomy is only realisable through the display of skills and capacities, specifically in self-discovery, self-direction, and self-definition, evident in interaction with others. She and other feminist writers[35, 123, 132] have developed the notion of a *relational* autonomy—one that attends to the socialisation processes that contribute to the development of the autonomous self, and the social relationships, practices, and institutions that form the context for decisions made. In addition, Meyers[131] distinguished between *episodic* autonomy (i.e., the capacity to formulate desires or choose behaviours in a given situation) and *programmatic* autonomy (i.e., the capacity to critically reflect and reflectively decide major life issues). These may not necessarily be congruent.

Responding to (predominantly feminist) claims that the heralding of autonomy has dismissed (and implicitly opposed) the moral weight of compassion, Hill[130] proposed three 'theses' of autonomy. The first of these conceptualises autonomy as *impartiality*, which he denied implies an emotional detachment that is antithetical to compassion. The second equates autonomy to *the right to make personal decisions*, a right which he nonetheless contended is limited by other ethical considerations such as justice and responsibility. He further characterised autonomy as *a goal for personal development*, stressing that the attainment of self-awareness and integrity need not preclude enactment of compassion.

In discussing *personal autonomy* (i.e., autonomy of persons rather than of nations), Young[133] distinguished between an "*occurrent* sense of autonomy, [an] autonomy of the moment" and what he saw as a "more important *dispositional* sense of autonomy, where the focus is on the … [individual's] life as a whole" (p. 5, italics mine). These respectively bear resemblance to Meyers' episodic and programmatic autonomy constructs. Young argued that sometimes respect for the latter might mandate overriding an individual's immediate expressed preference. Such an intervention within the medical arena—doctor overriding the patient's wishes—might be considered paternalistic. Accordingly, a physician might, for example, not comply with a patient's directive that the physician judges would cause harm to the patient—the aim being to respect the patient's dispositional autonomy, rather than their occurrent autonomy—which Young identified as "hard" paternalism. However, such actions may be classified as "soft" paternalism (and

therefore morally acceptable), specifically where the justification is that the patient's directive failed to meet required standards of decision-making (perhaps not being fully informed).[134]

Finally, in their seminal paper defining four models of physician-patient interactions, Emanuel and Emanuel[84] described four associated conceptions of (patient) autonomy. Within the paternalistic model, patient autonomy is conceived as *patient assent* to doctors' objectively determined values; within the informative, it is *patient choice of and control* over medical care; within the interpretive, it is evident through *self-understanding* relevant to medical care; and within the deliberative model, through *moral self-development* relevant to medical care. They contended that any of the four models (and associated versions of autonomy) might be appropriate in different circumstances, but that the deliberative represented the ideal model to direct clinical encounters (and the provision of healthcare), and recommended that deviation from this "ideal" should prompt justification.

However, Cook[85] has noted that the deliberative model is the least common in practice, and Emanuel and Emanuel[84] themselves observed that the dominant concept of autonomy within medical practice is that of the informative (sometimes called the consumer) model, a point echoed by others.[37, 135, 136] In this model, the patient is positioned as decisive in choosing and directing their healthcare, with the doctor positioned as the technical expert providing adequate information and implementing patient decisions. Schneider[37] has cogently argued further that current medical discourse (including theoretical argument and clinical practice) is dominated by *mandatory autonomy* (which insists that patients must make their own decision), with *optional autonomy* (which holds merely that they are entitled to do so) correspondingly diminished.

2.3.2 Patient autonomy and decision-making

Within the medical literature, Howell and Sale[124] have provided a typical definition of autonomy: "the right of the competent individual to make intelligent and informed decisions about their own health and well-being" (p. 131). Ideally, according to Emanuel and Emanuel,[84] in asserting this right "individuals [should] critically assess their own values and preferences, determine whether they are desirable; affirm on reflection these values … and be free to initiate action to realize the values" (p. 225). Although the version of autonomy most dominant within medical practice does not place such emphasis upon critical reflection, it similarly enjoins the patient to acquire and deliberate over information, then independently choose and sanction some course of action.[37] Autonomy is

often equated with the practice of informed consent, requiring that patients' decisions must be informed, rational, and free.[35, 37, 121, 129]

The value accorded these versions of autonomy (either in ideal theory or dominant practice) reflects the dominance of cognitive-based theories and models of medical decision-making. These presume that individuals undertake a reasoned deliberation of the probabilities and consequences of alternative choices—emphasising both rational choice and rational beliefs.[137-139] In drawing upon 'rational choice theory,' these dominant (traditional) medical models of decision-making further presume that the individual (1) is capable of making a reasoned judgement; (2) has adequate information regarding the probabilities and consequences of alternative choices upon which to deliberate; (3) wants to deliberate rationally upon such information; (4) has adequate time to do so; (5) has an explicit agenda that merely requires autonomy to implement it; and (6) can and will make decisions that are not constrained, coerced, or impeded in any way, independent of social factors such as effects of choices on others, or relative power-relations that affect the contexts of choice.[35, 37, 127, 137] Current good medical practice requires that healthcare workers attempt to maximise the likelihood that patients exercise their right to autonomy according to such precepts, and make rational decisions regarding their medical treatment, with the assumptions that this is what they would desire and is, in some way, beneficial.[37]

2.3.2.1 Criticisms of dominant concepts of decision-making

Recently the assumptions embedded within these models of patients' decision-making have been subject to critique. These emerge from theoretical and empirical observation.

First, the presumption of universality regarding the principle of autonomy has been subject to criticism. Fan[140] has noted that the dominant concept within bioethics is a peculiarly Western ideal, demanding self-determination, assuming a subjective conception of the good, and valorising individual independence. By contrast, what he called an "East Asian" principle of autonomy values family determination, an objective conception of the good, and harmonious dependence. Similarly, speaking specifically about healthcare, Pang[141] has noted that Chinese values do not elevate individual autonomy above all else, deeming that family interests may take precedence; further, that the concepts of truth-telling and informed consent are not held sacrosanct, with caregivers aiming to safeguard "vulnerable patients." These alternatives to the dominant model of autonomy are particularly pertinent given the rise of multiculturalism in contemporary societies.

Furthermore, feminist theorists have decried the autonomy presented in bioethical theory and medical practice as undertheorised, overly individualistic, and rationalistic, depicting the decider as disembodied, as divorced from, or rising above their cultural and social environment.[32, 35, 123, 129, 131, 142] This is, it is argued, theoretically flawed as it ignores both that fundamental socialisation processes see individual identities emerging in the context of social relationships, and that all persons are always socially located in a network of interpersonal relationships that influence who they are and what they do. In redress, some have promoted *relational autonomy* which, Donchin[123] asserted, takes "into account the network of relationships" that affect persons (p. 240), and, according to Mackenzie and Stoljar,[129] depicts autonomy as "a characteristic of agents who are emotional, embodied, desiring, creative and feeling, as well as rational creatures" (p. 21).

The sociologist Barnes[143] has likewise argued that models of rational choice purporting to model human behaviour are fundamentally flawed. He noted that, as humans, individuals are constituted through interactions with other individuals that render them both mutually accountable and susceptible to others. Accordingly, any individual's actions are both limited and morally evaluated by others, thus rebutting any concept of independent and individualistic decision-making in isolation from others.

Other criticisms of rational choice theories are derived from psychological studies demonstrating that individuals commonly use decision-making procedures that deviate from stipulated rational criteria. These include following habitual patterns, tradition, perceived behaviour of respected others or the majority, religious precepts, or whatever seems to have worked well in the past, and often rely upon heuristics (rules of thumb) that produce systematic biases and inconsistencies in decision-making.[137, 144-148] Janis[137] concluded that "rational choice" rarely occurs, and is particularly problematic in patients dealing with copious amounts of unfamiliar information, the stress and conflict generated by their awareness of the possible consequences attendant upon their decision, and the perceived need to decide quickly.

Similarly, Marta,[149] employing a post-structuralist framework, concluded that current medical models of decision-making represent persons as "unidimensional, rationalistic, medico-legally constructed players," and suggested that the emphasis on "cognition or rationality" be supplemented by incorporation of the "emotional, linguistic and socio-cultural dimensions" at play in medical decision-making (p. 255). Social constructionists have also noted that the individual may be conceived as rather more fragmented, complex, or conflicted than the rational, unitary subject that dominated scientific and political

thought in the twentieth century: Gergen,[150, 151] for example, has discussed the current relevance of the concept of the romantic, passionate self that flourished during the nineteenth century, and postulated the rise of the relational self.

Others have noted what Lupton[152] called a counter-discourse to rationality, championing the expression of emotions as defining the essence of humans, and leading to something of a paradigm shift towards emotionalism as a criteria for self-hood.[153, 154] There has been a corresponding questioning of the emphasis on rationality in medical decision-making, as writers note the importance of emotion, culturally determined values, relational ties, and contextual variables that shape patients' decision-making.[37, 121, 124, 149, 155-157]

In addition, it is argued that medical decisions about a patient are constrained by systemic and economic factors,[121, 158] as well as those associated with the condition of being a patient: Patients do not use, and may not comprehend medical terminology,[121, 159-161] nor understand the capacity and limitations of technological intervention to avert death.[85] Moreover, many decisions are urgently required at crises—times when the patient is in pain, in confusion if not unconscious, and in circumstances far from the abstracted and neutral conditions assumed in rationalist models of decision-making.[35, 37, 121]

Although advance directives are deemed to enable patients to make decisions when capable of adhering to the preferred model of decision-making,[30, 162] Drought and Koenig[121] have rejected presumptions that decisions about death can be made "long before the inevitability and reality of our dying becomes apparent," and that "rational and cognitive ways of knowing can subordinate our emotional, psychological, and embodied experiences" (p. 116). They and others further recommended that end-of-life decisions (including the DNR decision) should be driven by process rather than product (i.e., signed documentation).[16, 43, 163, 164] Other challenges to the legitimacy of advance care planning (including patient-authorised DNR orders) have included claims that advance directives incorrectly assume a clarity and continuity of patient preferences over time,[115, 136, 165-168] cannot cover all specific contingencies and are typically open to indeterminate interpretation,[115, 169] that autonomy can only be deemed preserved when an individual is making a valid contemporaneous choice,[115] that a previously voiced preference may conflict with a person's current best interests,[166] and that it cannot be presumed that the patient was competent, adequately informed, or free from coercion at the time of writing.[169]

In addition to theoretical challenges to the traditional construct of autonomy, there are, moreover, a number of empirical-based studies and observations attesting to its limitations and practical inadequacy as the dominant principle directing end-of-life care (including the DNR decision). For example, patients' preferences can only be put into effect when they are known (and documented) by their doctor. This presumes that discussions regarding preferences for treatment at the end of life actually occur, with appropriate clarity and exchange of information, culminating in an unambiguous statement of preference by the patient. Several studies have indicated that such untrammelled communication rarely occurs.[3, 43, 83, 87, 170-173] Various explanations for this have been noted, focusing on both doctor and patient contributions.

Even when endorsing patient autonomy, doctors may have convincing reasons why they have not (yet) approached individual patients regarding their preferences for future care—many are reluctant to foreshadow or discuss the patient's impending death and thereby upset the patient, and perceive a need to preserve hope—all contributing to difficulties in timing DNR discussions, or deferral to a 'best' time.[5, 121, 174-179] Several writers have commented upon the difficulty clinicians face in identifying the appropriate moment to ask a patient questions that refer to that patient's death, presenting this as a major obstacle to be overcome.[55, 178, 180] Others have noted that a doctor's hesitation to address these issues may be due to their own difficulties in accepting the inability of medicine to prevent the patient's death,[21, 67, 83, 174, 175, 181, 182] or even fear of the patient's reaction.[181, 182] However, it may be due to their perception that it is a clinical decision, and that patients should not be faced with a decision that (incorrectly) implies a choice between life and death.[32, 47]

Either way, DNR decisions and associated discussions typically occur when patients are mentally incompetent and unable to participate in decision-making.[28, 109, 121, 183, 184] However, many (if not all) studies report the presence of competent patients who are not consulted regarding the DNR decision.[51, 61, 65, 106, 183, 185] Furthermore, even when physicians are aware of patients' preferences, their compliance with these is not assured,[62, 170, 186-188] and medical futility is available to justify overruling patient preference.[61]

Others have noted problems with communication between parties, observing that doctors use language that patients may find overly medical, vague, ambiguous, or confusing[37, 43, 171-173] and often direct the discussion in order to obtain the outcome they desire.[67, 171] Studies have shown that physicians tend to underestimate patients' desire for non-intervention in dying.[189-191] The extensive and oft-cited Study to Understand Prognosis and Preferences for Outcomes and Treatment (SUPPORT) reported that, despite targeted

intervention to improve patient participation in decision-making at the end of life (and thus promote patient autonomy), there was no improvement in physicians' knowledge of patients' preferences—perhaps understandably, as patients often fail to state their preferences in advance, many not wanting to.[87, 192-195] This despite the fact that many say that they want to discuss and convey their wishes early whilst still capable.[196]

Accordingly, several writers have challenged the assumptions that all competent patients want to undertake, or are capable of the prescribed rational search for and consideration of relevant information inherent in dominant concepts of autonomy, and that this process will have only positive consequences for them.[37, 85, 197] Patients may find the decision or discussion—referencing their own death—confronting, overwhelming, or difficult,[43, 197-199] and view the request to decide whether or not to forgo CPR as tantamount to abandonment.[3, 121, 200] As a result, some medical writers have queried the ethics of requiring patients (or their families) to make such a decision.[57, 99, 163, 201] Others have noted that patient comprehension of what CPR is, or what DNR orders entail, is limited and variable, that patients consistently overestimate the efficacy of CPR, and that treatment preferences are often determined by their physical or emotional state at the time of making decisions.[73, 198, 202-206] Similarly, others have questioned patient capacity to understand the significance of factors surrounding medical decisions, including the nature of critical illness, prognostication, and the characteristics and consequences of high-tech intervention—with anxiety or depression over their condition, denial of death, and impairment inherent in their condition or associated treatment likely to contribute to this.[44, 85, 197, 198, 207-210]

Moreover, several studies support the conclusion that not all patients maintain that their choices should direct their future medical care—in contrast to the views of the majority of healthcare professionals and medical discourse,[38, 211] as well as those of non-patients.[212, 213] Many patients prefer that their physicians be responsible for decision-making, with increased sickness associated with less desire to make decisions.[212, 213] This finding has been consistently observed in cancer patients, with factors associated with patients preferring to leave decisions to their doctors including increasing severity of illness,[214-216] being older,[212, 213, 215, 217] being male,[213, 218] and being less hopeful.[217] Furthermore, a patient's articulation of a specific preference does not always entail that they want their directives to be slavishly followed, many preferring that they be overruled should their directives conflict with those of others, including familial surrogates or physicians.[219-222]

Similarly, patients' concept of autonomy or their priorities at the end of life might not mirror those presumed in dominant models of decision-making. Several studies have reported that some cultural groups view patient autonomy as embedded within familial relationships, such that the family, rather than the individual, is responsible for decision-making; others do not value the disclosure of 'bad news,' (including diagnosis of cancer and prediction of death)—which is required information for enactment of informed decision-making.[140, 156, 223-229] Moreover, rather than making decisions based solely upon predicted consequences for themselves, patients hold the effect of any decision upon others (specifically, upon family) as of vital import—even within cultures and societies that endorse patient decision-making.[198, 202, 223, 230-232] Finally, it is observed that many, if not the majority of patients, simply do not make these decisions, leaving them to others to do so.[121, 233] This, plus the fact that DNR orders are typically established when the patient is incompetent, raises the issue of surrogacy, and I now address arguments surrounding this practice.

2.3.2.2 Surrogacy

If the DNR decision is construed as primarily medical, patient competency is irrelevant, as responsibility for making the DNR decision about a patient would fall to their senior medical consultant. If it is deemed primarily personal, a matter of patient autonomy, then, as noted above, when the patient is incompetent, the issue of surrogacy arises.

As debated within the medical literature, surrogacy—sometimes called proxy-decision-making,[234] or delegated autonomy[235]—is indeed premised upon presumption of patient autonomy as the dominant standard for decision-making. It is presented as able to promote the values of self-determination or moral autonomy,[115] preserving patient autonomy beyond the limits of competency,[57] as the surrogate replicates what the patient's decision would have been.[236] Critically, the relative merits of the different standards applied to surrogate judgment, and of different candidates for the surrogate role are promoted or contested through implicit or explicit assessment against the principles held up as essential for realising patient autonomy.

For example, in order to decide as the patient would have decided, the surrogate must possess this knowledge about the patient. Family are most commonly cited in this role, presumed best able to know the patient's wishes due to their mutual longstanding intimate engagement.[112, 113] This intimacy is also deemed to constitute reason why family are most likely to care about the patient, and thus want to ensure that their wishes are effected.[112, 116]

In addition, family are construed as the context within which an individual's autonomy develops, and thus most likely both to have shaped and to share the values underpinning the patient's decisions.[111, 112] These criteria work to undermine nomination of others who lack such history (e.g., medical staff), and form the basis for claims that family should have a *prima facie* claim to surrogacy.[112, 116] However, they may also be drawn upon to query the nomination of family, who may be required to provide convincing evidence of an intimate and shared history before granted surrogate status.[237] Nonetheless, the common-law assumption that family or 'next-of-kin' are the appropriate and preferred surrogate decision-makers,[111, 168] attests to the taken-for-granted status of family in this role. Finally, others have supported nomination of family as surrogate through claims that they are patients' preferred and most-often named surrogates.[112, 222, 238]

Nonetheless, several writers have identified a number of practical circumstances as constituting grounds for challenging family as appropriate surrogate decision-makers. First, nomination of 'family' presumes a homogeneity that may not be present,[114] and patient and family interests may diverge.[111] Second, definitions of what constitute 'family' varies,[239] with some including close intimate friends.[115, 118, 235] Third, families of dying patients may not meet required standards of decision-making, being perhaps stressed, frightened, exhausted, or incapable of comprehending relevant medical information.[111, 240] Finally, asking family to make decisions about the circumstances of the patient's death may have negative consequences for them, and thus may be deemed unethical.[32, 62, 115] Despite these objections, others have claimed our societal understanding of the mutual obligations and responsibilities engendered within the family work to confirm family as appropriate surrogate decision-makers.[112, 116, 117] Nonetheless, with regard to requests or demands for CPR against medical recommendation, just as the limits of patient autonomy remain contested within medical discourse, so too do the limits of familial surrogate authority.[26, 57, 113]

When making the decision, the surrogate is presumed to apply particular standards. The dominant legally accepted standards are *substituted judgment* and *best interests.*[111, 116] Of these, the former is generally nominated as preferred, with the justification that it encodes and reflects the patient's wishes.[235] According to Moore and colleagues,[241] the surrogate applying this standard is required to consider "the patient's character, past preferences, and history in order to make a decision that is consonant with what the patient would have decided herself" (p. 3). It is implicit within this definition that the decision made is based entirely upon consideration of the patient's wishes. The significance of any other

considerations, for example, the well-being of the surrogate decision-maker, is marginalised. This is consistent with the model of patient decision-making for which this is deemed to substitute—focused on the individual and minimising the relevance of others. However, this condition can be drawn upon to weaken the claim that family should make the decision: Although qualifying as persons close enough to the patient to claim knowledge of their wishes, family will also likely be most affected by the decision, and to ask them to ignore their own (possibly conflicting) needs and values may be deemed to violate their autonomy.[118, 234] Furthermore, it is argued that the emotional attachment between family members may interfere with their ability to make a rational decision,[114, 115] with displays of emotion potentially constituting grounds for disqualifying their judgment.[115, 240] Some have further suggested that because the patient's autonomy is developed and realised in the context of the family, separation of patient and family is problematic—what the patient might want includes what they might want for their family, a point argued theoretically and on the basis of empirical observation.[95, 111, 114, 116, 123]

Advance directives are often cited as providing the clearest evidence of the patient's wishes, and thus are deemed the best option.[116, 168] They "stand alone,"[116] can "speak for" the patient,[240] and function as a "conduit" to implement patient autonomy.[115] Such language works to render the decision recorded as equivalent to a direct (verbal and contemporaneous) assertion of the patient, and may function to minimise the responsibility of the surrogate for making the decision.[115] It does, however, place responsibility on them to produce and disseminate the required documentation. Claims based upon the direct equivalence of advance directives with the patient's wishes are used to justify a hierarchy whereby advance directives are given priority over a surrogate's substituted judgment, itself given priority over assessments of the patient's best interests.[242, 243]

Nonetheless, some have promoted a surrogate's substituted judgment over compliance with advance directives on the grounds that the latter are inflexible to circumstance, that the patient may have altered their preferences in the light of some new event. It is argued that the surrogate, aware of current circumstance, can make the decision the patient would have made at that instant[234]—thus surrogates' contemporaneous decisions are endorsed as better able to represent patient autonomy. There is, however, disagreement regarding precisely what sorts of substituted judgments may be considered as legitimate manifestations of patient autonomy, some equating legal-based and informal processes,[244] others not,[115, 245] and some treating surrogates' judgments based upon patients' explicit wishes as equivalent to inferences surmised from knowledge,[115, 244] others rejecting this.[116]

However, others have argued that as informed choices cannot be made without contemporaneous consideration of present circumstances, neither the patient, nor their surrogate, can be sure of what the patient's wishes might be in the future,[165-168] and therefore a surrogate's decision is incapable of reflecting the patient's autonomous choice.[235] In addition, the problems listed above (see 2.3.2.1) regarding advance directives may also be drawn upon to challenge the accuracy, and therefore to undermine the legitimacy, of the surrogate's decision.

Furthermore, many researchers have reported that the degree of concordance between a competent patient's preferences for treatment and a surrogate family member's assessment of these is less than perfect (being close to chance levels of accuracy), whether with or without reference to structured advance directives and even after specific interventions designed to improve communication between the parties.[234, 246-249] Nonetheless, some have observed that no other potential surrogate does any better at estimating the patient's wishes,[112, 241] and therefore, where knowledge of the patient's wishes is deemed essential, family appear the best available surrogates.[117] Furthermore, discrepancies between patient and surrogate judgments may be a moot point in many cases: Several studies have reported that where judgments differ, patients vary as to how strictly they want their wishes followed, or to what extent the surrogate can override, or modify the patient's directives, with up to 78% of patients identifying some deviation from their wishes as acceptable.[219, 221, 222] Critically, however, the grounds under which surrogate judgments are legitimised remains the extent to which patients' preferences are observed, whether that is their deciding what is done, or who decides.[250]

The best interests standard, to cite Moore and colleagues again,[241] "asks the surrogate to consider only the patient's current state in order to arrive at a decision that best serves the patient's current interests," or "to weigh the burdens of life against continuing life in their current state" (p. 3). The assessment of the current state of a patient who cannot make or voice their own decision lends itself to assessment of their current physical state, often centred on pain, something which is supposedly readily and objectively discernable. Accordingly, this standard may be construed as more objective, and contrasted with the more subjective standard of substituted judgment.[116] However, the identification of something as subjective or objective carries with it various implications that can be selectively invoked to further either standard. Thus, the best interests standard can be promoted as avoiding precisely those issues deriving from the emotional involvement or conflict of interests that inhere in substituted judgments.[165, 166] Conversely, the argument

can be made that the focus on the physiological aspects of life divorces the patient from the values and context of their life history, and thus it can be denigrated as objectifying and dehumanising the patient.[116]

The supposed objectivity (and thus superiority) of best interests standard can also be undermined through claims that assessments about pain, or burdens, require value judgments about the relative meaning of these constructs, and furthermore, that these decisions implicitly weigh the value of life and death, thus entailing a subjective judgment on the part of the surrogate.[46, 116] Similarly, it may be argued that, at the moment when surrogate judgments are called for, many patients (lacking cognitive capacity) cannot be held to possess any current interests; thus judgments must incorporate the surrogate's subjective assessments of, for example, burdens and benefits of treatment, or how the patient might have perceived these.[116] This notwithstanding, where knowledge of the patient's wishes is lacking, emphasis on a supposedly objective assessment of physical criteria works to undercut the nomination of family as surrogate decision-maker, supporting nomination of the doctor. This position is strengthened when notions of medical futility are raised—doctors qualify as best able to assess the physical consequences of a treatment upon a patient.[251]

Although which standard is preferable remains contested,[240, 241, 245, 251] some have observed that the distinctions drawn between them are untenable, as both rely upon knowledge of the patient's past history, the significance of present circumstance, and necessitate value judgments.[116, 241, 245] One distinguishing feature between them may be the priority accorded different bioethical principles: Substituted judgment rests upon the value accorded autonomy, where best interests standard emphasises patient welfare or beneficence.[241] I suggest that two different types of knowledge of the patient (personal and medical) are therein made salient. Substituted judgment requires knowledge of the patient's personal history, used to relay or predict (perhaps more accurately, estimate) their wishes. Although family obviously qualify, this construal may underpin Forrow's[167] recommendation that doctors making DNR decisions should have a caring relationship with their patient. The best interests standard requires knowledge of the patient's medical history, used to predict the probable efficacy of a particular treatment (in this case, asking the question, what will be the effect of attempted CPR?), more obviously pointing to the doctor. Either types of knowledge then form justification for the surrogate's decision, and action taken. Put another way, and acknowledging that they may not be mutually exclusive, what constitutes

an appropriate decision is construed, respectively, as what the patient wants (personal), or, what represents good medical practice (medical).

In this section I have discussed current arguments for and against dominant theories, concepts, and practices associated with DNR orders, focusing upon autonomy, patient-decision-making, and surrogacy, in order to illustrate the complexity and controversy surrounding these. It has been noted, however, that the vast majority of this debate references DNR practices and policies within the US, with relatively little discussion or research within Australia.[38, 106, 252] Nonetheless, articles written by Australian researchers invariably cite American studies and experiences, implying that these have relevance for the Australian setting, and Australian legislation covering advance directives (which may encompass patient-authorised DNR orders) has followed American models.[253] Several further factors suggest that DNR orders are of critical concern for Australian hospitals and particularly Australian patients. Although acknowledging differences between American and Australian healthcare, Middlewood et al.[106] asserted that the treatment imperative to save life is common to both countries, such that Australian patients may be subjected to aggressive medical intervention (including CPR) even when death is imminent and inevitable. In addition, as in America, without a documented DNR order, CPR is the default option for patients experiencing a cardiac arrest within an Australian medical institution.[254, 255] Although data for the whole of Australia is lacking, a 1988 survey of 7697 deaths in Victoria found that 79% occurred within a medical setting.[256] Similarly, within South Australia, Hunt et al.[257] recorded a substantial increase in the number of deaths occurring within a medical institution, rising from 44% in 1910 to approximately 75% by 1970-1987. Other studies examining deaths from cancer within South Australia reported that, between 1981-1990, only 14% of patients died outside of a medical setting,[258] this number slightly increasing to 16% for the deaths between 1990-1999.[259] Accordingly, it seems likely that DNR orders will have relevance for the majority of Australians at the end of their lives.

In the next section, I shall briefly refer to Australian studies about DNR orders, and delineate current policies at the site for this research. I then present and justify the research questions that directed this thesis.

2.4 DNR orders in Australia and within the research site

Notwithstanding the relative (to the US) paucity of studies and articles addressing DNR orders within Australia, what there is echoes the debate as noted above in 2.2. For

example, in one of the earliest Australian commentaries upon DNR orders, Torda and Gerber[58] simultaneously construed them as medical, legal, ethical, personal, social, and economic issues: They claimed a need to involve patients and their families in the decision-making process, but observed the potential for conflict and division within those families, highlighted assessment of medical criteria in making the decision, but noted confusion over ethical and legal aspects of it, and implied that decreases in healthcare funding and consequential scarcity of resources had compelled the medical profession to review the default CPR policy.

Within Australia, there have been calls for and attempts to delineate appropriate hospital policies and guidelines regarding DNR or CPR policies,[21, 58, 184, 260] as well as studies examining compliance with these, or patient characteristics and medical management associated with DNR decisions.[17, 106, 252, 261] These establish DNR orders as part of clinical practice, but also attest to their legal status. Relevant legislation allowing patients to proactively direct their care has been enacted within three Australian states, and two Territories,[42] so there is variation across Australia.[13, 42, 106, 254] Despite this legislation, it has been noted by some that here, as elsewhere, advance directives are rarely used.[262, 263]

The hospital policy effective at the site for this research during data collection was intended "to protect a patient, (usually in the end stage of a terminal illness), from unnecessary and intrusive interventions…" (see Appendix A). It drew upon two pieces of South Australian legislation pertaining to decision-making at the end of life: the *1995 Consent to Medical Treatment and Palliative Care Act*,[264] and the *1993 Guardianship and Administration Act*.[265] Both allow a competent adult patient to nominate a surrogate to direct their future care, and the former permits completion of advance directives. The policy guidelines noted that the final responsibility for the decision rested with the "senior attending medical officer," but required that DNR orders included "a brief description" of discussions with patient and/or family member/surrogate, and that explanations be given where such discussions had not taken place. However, although it documented the right of the patient or their surrogate to refuse treatment, the issue of whether or not they have a corresponding right to demand it was not clarified (see Appendices A & B). This was in part due to ambiguity within the relevant legislation,[266] a problem that has been observed with regard to Australian legislation in general.[13, 97, 254] It must be noted furthermore that policy and practice are not equivalent: Similar polices may be differently applied,[61] and reviews have shown variable compliance with recommended policy, both at the present site[17, 267] and elsewhere.[4, 65, 106, 183, 185, 268]

Others have noted further problems associated with specific legislation (including the ones relevant to this project) and policies attendant upon them.[a] These include the presence of confusing and contradictory terminology,[253, 269, 270] and the defeasibility of advance directives through challenging the circumstances under which they were made.[42, 178, 269] The patient and surrogate rights to demand treatment remains uncertain, although it has been claimed that legal recriminations are unlikely to succeed (and have not occurred in practice), both because a terminally ill patient's subsequent death would be deemed caused by their disease, and refusal to perform CPR may be subsumed within the concept of medical futility (which is legally sanctioned).[58, 255]

However, in making DNR judgements some Australian doctors have been found to apply non-disease based criteria (i.e., criteria extraneous to medical futility),[66, 271] and others (as included in a group of health professionals) to overestimate the efficacy of CPR in a patient population.[73] Despite this, some have argued that decisions regarding the appropriateness of CPR should be a clinical or medical decision, rather than personal and directed by the patient—thus allowing for usurpation of patient preferences.[17, 21, 58, 178] Haines et al.,[21] for example, specifically rejected the construal of the decision as an ethical choice to be made by the patient or their families, intimating rather that deference to either constituted unethical behaviour on the part of the doctor. Others have similarly invoked ethical principles in suggesting that advance directives may fail to meet standards required for enactment of patient autonomy, with physician discretion to override an apparent preference accordingly endorsed.[42, 178] Such arguments work to construe these decisions as ethical, as do assertions that adherence to legal precepts does not guarantee good ethical practice,[97] and that the principles of autonomy and veracity should be tempered by concern for patient welfare (effectively, invoking beneficence and maleficence).[38]

Nonetheless, within Australian law and ethical debate pertaining to CPR decision-making and DNR orders, patient autonomy remains prioritised—thereby identifying these decisions as personal. Many have asserted the value of patient autonomy[38, 42, 50, 106, 260] or alluded to a need to determine patient preferences for CPR.[58, 178] Moreover, though not specific to CPR and DNR decisions, Australian researchers examining the content, preferences, and processes of patient decision-making have assumed the value of autonomy to be self-evident (e.g., [126, 216, 272-279]). Yet many have reported that the content of patient preferences and process of decision-making does not always mirror those presumed within medical practice: Patients do not always prefer to have responsibility for decision-

[a] For further examination of legislation covering the site of the present research, see Appendix B.

making.[38, 216] They may not always understand information provided,[207, 280] may have limited awareness of the probable outcomes of CPR,[73] and weigh information and circumstances not featured within traditional models of decision-making, including impact on family and interpersonal relationships with clinical staff[207, 216, 272, 275-278]—considerations which point to the interpersonal and social import of these decisions. Furthermore, despite the prioritisation of autonomy, and specific endorsement by healthcare workers (including doctors and nurses) of patient decision-making,[38, 50] patients do not always discuss CPR with their doctor,[38, 50, 178] and some do not wish to do so.[38, 178] Thus, as most patients are incompetent when the decision is required, many doctors reportedly do make the decision unilaterally,[50] although some suggest that family are typically enjoined to make the decision on the patient's behalf[252]—again establishing the social and interpersonal connotations of DNR orders.

I have argued that the content and form of Australian research and practice regarding DNR orders have many substantive similarities to their equivalent in the US. In the next section, I shall briefly point out some limitations of the current debate on DNR orders, and delineate the present research questions intended to address this.

2.5 The current research

2.5.1 What does it address?

Given the complexity and number of issues informing the DNR debate, it is not surprising that the medical literature is beset by contradiction.[54] Two of the more contested areas relevant for the clinician pertain to responsibility for the decision (i.e., who makes it?) and, raising the DNR discussion with the patient (i.e., when—if at all—should DNR discussions take place?). There are, however, a number of omissions within the medical literature, four of which are relevant to the present study.

First, much of the medical literature has been framed within the precepts of bioethics and focused upon autonomy, promoted as *the* bioethical principle to guide CPR and DNR decision-making.[55] However, some writers have criticised bioethical debate as characterised by philosophical discussion at an abstracted level, and called for empirical research to inform and ground these discussions.[37, 55, 124] Such research might aim to investigate or verify the relevance of theoretical assumptions, recommended guidelines, or hospital policies.[37, 55, 124] In this instance, this would include determining how patients talk about and construe DNR orders, and how this compares to medical discourse and associated medical practice.

On a related point, DNR research and commentary have been dominated by those from a medical (or at broadest, a medical ethics) background, leading to a restricted medicalised focus that does not adequately consider the cultural milieu in which decisions are made, nor the cultural assumptions that legitimise or problematise opinions or behaviour. Some have recommended collaboration between disciplines, with research involving social scientists trained in other research methodologies and bringing different perspectives and assumptions to bear on the issue.[55, 281]

Third, most of the literature reflects a medical perspective, with little examination of patients' perspectives about end-of-life (including DNR) decision-making.[78, 282] Thus patients are subjected to policies and practices over which they have had little input. Given the variance in the construction of the DNR issue and the salience of patient autonomy in medical discourse, it should be important to know how patients construe the DNR decision, what issues they deem relevant, and how (or indeed if) they want to deal with the DNR decision. Such information can only be obtained through the analysis of qualitative data obtained through talking to patients,[283] and preferably those for whom the decision had some significance. However, qualitative studies have questioned medical professionals,[72, 284, 285] patients' families,[286] and non-patients,[282] rather than patients.

Finally, it has also been observed that the majority of DNR studies are quantitative-based, drawing on data derived from structured questionnaires, hypothetical scenarios, descriptive epidemiology, or simulated discussions.[72] Quantitative methods enable comparisons between groups and events, and provide correlates of behaviour, but neither describe the meaning nor explicate the social context of the ethical issues involved.[55] Again, qualitative investigation is indicated.

2.5.2 What are the research questions?

The above omissions and controversies within the medical literature formed the basis for the present research. In it, I consider the following questions:

- Generally, how do patients talk about DNR orders? How do they account for, justify, or present their views or positions taken with regard to these? What discourses (or systems of meaning) do they draw upon to do this?
- To whom to they attribute responsibility for the decision? And, (addressing issues pertaining to surrogacy), who else do they nominate (specifically where the patient is incompetent)? Who do they identify as appropriately involved?
- When (if at all) do they believe DNR discussions should occur?

- What are some consequences of the positions taken?
- How do their construals of DNR orders and DNR decision-making match up with those available within the medical literature? And, What are the implications of this for medical policy and practice?

In the following chapter I discuss the methods and procedures employed, as well as the details of the participants in the research endeavour (including at times, myself).

Chapter 3. Method: Describing the approach, the process, and the participants

In this chapter, I first introduce and clarify the approach to research and methodology here used, then more precisely delineate the procedures and participants featured in this thesis. I have adapted the practice recommended by Silverman,[287] presenting a "natural history" of this research (pp. 233-7), showing the rationale behind choices and decisions made at different points in the research process.

Before commencing, however, I need to clarify my position in this research. The original project was initiated by Professor Ian Olver in 1996. A senior clinical oncologist and clinic director, he had some concerns about the development of hospital policy regarding decisions affecting patients at the end of life, particularly given a lack of data regarding patients' perspectives on these issues. Correspondingly he devised a list of questions of interest, enlisted a clinical psychologist to conduct interviews, and employed a psychology graduate (not I) as a researcher one day a week to commence analysis of the interview text. I was approached by the latter for informal advice on qualitative analysis, and practical assistance with using the software package NUD*IST, Version 4.[288] On the departure of this graduate from the project shortly after (before completion of transcription), I took up the position of researcher (one day a week) in 1998, redoing any finished transcriptions, and completing the others. I was at this time, a PhD candidate in abeyance, as my previous project had foundered approximately 13 months in, due to lack of supervision (my supervisor moved interstate). I asked Professor Olver if I might resume my PhD candidature based upon this set of data, with him as my primary supervisor. He agreed, and the University of Adelaide granted me another PhD candidature (on a half-time basis). This allowed me greater responsibilities with regard to the direction of the research, and I continued analysis of Study 1, and subsequently, devised and carried out Study 2. Thus, I had no control over the content and format of the interviews in Study 1, but was responsible for transcription and analysis of these, as well as the process from interview development to final analysis of Study 2.

3.1 Approach

My theoretical perspective in this thesis is social constructionist, with the specific use of discursive analytic techniques. It is not my intent to cover the entire field of these, but to outline what has shaped my approach to data, with the aim of providing a foundation on which to justify my analysis. To summarise: In this *qualitative research*, I used *discourse analytic techniques* (i.e., discourse analysis) to analyse *semi-structured interviews* with *two*

groups of patients with cancer (not dying, and dying)—more specifically, to analyse the *transcription* of *audio-recordings* of these, using the *software package N6* to help organise the data. Below I justify the choices about these in the context of the research aims.

3.1.1 Social constructionism, qualitative research, and discourse analysis

Recent years have seen an increase in the use of qualitative methods in health-related research, often seen as a useful and complementary approach to the dominant quantitative paradigm.[289-291] The following, written by Smith,[291] perfectly describes (and works to justify) the approach taken in this thesis.

> Qualitative approaches are generally concerned with exploring, understanding and describing the personal and social experiences of participants and trying to capture the meanings particular phenomena hold for them. ... For some qualitative researchers, the primary interest lies in how meanings are constructed and shaped discursively. ... Qualitative approaches are particularly useful when the topic under investigation is complex, dilemmatic, novel or under-researched and when there is a concern with understanding processes, not measuring outcomes. (p. 417)

As noted in Chapter 2, DNR orders are a complex issue, with many competing representations of it available within the medical literature, yet the perspective of the patient is certainly under-researched. This is particularly poignant in light of the pre-eminent position within medical discourse of patient autonomy—which would seem to prioritise the viewpoint of the patient. Qualitative research methodology is the appropriate method to address this omission, enabling the researcher (me) to analyse (for example) patients' construction of DNR orders, what meanings they attributed to them, and what discursive resources were drawn upon as patients made sense of the issue.

The specific analytic tool of discourse analysis (DA) is ideally suited to this task. Falling under the rubric of social constructionism, DA posits that language (sometimes comprised of text, but here speech) is, as Willig[292] has said, "constitutive of experience rather than representational or reflective" (p. 3). That is, that the language used in discussing concepts, objects (including persons), or events does not represent a neutral description of an objective world, but that the world and how we experience it is 'constructed' through language.[150, 293-296] This is not to deny the existence of a reality, of objects and persons, but to stress that we—as social beings interacting through language—cannot access that reality outside of language.[295, 297, 298] Consequently, any phenomenon only has significance or meaning to us (is only made 'real') through the language used in discussing it. In interaction, in using language, individual speakers draw upon available, pre-existing ways of talking about things, patterns of meanings that are culturally and historically specific to

their society.[293, 296, 299] In so doing, speakers re-produce (and collectively re-construct) the social world in which they live.

A further fundamental principle of DA is that language is action-oriented—that is, that people use language to different effect, to achieve different things. Thus an individual's account (or description, or version, or construal) of the same phenomenon—or the accounts of different individuals of the same phenomenon—will exhibit variation according to the specific context within which the account is produced.[296, 300] Accordingly, discourse analysts propose (1) that the language used for discussing and understanding experience will vary within and between speakers, and (2) that each variation will have specific and different functions and consequences for the speaker. But that nonetheless, (3) some ways of speaking will be more 'available' than others. These reflect culturally dominant, taken-for-granted ways of constructing the world.[296, 300, 301] Discourse analysts therefore attend both to variation within and the function and consequences of language.

However, the category DA is heterogenous, encompassing a plurality of methods and spanning many different disciplines.[293, 302, 303] Nevertheless, all examine language as it is used, searching for patterns in use, aiming to deliberately systemise ways of talking in order to understand them better.[299, 300] Two distinct strands of DA have been defined.[302-306] One of these examines speech within a local context—for example, considering sequential turns of talk in interaction, and examining what the talk is doing at each moment—an approach commonly known as 'Conversational Analysis.' The other considers language as situated within a wider societal context, noting that patterns of meaning, sometimes known as 'discourses,' carry with them particular power relations, enabling and constraining what can be said and done—often identified as 'Foucauldian' or 'Post-structuralist' Analysis. Discourse, in this sense, typically refers to language and social practice, with emphasis on how a discourse 'creates' that to which it refers.[307, 308] One relevant concept within this approach proposes that individuals, as subjects, are also constructed within discourses: That is, individuals are allocated a position (are positioned) within a discourse, one that carries with it a set of rights and responsibilities that act to delimit what they can do and say:[301, 309] For example, within the biomedical discourse, the doctor and patient are positioned differently, with language used and practices permitted varying accordingly.[292]

Proponents of each camp have criticised the other: Conversational analysts have been charged with denying the social and historical context in which conversations take place, of dealing with minute and fragmented sections of conversations, and of failing to acknowledge the cultural resources that make what is said sayable.[305, 310] On the other

hand, poststructuralists have been criticised for imposing their own (often abstracted or theoretical) frames of reference upon the data, ignoring both the exigencies of talk-in-interaction, and how individuals negotiate meaning within each interaction.[305, 310, 311] Recently, some writers have argued for integration of these two traditions, noting that although participants' talk will always function to achieve some specific action in situ, it will also engage with the specific social, cultural, and historical context, whether that be to reproduce or challenge available discourses.[301, 305, 306, 312, 313] Riley[313] has suggested that a "synthetic" approach, combining analytic techniques, can enable highly productive analyses, allowing examination of the situationed nature of meaning-making, relating these to background normative conceptions, and contextualising the talk within the ideological and institutional framework of the broader society (pp. 446-7).

Given this diversity of opinion regarding DA, I now set out the primary principles and practices that informed this thesis. According to Parker,[299] discourse analysts continually ask "Why was this said, and not that? Why these words, and where do the connotations of these words fit with different ways of talking about the world?" (p. 4). These were the questions that shaped my approach throughout the analytical process. Considering 'why these words, why here?' allowed me to investigate and draw attention to the action-orientation of speech, to focus on talk as part of social practices, examining how speakers discursively negotiated issues that may be contentious or problematic—an approach more closely aligned with Conversational Analytic techniques.[294, 313] However, I also considered 'what is taken for granted?' in specific accounts, which enabled me to identify the discourses drawn upon (including the procedures and practices that constitute the wider society), considering how they constituted and reinforced different outcomes or practices,[298] particularly with regard to the patient, and end-of-life decision-making. To this extent then, I identify my approach as aligned with the emerging "synthetic" tradition cited above.

I further found Willig's[306] concept of "critical realism" to be compatible with the specific aims of this thesis.[b] She drew attention to the importance of giving a voice to participants, examining the ways that various discourses are deployed and to what effect by them, to considering these in situ, that is, in the contexts (including the institutional) in which they

[b] I acknowledge some differences with Willig's recommended approach and mine. For example, she advocated for a form of participatory action research that involves participants in the entire research endeavour, including of analysis and recommendations for practice. Participants in this research were only 'given a voice' to the extent that I re-presented their views. However, given the absence of patient voice in the DNR debate, one might conclude that this constitutes an improvement on the status quo. Willig further recommended an exploration of the historical emergence of discourses, which, though important, was beyond the scope of this thesis.

are articulated, to exploring the implications of these for practice, and, above all, to applying the research to make recommendations on how things might be done better.

In terms of the actual process of analysis, I have been influenced by Potter and Wetherell:[296] They suggested that DA consists of two intertwined phases, the first of which includes the search for *pattern.* During this phase, the analyst looks for variability within the data (i.e., notes differences in content and/or form), as well as consistency (i.e., identifies shared features), and for the function and consequences of a particular account. The second phase encompasses the *formation of hypotheses* based on these functions and consequences, and further examination of the data for evidence relevant to these hypotheses (pp. 168-9).

Potter and Wetherell[296] further proposed that in everyday speech people draw upon "interpretative repertoires" to account for a position currently espoused (p. 138)—a concept that emerged as suitable for certain parts of this analysis. Interpretative repertoires, which Edley[301] defined as "relatively coherent ways of talking about things" (p. 198), are very similar to 'discourses.' The latter, however, typically implicates notions of power, referencing societal practices and institutions, whereas interpretative repertoires appear more suited to analysis of how individuals might represent themselves (and others) in talk about an issue.[301] It is precisely because talk serves to fulfil different functions that contradictions may arise in speech. Potter and Wetherell[296] suggested that, should individuals simultaneously expound two contradictory arguments, resolution may be achieved through recourse to a "particular interpretative device" (p. 171). This rhetorical device "reconciles potential contradictions between versions" (p. 155) of an issue, enabling the speaker to assert multiple, even opposing, viewpoints. Often taking the form of a commonplace maxim that is widely available within the speaker's social environment, such a rhetorical device may be difficult to rebut,[301] signalling an acceptable resolution to what Billig et al.[314] have called an "ideological dilemma."

Willig[292] has also noted that DA is a useful method for problematising categories used in mainstream psychology, a point that may be extended to include mainstream medicine. She gave the example of 'trust,' suggesting that DA enables the researcher to challenge the conceptualisation of trust as "a stable trait or as a set of cognitions residing within the individual's mind" (see also Stenner[315] on jealousy). Rather, Willig[292] suggested, one might view the concept "as situationally specific, negotiated and purposeful social action" (p. 3). I applied discourse analytic techniques, as exemplified by Parker's[299] questions cited above, to similarly examine the concept of 'hope,' looking at how 'hope' featured, both in

medical discourse, and in participants' talk, considering, as did Willig[292] regarding trust, "what social or interpersonal objectives … [were] achieved through its deployment" (p. 2).

To recap, I applied discourse analytic techniques to analyse patients' talk about DNR orders and decision-making, to determine how patients construed[c] DNR orders, what discourses were invoked in their talk, and some probable functions and consequences of how they talked about the issue, considering the implications of these both for the patient and for medical practice. I particularly focused upon variation and contradictions within the data, as well as how patients' accounts of DNR orders and decision-making (plus associated issues) compared with those represented in the medical literature.

3.1.2 Semi-structured interviews

In order to analyse how patients talk about DNR orders, one obviously needs some talk to analyse. This could be garnered through observation of naturally occurring conversations—producing *naturalistic* data, or specifically elicited for the research project—producing *contrived* data.[316-318] There are advantages and disadvantages inherent in both approaches: Naturalistic data has the merit of being unprompted, producing speech not shaped by particular questions or agendas of the researcher. However, apart from the practical problem of access to such conversations and associated ethical issues[300]—short of continual monitoring, it seems likely that the researcher might miss the salient moment/s—we might find quite a low signal-to-noise ratio, with relatively little talk focusing on the issue of interest. Contrived data, specifically elicited during *interview*, have the complementary features: Talk is focused, obtained under controllable and time-limited conditions. It is, however, to greater or lesser degrees, shaped by the researcher and predominantly comprised of a question-and-answer format.[296] Some have argued against the use of interview techniques, suggesting that talk produced is artificially oriented to the research question and thus not reflective of everyday practice.[319] However, this objection becomes less relevant given the philosophical foundations of social constructionism, which holds that interview talk is not a window into the reality of the speaker's experiences. In requiring the interviewees to respond coherently to the researcher's questions, interviews elicit speech that draws upon available systems of meanings within participants' culture, which can further be examined for how they are employed.[294, 319, 320] In addition, interviews—particularly in the form of question-and-answer sequences—are an ordinary

[c] I have here (and throughout this thesis) favoured the word 'construe,' rather than 'construct' because although language may be said to construct reality, individual speakers do not. Rather, they use the language available to them to discuss/understand/experience phenomena in particular ways. 'Construe,' carrying with it the sense of interpretation of phenomena, better captures this process than 'describe' which implies that the object so discussed exists independently.

activity ubiquitous in every day life, thus arguably eliding the distinction between natural and contrived speech.[316, 321, 322] Moreover, several researchers have asserted the merits of interviews, arguing that they are eminently suitable for accessing meaning and exploring diversity about an issue.[321, 323] As a final point, interview techniques are dominant within qualitative research,[287, 324] discourse analysis,[295] and qualitative research into end-of-life issues.[289] These reasons collectively comprised the rationale for employing interviews in the current research.

Interview formats are typically conceptualised along a continuum from unstructured, through semi-structured, to structured,[321] sometimes called informal, guided, and structured respectively.[325] These represent an increasing degree of control by the researcher. Thus with unstructured interviews, both interviewer and interviewee know the topic of interest, but the interviewer minimally intervenes in the interaction, allowing interviewees to range around the topic as they see fit. Unstructured interviews tend to be long. At the opposite end of the continuum, the structured interview consists of a series of questions, identically phrased and asked in a consistent order. Although structured interviews are relatively short, this approach can stifle the variation celebrated by discursive research.[299]

Semi-structured interviews (used in this study) are based upon an interview guide,[326] or detailed schedule,[296] that is, a list of broad-ranging questions and topics derived from theory, previous research, and the researchers' intuition, that are designed to produce talk about a relatively standard range of themes.[325] Although some have suggested that semi-structured interview questions should follow a specific order,[326] others have argued that it is preferable to cover issues as they arise, rather than slavishly adhering to the scheduled questions.[324] The aim is to focus the interviewee upon the topic of interest—thus shortening the interview time (as compared with the unstructured interview), whilst refraining from excessive control of their responses, ideally allowing all parties free to explore whatever arises during the interaction—rather than being limited to the researchers' preset categories (as compared with the structured interview). This flexibility to explore can be furthered by the use of 'open-ended' or in-depth' questions.[323, 327]

Inevitably, the mere introduction of a topic or question must identify the subject of these as important,[295] potentially engendering responses that are deemed socially desirable, or that omit or avoid controversial or contested views.[328] However, I suggest that these short-comings of interviews are insufficient to negate their advantages, specifically given the research aims of this project: I consider that DNR orders and end-of-life decision-making

are important subjects, and as alluded to above, did not approach participants' speech with a view to accessing a truth about themselves or their experiences, but to identify the range of linguistic resources to which they had access, and to explore the functions and consequences of the language that they used in responding to the questions asked. Choosing to conduct semi-structured interviews had a further rationale: Given the physical and mental fatigue likely present in patients being treated for cancer, and particularly those in the final phase of this disease, they are the most considerate (therefore most ethical), yet productive interview format, meeting the needs of both patient and researcher.[329]

There were differences between the interview formats and settings of the two studies. In Study 1, the interviewer was a female clinical psychologist unknown to the participants, trained in clinical interviewing skills, but a novice to qualitative research interviewing. The setting was a clinical consulting room. I conducted the interviews for Study 2, and had relevant skills derived from training and experience in counselling, and conducting group interviews. There were several different interview locations within the hospital: a single-bed room, an open ward, and a private office.

There were some problems with the interview guide for Study 1 (see Appendix C): For example, the question "Do you think the patient would want to know about a DNR decision" can be interpreted as "Do patients want to know that there is one to be made?" or "Do patients want to know that someone else has made it?" Based on my previous training, my experience with transcribing and analysing the first set of interviews, and others' advice on interview techniques and crafting a theme list,[321, 323-327, 330, 331] I refined the interview guide to remove such ambiguity (see Appendix D).

In addition, the interview guide in Study 1 remained constant, with interviews somewhat resembling a structured interview. However, the interviewer did follow-up issues arising, using probe questions[324] such as "Can you tell me more about that?" and "What happened then?" asking for clarification on points that were ambiguous—features that are prohibited in structured interviewing.[321] In Study 2 the interview guide evolved, as I endeavoured to find better ways to approach dying patients regarding these issues. By the eighth interview the format had stabilised and guided the rest of the interviews (see Appendix E). Nonetheless, the substantive topics of this dissertation introduced by the interview questions remained the same both within and between the two studies (see Table 1).[d]

[d] There were additional questions in either or both studies that are not covered within this dissertation, including questions on alternative medicine, hope, and euthanasia.

Table 1. *Concepts shaping DNR questions asked during interviews, with examples of the prototypical questions addressing these, and probe questions to follow*

Focus of main concept about DNR orders	**Prototypical questions**	**Probe questions**
Definition	What do you understand by the term DNR orders?	NA
Responsibility	Who should make the decision about what to do if a terminally ill patient's heart stops?	Is there ever a time when they shouldn't? If they don't who should?
Required information	What would you need to know when thinking about the DNR decision?	Do patients need to know? What do patients need to know?
Factors in process	How should we arrive at a decision about what to do if a terminally ill patient's heart stops?	Why would someone make that decision?
Appropriate involvement	Who should be involved in making the DNR decision	Would you discuss it with anyone (else)?
Timing of discussion[e]	When is the best time to discuss DNR orders?	Is there ever a time when you shouldn't discuss this?

One of the changes I initiated was the introduction of what Crabtree and Miller[330] called a "grand tour question" (p. 147), asking patients to tell me something of their experiences since they were diagnosed as non-curable. This fulfilled several aims: I felt uncomfortable beginning the interview with dying patients with a question about DNR orders. As recommended by many writers referenced above, I wanted to encourage participants to tell their story in their own words, to position them as the expert, and allow time to ease into more challenging themes, whilst aiming to establish some rapport that might make the interview more rewarding for all parties. Often participants brought up issues that pertained to the DNR decision, which obviated the need for me to artificially introduce the topic. Certainly, the later interviews 'ran smoother' than the earlier ones, though this may be a function of my improving interview skills derived from practical application: As Bernard[326] noted, interviewing is a skill that improves with practice.

[e] The responses to this specific question in Study 2 have not been included in this thesis, in part because the issue of timing invariably arose during other parts of the interviews, but in part because of space restrictions.

One of the more salient lessons was learning not to be precipitous in speech—many participants left long silences, and initially I filled these in. When transcribing these early interviews I realised how unhelpful (and inappropriate) this was, and began (practiced) giving participants time to gather their thoughts, or to rest.[324, 326] I also noted that I sometimes contradicted, brushed off, or laughed in response to their expression of something I felt uncomfortable with: For example, my response to a patient's assertion that "no-one would miss me when I'm gone," was to laugh (nervously) and say "I'm sure that's not true." On reflection during transcription, I realised that this represented my discomfort with death, and production of the preferred social response of rebutting self-deprecation.[294] Although understandable given my cultural heritage, validation and further investigation of this assertion might have revealed useful information, perhaps something about the value attributed to dying persons. As far as was possible I began to refrain from limiting participants' opportunities to speak of difficult issues.

I have gone into some detail here, primarily because I recognise that in qualitative research the investigator is relevant, is 'the instrument' of research,[324, 327] requiring the researcher to be reflexive, reviewing their own participation in the process.[299] Indeed, Rice and Ezzy[324] deemed this an essential component of rigorous qualitative research (pp. 40-1). Many have noted that the interviewer is an integral part of the research, with both their own experiences and how they are perceived by interviewees contributing to the speech comprising data for analysis (see Fontana & Frey[321] for a useful summary). Some have recommended that the researcher have similar demographic characteristics as those interviewed,[332] although others place more weight upon the use of good interview skills.[324, 326] Interviewers shared characteristics with participants that constitute a common cultural background (being Caucasian, with English as primary language, and resident in Australia), thereby facilitating interpretation of cultural clues embedded in the interaction[296, 325]—which has relevance for analysis as well.[300] However, pragmatically, attaining similarity on all fronts was clearly impossible: Both myself and the first interviewer were female, married, tertiary educated, and middle-aged, features shared by some, but not all of the patients. More critically, neither she nor I were dying of, nor had personal experience with, cancer. I was, moreover, pregnant when interviewing approximately one-quarter of the patients in Study 2. Some patients (mostly female) commented upon this, but most did not, perhaps demonstrating familiarity with interview protocol.[321] Nonetheless, mindful of claims that the interviewer's presentation is crucial to the success of the interview,[321, 325] I considered my self-presentation before each interview, dressing and grooming conservatively. At the beginning of each interview I identified

myself as a researcher, and not part of their clinical care team (stressing the confidentiality aspect of the interviews). Despite this, at least two patients appeared to assume that I was trying to determine their position on DNR orders in order to pass it on to their clinical team—mis-reading my self-presentation perhaps, as has occurred in other research settings (see Johnson in Fontana & Frey,[321] p. 655).

At the end of Study 2 interviews, I asked each participant if there was anything that they wanted to add, or wanted me to know regarding the topics discussed. Finally, I asked questions to clarify details about them—both demographic, and treatment-based (see Appendix F)—with the aim of effectively lowering the emotional tone of the interview, so that participants did not leave the interview situation dwelling upon the subject matter.[333] In Study 1 participants completed a questionnaire (independently and outside the interview setting) designed to elicit these details (see Appendix G).

Regardless of any differential impact of the interviewers, the settings, or the interview guides featured in these studies, patients did talk, producing data that enabled fruitful (or so I hope) analysis. I suggest that this indicates that the approach taken was sufficient for its purpose. One final point: These two studies comprised the first in a series with aims and scope outside those of this thesis. Thus, some features of the process were shaped by other aims: For example, data produced in response to some questions in the interview guides were not included in this thesis, although some have been reported (and others will be) elsewhere.[270, 334-339] In addition, the participants in Study 2 were selected to be homogenous with regard to cultural background, with the aim of enabling comparison with another study interviewing dying patients from a contrasting cultural background (Tamil-speaking patients in Vellore, Southern India). Thus, and not reflecting the cultural diversity within Australia, all participants had English as their first language. This pertains to the issue of sampling which I now discuss.

3.1.3 Sampling the population

Both the method of sampling, and number of participants were determined by the research questions. Thus, the focus on the language used and meanings that patients associated with DNR decision-making dictated talking to patients, and particularly patients for whom the issue might have some significance. In selecting these, there was no attempt to achieve representative sampling involving probability techniques (typical features within a quantitative paradigm). Rather, the sampling strategy was purposive and homogeneous,[324] selecting information-rich cases, sharing an important characteristic (here being patients

with cancer who were not considered close to death, and patients in the final phase of cancer who were considered close to death).

The results of Study 1 were also drawn upon to shape the sampling protocol for Study 2: Briefly, participants in Study 1 spoke hypothetically about the issue of DNR decision-making, either speaking in the third person, or suggesting that they had not thought about the issue as it was not relevant to them (see 5.1). Therefore, in Study 2, participants were selected according to what Patton[340] called "critical case" sampling: people who can provide the most information on the topic, here, patients for whom the decision had immediate and personal import—who were very close to death.

The focus on language used by participants also justified the sample size: As Potter and Wetherell[296] have noted, "because a large number of linguistic patterns are likely to emerge from a few people, small samples are quite adequate" (p. 161). In both studies, as is common in qualitative research, data collection ceased when the interviewers considered that the interviews were repeating the content of previous interviews—sometimes known as the point of "data saturation"[341] or "redundancy."[342]

3.1.4 Recording and transcription

The research questions also dictated the choice to audio-record interviews rather than rely on interviewers' memories or field-notes,[287] and the mode of transcription used. In order to allow detailed analysis of participants' speech, all interviews were audio-recorded using audio-cassettes, and I used a foot-pedal operated audio-machine to transcribe all the interviews into text as soon as was feasible. Although Gillham[323] (pp. 56-7) has recommended that transcription should promptly follow each interview as "recency" facilitates more accurate transcription of material difficult to hear, the time interval between interview and transcription ranged from one day to 19 months. This longer time was due to two factors: All interviews from Study 1 were completed, but not transcribed before my involvement nineteen months after the completion of the first interview; and, during the interview phase of Study 2 I twice took maternity leave, and although I conducted some interviews during this time, I did not transcribe.

Taylor[300] called transcription the process that turns "talk into a document" (p. 29). She and others observed that no transcript can be a complete record of what occurred, as the researcher chooses to selectively omit specific features of the interaction according to what is required in order to achieve the research aims.[296, 299, 343] My decision to use what Taylor[300] named "standard written text" (pp. 32-3)—not transcribing features such as

pauses, intonation, extended speech sounds, or volume—was taken on several grounds: First, because the aim of this research is to identify patterns of meaning (e.g., discourses, interpretative repertoires, linguistic patterns) drawn upon by participants in accounting for what they said, I agree with Potter and Wetherell[296] that the notation of "fine details of timing and intonation" (p. 166) is superfluous. On a pragmatic level, although some have argued for the significance of these conversational features,[294, 344] and indeed, including these features within the transcription implies that they are meaningful,[300] I remain unconvinced as to the extent to which such meaning might be consistently present in (or deduced from) the speech of (terminally) ill patients with cancer. Although a pause might signify a speaker's dissent, it equally might be prompted by breathlessness or fatigue. Second, notation of these details (as favoured for example, by those employing Conversational Analysis) interfere with the readability of the script by those unfamiliar with the appropriate protocols.[296, 300, 313] As the intended audience for my research was (and is) primarily medical practitioners and policy makers, it is important that the data be accessible to them. Finally, I note that many other health researchers have drawn useful conclusions using standard notation when transcribing their data.[229, 277, 285, 313, 345, 346]

Practically, although every effort was made to ensure that participants' speech was audible, when transcribing (and particularly for Study 2) it was sometimes difficult to hear what was said. In part this was due to (1) occasional interjections from others in the room; (2) the physical location of the interview (sometimes on a noisy ward); or (3) occasional interruptions by other staff members carrying out their responsibilities to the patient. By far the greatest contribution to inaudibility, however, reflected the selection criteria for participants—and particularly in Study 2 where participants were terminally ill: Some were using oxygen, many were fatigued, and spoke softly. During transcription I listened to passages that were unclear three times only, and then marked speech that I could not decipher as inaudible.

Transcription was initially formatted for entry into the software package N6 and I discuss this further at 3.2. Apart from myself, the names of all persons referenced within the data—including patients interviewed, families and others contributing verbally to the discussion, persons mentioned by speakers in the interview (including family, friends, and treating clinical staff, but excluding persons known in the public domain)—have been changed. The protocol for transcribed excerpts presented in this thesis is as follows:

Excerpts from interview transcripts are indented, single spaced, and consecutively numbered according to the section of the thesis in which they appear—a practice that

Silverman[287] noted enables cross-referencing of quotations (p. 246). Thus the second quote presented within Chapter 5, section 1, appears thus:

> Helen. I want to be in control of what happens to me, it has to be my decision. (5.1/2)

The name of speaker is underlined, thus: Steven. Where this was neither the Interviewer (nominated Interviewer) nor the patient, I have identified the speaker's relationship to the patient on their first utterance, but used their name subsequently, thus:

> Steven's wife Marie. I said something here.
> Steven. I said something next.
> Marie. I kept talking after.

Speech that was inaudible is indicated by an ellipsis placed inside round brackets, thus:

> Steven. Now my speech gets softer so (…) can't hear me.

Words that were transcribed and are present in the original interview transcripts, but that are omitted in the speech excerpt featured in analysis are indicated with an ellipsis, thus:

> Steven. This section of speech … is omitted.

Words inserted to make sense of the quoted excerpt, or to clarify a referent, are presented in square brackets, thus:

> Interviewer. According to CA [Conversation Analysis] this is wrong.
> Steven. We [Steven and his wife] disagree.

Speech that immediately followed on, or interrupted one speaker is indicated with an equal sign at the end of the first speaker, thus:

> Interviewer. My question is =
> Steven. My answer is this.

Paralinguistic noises such as laughing and crying, or emotional responses such as becoming distressed are indicated in parentheses, thus:

> Steven. I'm talking about this (laughs) and I'm feeling this (getting upset).

Paralinguistic noises such as "um" or "er" were not transcribed, because (as noted above) I did not intend to draw any conclusions from their presence.[f] Moreover, I also omitted what

[f] I did transcribe such features for the interviews in Study 1, but realising that I had not drawn any conclusions from their presence, omitted them when including them in this thesis, and did not include them when transcribing the interviews in Study 2.

I identified as 'distracters' or 'idiosyncrasies' of speech. For example, many persons repeatedly said "like," "sort of," or "you know" between phrases of speech, or prefaced each turn of speech with "well." Deeming that these features contributed nothing significant in terms of what I was interested in analysing and made reading the material somewhat difficult, I omitted such continual repetition. Some participants also stumbled over phrases, or repeated word-for-word a phrase used. I recognise that this represents a judgment call on my part, but consider that the presence of such speech characteristics are not crucial for the level of analysis used in this thesis, and so 'tidied up' the speech to improve readability. Again, other types of analysis would preclude such an option.

Throughout, I used punctuation as typically used in written English, with full-stops indicating what I took to be the end of a sentence, commas to be logical breaks within a sentence, and question marks to indicate a query. Again, this represents my interpretation of the interview speech, necessary because individuals do not talk written English.[296, 300] Within the body of my analysis (i.e., not in indented examples), participant quotes are presented in double quotation marks, thus: "identifying direct quoted speech."

Pseudonyms of patients were selected to be short, and were consecutively and alphabetically assigned: Thus the first two males interviewed were called "Alex" and "Ben," the first two females, "Anne" and "Betty."[g] Initials of names in Study 1 went from A to I (females), and A to N (males), with initials in Study 2 carrying on from those alphabetical locations (females J to W; males O to Z). However, because there were more than 25 males in total, the initials O to S were used twice (e.g., Study 2 features "Oliver" and "Otis"). The adoption of pseudonyms was done to preserve the anonymity of the participants, a condition fulfilling ethical requirements set out in the information and consent form. I now further discuss ethical guidelines and protocols that were applied or considered in this study.

3.1.5 Ethics

Before data collection commenced, both studies were approved by the Royal Adelaide Hospital Ethics Committee, and met the typical criteria for ethical research as detailed by Seidman:[331] voluntary participation, non-coercion, confidentiality, and anonymity. Prior to participation in the interview, each participant received (and theoretically read) an information sheet detailing the research project, and providing contact details for participants should they have any concerns about it (See Appendices H-J). Before

[g] Names starting with letter Q were omitted, due to their rarity for both genders.

interviews commenced, patients signed and dated a consent form stating that they understood the terms of the interview and consented to the process (See Appendices L-M). This guaranteed their anonymity in terms of dissemination and publication of the research findings, that counselling would be provided if they became distressed during interviews or had lingering issues to resolve as a consequence of participation, that they could withdraw at any time, that their future care was not contingent on their participation in the research, and that they had been able to discuss the research with family or close friend. These latter two points addressed possibility of coercion to participate, and in fact, some potential participants within Study 2 withdrew from the project after discussion with family (see 3.2). No patients requested counselling (in either study) although some in Study 2 became somewhat distressed during the interview. I considered this understandable given the topic matter, and supported them through this, providing tissues and silence where appropriate. In one case, a patient asked to stop talking about the subject matter, but when I made preliminary moves to terminate the interview, made it clear that he was happy to discuss other topics within the interview guide. I therefore continued. Throughout, I endeavoured to ensure that patients were comfortable, that their well-being, both physical and emotional, was paramount, and that their wishes regarding the interview process were considered. Accordingly, I sometimes called for nurses to physically position patients comfortably, provided opportunities to take a drink or rest, interrupting the interviews for treatment, or in one case, because the patient, though keen to continue the interview, was (in my assessment) too fatigued to do so. In that case, with her consent, we continued the interview the next day. Finally, on this topic, three patients in Study 2 requested transcripts and copies of the interview tapes, holding that these would be both a legacy to their families, and a record of their thoughts in what was deemed to be their final days. Two also requested copies of the findings of the previous study. In these cases, I promptly transcribed the interviews, and forwarded requested items on to the patients.

After the interviews with these dying patients, I, as interviewer, had the opportunity to debrief with my primary supervisor, an ethical necessity in this type of research, ensuring the well-being of all participants in the research interview. To maximise confidentiality, I had sole access to a document linking patient with pseudonyms, only consulted for follow-up of their case-notes. All consent forms, recordings, and transcripts were and are kept in a locked filing cabinet in a secured office, and electronic files (word documents and N6 data) are secured with passwords.

There were some unexpected ethical dilemmas that arose throughout Study 2. First, despite my best efforts to represent myself as outside the patient's clinical team, some patients requested that I ensured that their views on DNR orders were made known to others. I also sometimes became aware that a specific patient's position regarding DNR orders was non-congruent with that held by their medical carers—specifically that a DNR order on file did not reflect what a patient said during interview. To deal with these issues, I spoke to my primary supervisor (who was also the clinic director) who made arrangements to ensure that these patients' case-notes reflected their position. A further ethical dilemma, discussed further at 3.2, arose because of the inclusion in the interview talk (predominantly in Study 2) of persons other than the patient. Finally, although it is an irresolvable conundrum in this context, I acknowledge the ethical ambiguity inherent in eliciting patients' views on any topic, but then subjecting these to critical analysis. Although I might claim to represent the patient voice, it is, nonetheless, filtered and fragmented through my analytical gaze (for discussion on this and related topics, see Fontana & Frey,[321] pp. 655-62).

3.2 The process (procedure and participants)

In this section I discuss the process of gathering the data. Because it was very similar for both studies I cover both together, noting points of difference. Some issues relevant here have been covered previously (i.e., details of ethical concerns, recording, and transcription practices).

Data gathering (i.e., interviews) for Study 1 commenced in October 1996, finishing November 1997; for Study 2 it began in May 2000 and finished March 2003. Participants were all attending patients at the Royal Adelaide Hospital Cancer Centre. Patients were identified as suitable candidates for the research purposes by their primary medical carers (either medical oncologist, or palliative care physician), by meeting stipulated inclusion criteria. These were that patients:

1. had cancer
2. were fluent in English (Study 2: had English as their first language)
3. were older than 18 years
4. had no cognitive impairment which would preclude them from participating in interviews
5. were assessed by their primary medical carers as emotionally stable enough for participation in the interview

A primary difference between studies (see Table 2 for specific details for comparison) was that patients in Study 1 had cancer, but were not in the final stage of that disease. Although half had stage IV cancer, six of these receiving palliative treatment, it was considered that they were not actually dying and therefore that the issue of DNR orders would not be an immediate concern for them or their medical carers. Nonetheless, due to the seriousness of their diagnosis and association with intimations of mortality,[347] it was envisaged that these patients might take the issue seriously. It was further considered important to establish that discussions on end-of-life issues with a non-dying population of patients could follow ethical precepts, and pave the way for developing and conducting research with dying patients, that would meet ethical criteria. In Study 2, patients met all the above-listed inclusion criteria, with the additional caveats that they were assessed by their primary medical carers as likely to die within 3 months and, critically, as aware of this.

Because the interviewer in Study 1 was only available one afternoon per week, consecutive eligible patients attending the outpatient clinic at that time were approached by their primary medical carer who briefly outlined the project, and asked them if they were willing to participate. If they agreed, they received an information sheet (see Appendix H) detailing the study and were scheduled for interview after consent was obtained (see Appendix K). None approached refused participation. Study 2 followed the same procedure, with some variation. Times available for interview were not restricted by the interviewer.[h] However, times were determined by patients' level of fatigue, or their hospital regimen. After initial contact by primary medical carers, I visited potential interviewees, gave them the information sheet and consent form (see Appendices I, J, L, & M), and arranged a future convenient time for interview (see Table 2 for details of specific differences between studies).

Six patients (2 females, 4 males) approached for participation did not continue to interview, and although not featured in the analysis to follow, I recorded details surrounding their refusal in my research journal. The first of these, a female, agreed to participate, but when I gave her the first version of the information form with the title phrase "Assessing the views of patients with cancer in the terminal phase of their illness" (See Appendix I), she excluded herself, claiming that she did not qualify as she was not terminally ill. This experience prompted me to complete the appropriate ethical protocols to change the wording on the information form to "... in the final phase of their illness,'

[h] This excludes two two-month periods covering the birth of my two children. Even though my maternity leave was longer than two months, the relative scarcity of eligible candidates for interview meant that I made myself available for interviews if suitable patients were identified.

considering that this was less emotionally loaded, and better reflected the rest of the information form (see Appendix J). Similar changes were made to the consent form (see Appendices L & M).

Table 2. *Details of interview-based characteristics of participants*

Detail	Study 1 N = 23	Study 2 N = 28
Interview location		
Interviewing room	23	7
Open ward	-	3
Single ward room	-	18
Others present at interview		
Yes	1	14
No	22	14
Patient status at interview		
In-patient	-	24
Out-patient	23	4
DNR order recorded in file at interview		
Yes	-	15
No	23	13

The second non-starter, also female, consented to be interviewed, but on three occasions when I arrived at her bedside, she demurred, saying that she was too tired, or too weepy to proceed. After the third occasion I suggested that perhaps this was not the right thing for her to do right now, and she agreed.

Two males initially agreed to participate, receiving the information and consent form, but in each case, when I returned for the interview family members (wife in one instance, son in the other) intervened outside the patients' rooms, saying that their relative was too tired to proceed, and had changed their mind. Another male, when I first met him, told me at length that he was not eligible to participate as he had not really thought about "these things" because "you don't while you're alive, do you?" concluding that he would be wasting my time. Despite my assurance to the contrary, he declined to continue.

The final male proceeded to interview, but having recently had surgery on his throat, he was somewhat sedated and fell asleep twice during the first 10 minutes I was there. After the second occasion, with his knowledge, I terminated the interview and quietly left him to sleep. In each case, I informed patients' primary medical carers of what had happened.

A further difference between Study 1 and 2 was the inclusion of others in the interview setting. Rice and Ezzy[324] (p. 57) have noted that it may be appropriate that persons close to

the participant be present at the interview in order to provide "support," and this option was put to participants. In Study 1, only one patient (Keith) asked that his female companion[i] attend. However, in Study 2, half the interviews were conducted with others present (usually one, but up to three), primarily family. I suggest that this difference is a product of the relative seriousness of the patients' condition: In Study 1, patients often attended the clinic alone, whereas in Study 2, family were regularly at the patient's side. This had some consequences: These other persons (one in Study 1; a total of 20 in Study 2) inherently became part of the interview setting itself, as patients' responses occurred in the context of interaction with these (significant) others—others who, moreover, had some interest in the patient's predicament. In these cases, as part of the preamble to the questions, I stated that the primary aim of the interview was to talk to the patient, but that these others were welcome to talk if they chose. Many did so, producing a dilemma of what to do with the talk so produced. Practically, as the microphone was invariably placed close to the patient, with others relatively distanced, their speech was sometimes difficult to transcribe. On the few occasions when several others were present, their speech sometimes overlapped, again making it difficult to accurately transcribe the interaction.

Although in retrospect I acknowledge this as an oversight, I did not formally gain their consent to 'participate' in the research process, causing some ethical angst on transcription and analysis. On balance, and consultation with others, I made the decision that they could be said to have 'informally' agreed to participate in the research. My justification for this was that their knowledge of the interview and research protocols gained from my verbal reiteration of the conditions delineated in the consent form, and agreement (tacit or explicit) to abide with these terms (including the stipulations that the interview was focused upon the patient, and would be recorded for later analysis) could be taken as consent to be included in the research; I further presumed that if they did not wish to be included, they would have not contributed to the ensuing conversations. Any similar future studies certainly should include others present in the process of consent. However, on a pragmatic level, their participation added valuable information to the study, particularly in terms of representing family perspectives (including the patient within that family) on end-of-life decision-making, and allowing examination of the interactions between speakers.

Finally, I consulted patients' case-notes to obtain details of their DNR status at interview, and later checked hospital records to determine whether any patients had subsequently died (and if so, when). After the interviews I conducted I noted any details of the interaction

[i] The identity of Keith's 'companion' was not revealed in documentation or interview.

(similar to field-notes) that would enable me to recall the interview and the interviewee later. Table 3 summarises the demographic, disease, and aims of treatment details of participants in both studies, reflecting criteria used to select patients for inclusion.

Table 3. *At-interview demographic and disease-related status of participants*

Detail	Study 1 N = 23	Study 2 N = 28
Age		
Mean (SD)	54.7 (15.3)	61.4 (12.8)
Range	22-81	39-79
Sex		
Male	14	15
Female	9	13
Religion		
Christian	14	19
Druid	-	1
None	7	8
Unknown	2	1
Birthplace		
Australia	14	23
United Kingdom	6	3
Europe	2	-
Zimbabwe	-	2
Unknown	1	-
Site of primary cancer		
Colorectal	8	6
Breast	5	3
Lungs	-	6
Lymph	8	3
Renal	1	3
Other	1	7
Stage of disease		
I	2	-
II	5	-
II	2	-
IV	14	28
Treatment Intent		
Cure	12	-
Observe	2	-
Prolong life	3	-
Palliate	6	28

The most salient difference between these two populations was that the majority in Study 2 died shortly after interview, all dying within 9 months. However, although no participants in Study 1 were expected to die in the near future, five did die within the year with a further seven dying to the point of writing (see Table 4).

Table.4. *Details of time interval between interview and death of participants**

Detail	**Study 1** N = 23	**Detail**	**Study 2** N = 28
Time between interview and death		**Time between interview and death**	
≤ 6 months	-	≤ 1 week	4
6-9 months	2	1-4 weeks	4
9-12 months	3	4-8 weeks	8
1-2 years	3	8-12 weeks	7
2-5 years	4	3-6 months	2
		6-9 months	3
Current status		**Current status**	
Deceased	12	Deceased	28
Alive	11	Alive	-

* The two studies are presented separately due to the different time frames involved

To summarise Table 4: In Study 1, no-one died within 6 months, although 25 (89%) did so in Study 2; in Study 1, two persons (9%) died within 9 months of their interview, whereas all 28 (100%) died within that time in Study 2. Thus the time interval for the longest-lived (after interview) in Study 2 overlapped with that of the shortest-lived in Study 1.

A further difference between the two groups was that more than half the participants in Study 2 had DNR orders recorded on file, whereas none did in Study 1 (see Table 5). This suggests that the selection criteria pertaining to the relevance of DNR orders for the two populations was effectively applied. Table 5 also shows the number of persons who during interview stated that, independent of the hospital system, they had documented their preferences regarding treatment options at the end of life (including their desire to forgo CPR). Apart from one instance in each study, the existence of such documentation was not noted within these patients' case-notes.

Table 5. *Details of DNR status on file and independent relevant documentation made by participants*

Details	**Study 1** N = 23	**Study 2** N = 28
DNR order recorded in file		
At interview	-	15
Not at interview	23	13
End-of-life preferences independently documented*	3	8#

* This information was volunteered during interview

These patients had documented Medical Power of Attorney

As noted above, I also identified a number of cases in Study 2 wherein participants' expressed preferences during interview regarding DNR orders contradicted their status as noted within their case-notes (see Table 6).

Table 6. *Details of DNR status and patients' preferences expressed at interview (Study 2 only)*

		Was a DNR order on file?	
		Yes (n = 15)	**No** (n = 13)
Did the patient want CPR attempted?	**Yes** (n = 6)	5*	1
	No (n = 21)	12*#	9#
	Unclear (n = 4)	1	3

Note. Shaded cells are non-consonant: The status of the patient's DNR order contradicted what they stated (during the interview) they wanted to occur (fourteen in total)
* Three patients said that they would, and would not, want CPR attempted
# Four of these had established Medical Power of Attorney (eight in total)

Identifying the discrepancies shown in Table 6 prompted further investigation of the relevant interview data. In the following section I discuss the practical details of how I identified these cases, and indeed, how I dealt with all the data generated by the interview, as well as the analytical process I followed to arrive at my conclusions. I begin with a discussion of the computer software used.

3.2.1 Details of the analytical process: N6 and beyond

As stressed by a number of writers, qualitative computer packages assist, but do not do analysis,[324, 325] and cannot replace the analytical thinking of the researcher.[348] There are both advantages and disadvantages in using such packages, and I discuss these in relation to my project as I describe how I used the computer package commonly known as NUD*IST (Non-numerical Unstructured Data, Indexing, Searching and Theorising), Versions 4 [288](Study 1) and 6 (Study 2), later named N6.[349] As Version 6 represents a refinement of Version 4, I discuss both as N6. The details of N6 are drawn primarily from Richards[350] and the N6 Reference Guide.[351]

Rice and Ezzy[324] claimed that a main feature of computer software packages is that they allow the researcher to "code and retrieve" data with relative ease (pp. 202-4). Basically, the researcher 'codes' the data, that is, attaches a label to items of text that share some feature in common, and can later 'retrieve' all these sections together for detailed analysis.

This facilitates the handling of large amounts of data, thus (at least theoretically) freeing the researcher to explore the nuances of the data in more detail.[348] In my case, the transcription of a total of 51 interviews lasting between 20 minutes and 75 minutes generated a lot of data: At 10 point font, single spacing, Study 1 produced approximately 76 A4 pages of text; Study 2, approximately 221 pages. Seale[348] used the analogy of computers assisting with boring clerical work involved in analysis (p. 155), and N6 is particularly appropriate for this.[j]

N6 uses "an inverted hierarchical tree system"[325] to structure data, usefully explained through describing my process. Because N6 can recognise certain features within a document, and then search and retrieve data based upon these features, after each interview was transcribed, the resulting text-file was specifically formatted accordingly. When formatting for N6, there are three different proportional sizes of text which require consideration, based upon the research aims. From small to large these are delineating what is a *text unit*, a *section*, and how to process the *document* as a whole.[350]

A *text unit* is the smallest retrievable segment of text that can be coded: I typically chose sentences as the basis for text units, as they most regularly contained a single item of meaning, but where sentences were short, or ran on from another, I sometimes included two sentences in one unit. Pragmatically this decision was non-critical as N6 easily allows you either to jump (using a Jump function) from a retrieved text unit to the original context within the document, or to spread (using a Spread function) the retrieval to a designated amount of surrounding text. N6 also allows for identification of *sections* within each text-file, through the use of 'sub-headers.' By identifying each question as a sub-header I was able to search for single questions, spread a retrieval to include the whole response to the question, then code these at a single location (called 'nodes').

In addition, N6 recognises each individual text-file as a whole *document*. Once imported into N6, documents are accessible for perusal via a Browse function. While browsing each document, individual text units can be selected and coded in another node without altering the original document. Thus using N6, all data that was (identified by me as) relevant to a particular topic was 'placed' within a node, and given a specific numerical designation and

[j] The decision to use N6 was taken before my recruitment to this project (which was on the basis of my experience with N6!). It probably reflected N6's position at that time as one of the few qualitative software packages available, and the only one released and marketed by a prominent publisher (Sage). Pragmatically, as N6 was developed in Australia, there is considerable local technical support available, as well as an active and responsive newsgroup available on-line (http://forums.qsrinternational.com/).

appropriate descriptive label. These were developed in a logically-linked hierarchy of sets and subsets, known as 'parent' and 'child' nodes, to form a hierarchical tree structure.

Finally, a further feature of N6 enabled me to identify different characteristics within the group of participants, and, using a command file, to automatically group different documents (i.e., transcripts of individual patients) together according to those characteristics.[350] For example, at the beginning of each document I included a description of the data, with females identified as "S:F." By searching for this unique 'string' of text, specifically included to exploit this function of N6, I was able to spread the retrieved data to the entire set of documents (all females) and auto-code these at the appropriate node (Gender/female)—all using command files. Other demographic characteristics, including disease and treatment options, and the interview questions were so treated. This knowledge of N6 programming, acquired between studies, saved an immense amount of time in processing the data from Study 2. For Study 1, I manually entered each document into the program, and manually coded them separately at the appropriate demographic node, and appropriate sections according to interview context.

Thus, in first approaching the data and building a 'tree structure' within N6[351] I used 'factual codes' that identify something as 'being' something.[348] The first level I employed was based upon the above-named characteristics. Using Study 2 as an exemplar, all text produced by females were coded as Base Data/Gender/Females, written numerically as (1 1 1), with males as Base Data/Gender/Males (1 1 2). Similarly, all text produced by persons with colorectal cancer could be coded as Base Data/Diagnosis/Colorectal (1 2 1), those with breast cancer as Base Data/Diagnosis/Breast (1 2 2) and so on. The developed tree structure can be displayed graphically in N6, enabling one to see the levels of stratification of data, with the aforementioned represented in Figure 1.

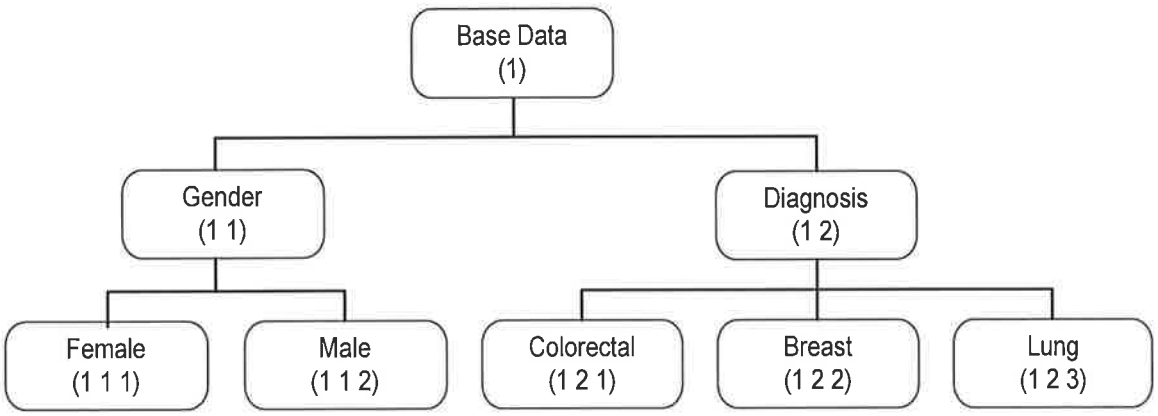


Figure 1. *Detail of the hierarchical tree structure within N6 showing examples of demographic level of coding*

In Figure 1, node (1)—"Base Data"—is the 'parent node,' with 'child' nodes within a 'subtree' below. Nodes (1 1) and (1 2)—"Gender" and "Diagnosis" respectively—at the second level down, are both parent and child nodes, with descending levels representing increasing differentiation of the data. As with documents, once a node is created the data within it can be accessed for further examination and coding, using a Browse function.

The second level of factual codes I established was based upon the interview context within which it occurred. Thus, and using another command file, all answers to each question were located together, and represented in Figure 2.

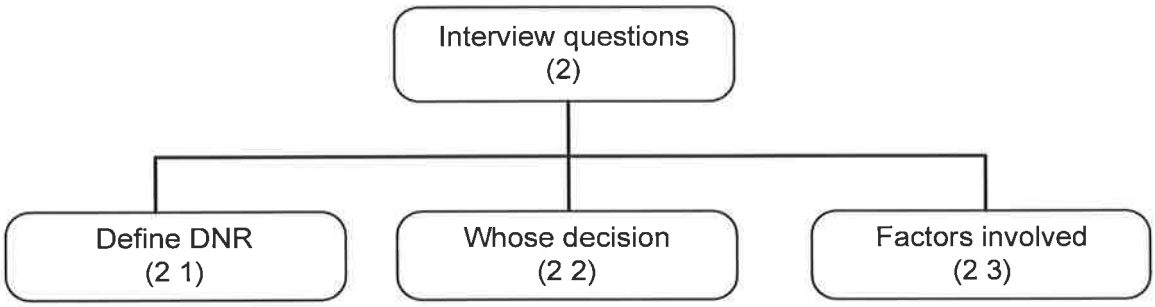


Figure 2. *Detail of the hierarchical tree structure within N6 showing examples of interview-based level of coding*

By far the most critical level of coding within N6 involved the creation of 'heuristic' codes[348] or nodes, reflecting how the researcher begins to dissect and examine the text. This, for me, occurred in several different ways, but initially most resembled a form of content analysis. As noted by Gillham,[323] this approach is a useful preliminary for more detailed analysis of text, enabling the researcher to become familiar with the content of the interviews, and begin to get a sense of what might be important (pp. 59-79). For example, I reflected on responses to each individual question, working only with the text within the relevant node, but coding on[350] to identify different responses to the question, different issues that arose, different phrases that recurred, or even different ways of talking about the question. For example, my coding of participants' responses to Qu. 4 based upon "Why would someone make a decision not to resuscitate" developed as shown in Figure 3.

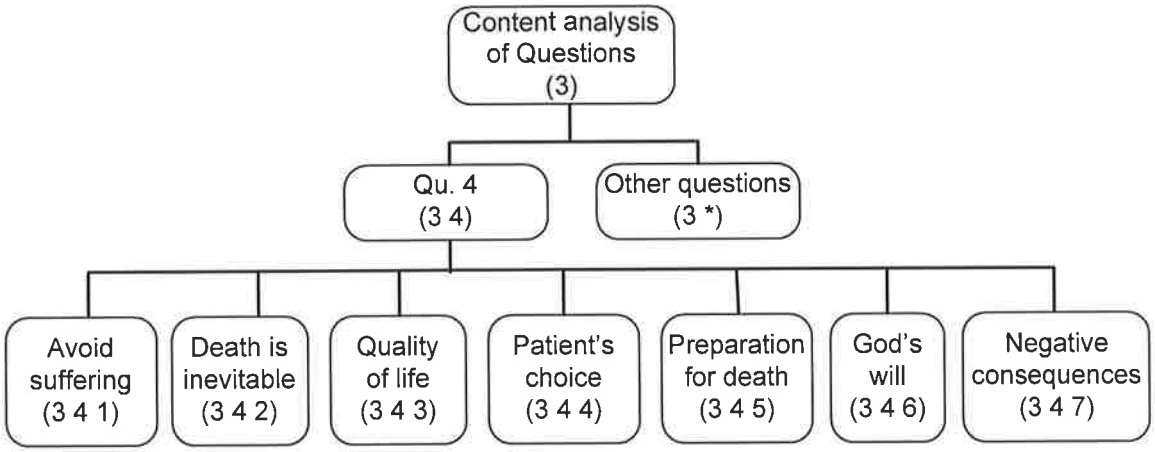


Figure 3. *Detail of the hierarchical tree structure showing initial coding within N6 of Question 4*

Figure 3 illustrates my preliminary sweep through the data produced in response to Question 4. However, continual re-reading of the data suggested that some of these nodes included major variations on a theme, and could be usefully further divided as shown in Figure 4. Furthermore, some of the issues arising in this context were very similar to those produced in response to Question 3 based upon "What would the patient want to know when thinking about the decision?", so I re-coded those responses to include them within the subtree for Question 4. N6 allows such changes to be recorded with a log-file, with the additional provision for appending a Memo to document the reasons for any decisions taking with regard to analysis, or thoughts about any aspect of the process.

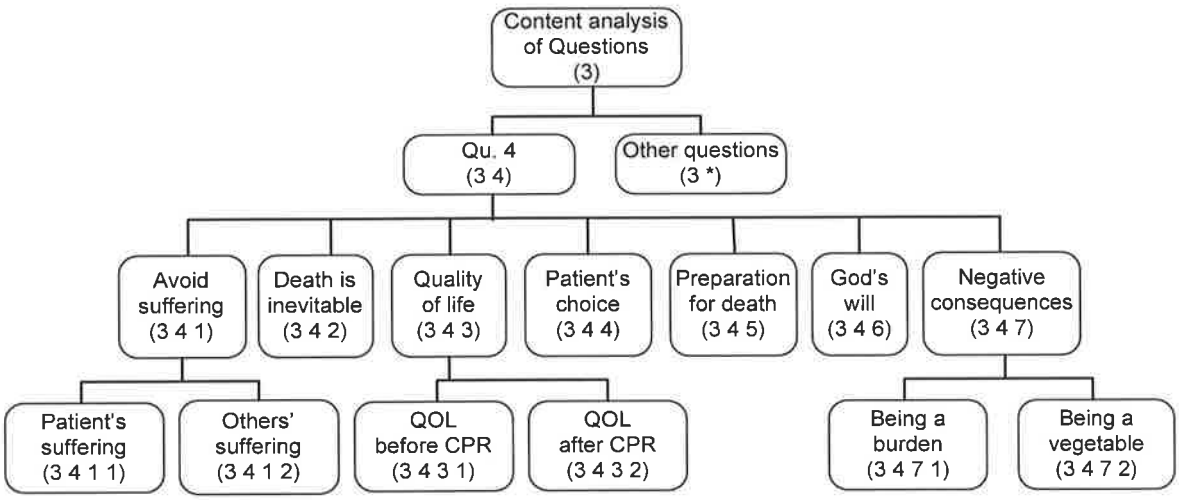


Figure 4. *Detail of the hierarchical tree structure showing developed coding within N6 of Questions 3 and 4*

With increased familiarity with the interviews, I began to identify recurrent patterns of meanings, as well as to note variability in how particular terms were used, sometimes creating 'free nodes,' that is, nodes that had no hierarchical relationship to others, but

referenced data worthy of further exploration. Hope, for example, was initially coded within a free node, although I went on to move this data within a newly created node and subtree to enable consistent categorisation of how hope was used (see Chapters 6 & 10). Similarly, for Study 2, I noted that most patients, at varied points throughout, directly articulated their desires regarding DNR orders or CPR, and, while most rejected CPR, some did not. This prompted me to scan through all the interviews to select those text units wherein patients said what they wanted, and code them accordingly (see Figure 5).

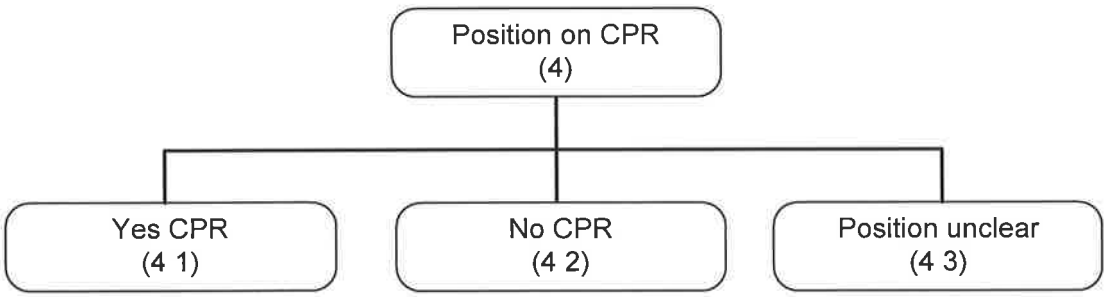


Figure 5. *Detail of the hierarchical tree structure within N6 showing developed coding structure regarding patient's expressed views on CPR or DNR orders (Study 2 only)*

One of the useful features of N6 is that it can produce a report regarding the content of any node: Thus, by selecting various nodes represented within Figure 5, I could identify how many persons and who specifically were in each category. In this case, adding the total numbers of persons within each node, I realised that some persons must have expressed a preference both for and against CPR. Again N6 enabled me to readily isolate those persons, and then consider what processes might be discernable within their speech. It also enabled me to match the status of patients' expressed views against their documented DNR status, thus to identify and follow-up those instances wherein a patient's documented DNR status was not congruent with their expressed preferences.

The above examples illustrate some of the specific advantages of using computers (here N6) to assist analysis: speed of sorting and retrieving data, ease of identification of deviant cases, the abilities to view all data identified as sharing some characteristic, to contextualise an excerpt by returning to the source, to re-work or refine a coding system whilst documenting this process, to cross-reference with data coded differently, or to identify overlap between coded data, to map relationships between codes, even give statistical data regarding codes.[348]

The account given above nonetheless overstates the extent to which I 'relied' upon N6 to reflect upon the data, and develop my analytical categories. For example, before working

directly with N6, I listened to each interview at least three times, sometimes taking the opportunity to correct errors in transcription, but also making notes on hard-copies of the transcription regarding my thoughts about the interview content. As is fundamental to qualitative (specifically discursive) analysis, I repeatedly read and re-read each interview, noting points of interest on the transcripts, beginning to identify pattern and variation in the data. Although N6 permits one to append memos to and within individual documents, I found it easier to retain a sense of the interview as a whole by working with hard-copies. Using the annotated transcripts, I summarised each interview in a single paragraph, identifying what I saw as the most salient points about each interview and interviewee. I then attached these summaries within N6 as Memos to each separate document, and kept a hard-copy at hand, so that I might consistently reference each individual patient behind each individual text excerpt under consideration. Combined with regular use of the Jump function in N6 (moving from text unit to the source), I suggest that this practice acted as a counterforce to the potential fragmentation of data, the decontextualisation and disembodying of interviews that critics have noted may readily occur through using computers in qualitative analysis.[325, 348, 352] In addition, although the views of individual patients were not the focus of this research, remembering who these patients were helped me to identify discrepancies, potential contradictions, or dilemmas represented in speech, and thus available within the wider cultural system of meaning.

A related criticism of using computers in qualitative analysis, is the tendency to "over-code," simply because it is easy to do, thus continually deferring actual analysis.[324, 352] To counteract this, I kept a journal throughout, recording insights into, noting potential connections within, or queries I had about, the data (including, for example, the points noted on the annotated transcripts), referring back to this when I began to 'write-up' my analysis. Practically, I found it easier to export specific data within nodes that I wished to analyse into a Word document, and then write about (analyse) those excerpts. In fact, I found that whenever writing about a group of excerpts was difficult, this usually indicated that more than one process was going on—that these excerpts, though having aspects in common, differed on a critical level, which prompted me to rethink and refine my analysis. At this point, I did not re-code these data within N6, but dealt with them within the Word document at hand. I also kept a record of which excerpts within one node were cited in my written analysis, and which were not, revisiting this to check that I had not omitted, for example, a deviant case (as recommended by Gillham,[323] p. 72).

However, responding to the breadth of the interview content, I fine-tuned my methodological approach to best account for the data: Potter and Wetherell[296] asserted that DA is not defined by a codified method, but rather a "broad theoretical framework concerning the role of discourse and its role in social life" (p. 175). Brannen (in Pope & Mays,[290] p. 45) similarly noted the importance of matching method to the data, rather than pre-existing conceptions or preferences of the researcher. Accordingly, there are differences discernable within the thesis, but primarily between the two studies. My intent in Study 2 was not merely to replicate the process and findings of Study 1, but to extend the analysis, exploring different aspects of patients' talk. In Study 1, the focus was the big picture—for example, I aimed to identify discourses drawn upon by patients to justify a position taken with regard to DNR orders, and to examine how medical representations of patients' decision-making measured up against those of the patients in the study. In reflecting upon these, I found Potter and Wetherell's[296] concept of "interpretative repertoires" to be singularly suited to represent the data, and thus drew upon this to structure parts of this analysis. One significant finding, in part reflecting patients' disease status, was that participants in Study 1 generally spoke of DNR issues as if they were irrelevant to themselves (a position also taken by their doctors, as DNR orders were absent from their case-notes). However, in Study 2, as a group, patients and their doctors identified DNR orders as immediately pertinent. There were, nonetheless, instances where the positions of individual patients and their doctors appeared to diverge (see Table 6). This prompted me to explore in more detail how individual patients accounted for their own position with regard to DNR (particularly where their position appeared to contradict dominant discourses featured within the interviews), as well as to explore the implications of the language used, the various different construals of the issues, including how patients, families, and doctors were positioned in participants' talk.

Additionally, because there was simply more talk in Study 2, there were more issues to consider, more opportunity for patients to represent contradictory arguments which then required analysis (for example, construals of the DNR decision as personal, medical, and social). Similarly, the interactive contribution of patients' family members occasionally produced data that drew attention to the problematic nature of what otherwise might have been presented as uncontroversial. Thus, in Study 2 (and in contrast to Study 1) I had and took the opportunity to examine talk-in-interaction,[295, 353] drawing on some aspects of Conversation Analysis to analyse some interchanges between persons, considering participants' talk at the immediate level of interaction, but also addressing the implications at a wider level (e.g., for medical practice and policy).

My analyses in Chapters 6 and 10 on hope also feature a somewhat different approach to selecting the data. Here, the focus was upon the variable ways that 'hope' as a word featured in participants' talk about DNR orders. Thus, exploiting a specific capacity of N6, text units featuring hope were automatically extracted from the interviews, then subjected to analysis—something only possible because of the exclusive focus on a word and limited permutations of that word. Nonetheless, the aims of analysis followed those directing the rest of the thesis: to determine the functions and consequences of the language used by patients in discussing DNR orders (but with reference to hope, considering patients' construction of hope as compared with that represented in the medical literature).

Taylor[300] noted that any reading of data is necessarily limited as an exhaustive exploration of qualitative data is impossible (p. 39). The analysis to follow represents my reading of the data. It highlights the issues that I identified as important and I acknowledge that another researcher might read it differently.[354, 355] Nonetheless, I endeavoured to ensure that it attained credible standards of academic scholarliness: This pertains to issues of evaluation of qualitative research, which I now discuss.

3.3 Evaluating this research

Lincoln and Denzin[356] have observed that qualitative research has experienced a "crisis of legitimation," simply because of the fundamental epistemological position that refutes any claim that an analysis can be "accurate, true, and complete" (pp. 1052-3). Standards used for evaluating quantitative research take such claims as given, requiring that the researcher demonstrate that their findings are replicable, consistent, and accurately reflect the phenomena of interest; however, such standards (typically phrased as addressing reliability and validity), are inappropriate for evaluating qualitative research.[295, 324, 357-359] Nonetheless, qualitative research can claim to be valid, according to Lincoln and Guba,[360] to be "sufficiently authentic" to be a foundation for action based upon them, including social policy or legislation (p. 178), and to be rigorous, that is, as stated by Rice and Ezzy,[324] to "provide information that is related to events that happen in the world" and "that can be relied upon by other researchers" (p. 31). Given that the finding of this thesis were intended to have import for hospital policy regarding DNR orders and CPR, and to add to the current research around these issues, establishing validity was deemed vital.

There are several criteria put forward as useful for evaluating qualitative analysis in general, and discursive analysis in the specific. These are not mutually exclusive, and many such criteria are applicable to any good academic research.[359] They range from

check-lists[361, 362] to descriptive recommendations.[287, 295, 304, 324] I now discuss some methodological and theoretical aspects of evaluation considered during the present research process.

According to Rice and Ezzy,[324] (p. 35) theoretical rigour is enhanced, first, through the selection of an appropriate method and of the population (these are discussed in 3.1.1-3); and second, through presentation of soundly constructed arguments and analysis, sometimes assessable through demonstration of peer review through publication (substantial amounts of this thesis have been pre-published). They and others[296, 359] have also noted the importance of locating research within the wider academic literature, a point I have endeavoured to address throughout the analysis.

Several writers have stressed the value of documenting the process of research[287, 324, 363] thus establishing what Rice and Ezzy[324] called "procedural rigour" (p. 36). In this research, this was achieved through systematic recording of how data was collected, how participants were approached, noting any refusals to participate, and changes in the process of data collection (see 3.2); I also kept a journal as an audit-trail of important analytical decisions and choices, the development of analytical concepts, and explanation of how data was coded and further analysed.[287, 289] The inclusion of appropriate quotations from the participants has been noted as minimising the likelihood of making inappropriate generalisations or conclusions,[364] further facilitating appraisal by the reader.[359] With regard to this point, checking with others regarding the validity of your results is sometimes recommended, with the proviso that, rather than demonstrating the 'truth' of the analysis, it is taken as indicating some degree of community consensus that the analysis make sense—that it is useful and meaningful with regard to the topic discussed.[299, 324, 356] This analysis benefited immensely from comments made following on presentations at conference presentations, academic seminars, and research groups, as well as discussions with clinical staff.

There are many different criteria for evaluating discursive analysis, some better suited to particular versions than others.[359] Potter and Wetherell[296] claimed that the validity of their seminal version of discourse analysis lie in the application of four criteria. These are

> (a) coherence, in that the analysis reveals how it fits together to produce various effects and functions, considering both the 'broad pattern' and 'micro-sequences.' Subsumed within this category, but made more explicit by Potter[295] and Seale[361] is consideration of "deviant cases," or negative instances in the data. Taylor[359] also

cited coherence as an appropriate evaluative criterion, but defined it as demonstrating that the analysis was academically, rather than emotionally persuasive—showing systematic investigation;

(b) that aspects of participants' understandings are illuminated and their construction of and orientation to their social world revealed. This requires that the analyst relate participants' speech to the wider social milieu, drawing out any implications for participants within that context;

(c) that the analysis demonstrates that if inconsistencies between accounts exist, these are resolved or explained by reference to particular interpretative devices or practices. This requires that the analyst demonstrate how participants resolved contradictions by, for example, calling upon acceptable rhetorical strategies to end the discussion. Thus, for example, in this thesis the arguments that patients should and should not make the DNR decision were resolvable through assertions that 'it's up to the individual';

(d) that the analysis can be related to previous research results, whilst generating new understandings, and fresh solutions to the problems in a field of research. A similar point was also noted by Taylor[359] who spoke of this in terms of how useful the analysis was. Parker[358] further suggested that the researcher should consider the probable consequences of accepting the research as valid.

Potter and Wetherell[296] also stressed the importance of documenting the process undertaken and justifying conclusions drawn through selective quoting of original data. These criteria were consistently considered throughout the research process and thesis writing, with analysis and discussion of the data presented together to facilitate reader assessment of the validity of conclusions drawn.[325]

Two oft recommended forms of enhancing validity of results were not here applied. The first of these was respondent validation[287] (or face validity[325]), that is, returning transcripts or analyses to participants for feedback. Apart from the obvious problem with Study 2 (82% died within three months, certainly before analysis was completed), this form of validation assumes that a truth exists, and that participants have a privileged access to it, neither of which are commensurate with the philosophical precepts (i.e., social constructionism) guiding analysis (see Taylor,[359] pp. 321-2). The second was that of 'triangulation,' that is, attempting to validate results through use of more than one method or type of data, presuming that convergence of analyses demonstrates their accuracy. However, using multiple data sources often increases the opportunity for variation and

inconsistency between accounts,[296] and moreover, does not guarantee that any inferences made will be accurate.[325] In addition, as with face validity, triangulation contains the presumption that truth exists, implying an ability to access it.[359] For these reasons, I avoided these methods of 'justifying' my interpretation of participants' talk.

Ultimately, although the onus lies on me to present a persuasive argument,[359] it is for the reader to assess the importance of this analysis, deciding whether it has vital consequences for the research area, and possibly for others.[296, 365] In the following chapters, I present my analysis of patients' (and some families') talk centred on the DNR decision: Chapters 3 to 6 cover Study 1, and Chapters 7 to 10, Study 2. It is my hope that they are informative and enjoyable to read.

Chapter 4. Study 1. Constructing DNR orders

In this chapter I examine how participants (patients with cancer) defined DNR orders, showing how they construed DNR orders as appropriately instantiated in specific conditions. There was some variability in definition of DNR orders, participants focusing on their practical application, their predicted outcome, or confusing the process with pro-active intervention akin to euthanasia. Despite this variation, they consistently viewed DNR orders as appropriate and desirable, and as ensuring medical non-intervention following a patient's cardiac or respiratory arrest. Legitimisation of the patient's subsequent death was achieved through identification of this as *natural*, as curtailing suffering, and as what the patient wanted. By contrast, the provision of CPR was negatively construed as prolonging suffering (as cruel), as futile, and as a violation of patient autonomy.

4.1. Defining DNR orders

Participants' responses to the question "What do you understand by the concept of DNR," showed some variation in focus. Although, as part of the process of obtaining informed consent, participants were provided with an information sheet specifying a precise medical definition of DNR orders (see Appendices I-J), very few persons actually commented on the practical application of DNR orders (i.e., to preclude CPR) following cardiac arrest.

> Harry. Once a patient is under an order or an instruction that if they arrest while in hospital that there's no attempt to resuscitate them and bring them back to life. Just to [let them] slip away. (4.1/1)

> Ivan. Basically when somebody's stopped breathing, heart stops whatever, they don't start it again or don't try to. (4.1/2)

For some participants, DNR orders did not appear to preclude CPR. These spoke of some possible outcomes of resuscitation attempts, suggesting that DNR orders meant that any "machines" or "procedures" needed to sustain life would be avoided, or "turned off."

> Ben. [DNR orders are] a request not to continue with procedures that might be necessary to keep you alive … .(4.1/3)

> Helen. If I'm on any machines or anything, [DNR orders means] that you would just turn them off. (4.1/4)

Many stipulated particular biological markers—basically, biological deterioration involving the whole body—as indicating circumstances in which it might be appropriate to

forgo attempts to maintain life. These were taken to indicate that death was imminent and inevitable, with no efficacious medical intervention available or justifiable.

> Gavin. … where everything's sort of packing up, … really why continue? (4.1/5)

> Ingrid. … when all systems fail, do not try to bring back to life. (4.1/6)

Some named the absence of hope as significant.

> Anne. [DNR orders should apply at] the end of your life when you're past all medical help, and there's not much that can be done … . [I]f there's no hope, [the patient wants] not to be resuscitated … . (4.1/7)

> Mike. … use no means to prolong it any longer than necessary. … If I ever get to the stage where there is no hope, I would like somebody to put me to sleep. (4.1/8)

In speaking of 'no hope' Anne and Mike (above) refer to the limits of medical efficacy in stopping a disease (cancer) from killing the patient. This is given as justification for actions which result in the patient's death, whether through withholding or taking action (see also 5.1.1 and Chapter 6).

Nocera[366] has suggested that the lay person is likely to interpret CPR as the provision of basic life support, and certainly these participants' representations of DNR orders support this claim. Furthermore, given their access to the precise medical definition, this variation in definition of DNR orders could be taken to confirm research indicating poor patient comprehension of written information regarding medical procedures.[7, 197, 367] Nonetheless, despite the variation evident, participants' talk functions to construe medical attempts to ensure the continuation of life as undesirable, and the patient's subsequent death as desirable. This does not support the claims that, when offered CPR, patients will not refuse it, that being in hospital equates to a desire to be kept alive,[47] or that patients will always choose life over death.[21, 368] It also appears to assess as inappropriate the medical stipulation that medical practitioners should always attempt to preserve life.[119] Participants' identification of total systemic failure as justifying cessation of medical intervention could also challenge the presumption that CPR should always be a default option, even in the absence of a specific DNR order.[1] What follows is a more detailed discursive analysis of how institution of DNR orders and concomitant limitations on medical intervention were rendered legitimate by these participants, and some possible consequences of this.

4.2. Legitimating implementation of DNR orders

Legitimation of medical non-intervention following cardiac or respiratory arrest was achieved through a number of related strategies. These included the positive construal of DNR orders as in accordance with 'nature,' and as reducing suffering. This was often supported by the negative construal of CPR as 'bringing the patient back,' or as 'prolonging life longer than necessary.'

4.2.1 Positive construal of DNR orders

For some, compliance with DNR orders was depicted positively as facilitating a *natural* death, while medical intervention following cardiac or respiratory arrest was construed as artificial.

> Ben. … when one's come to a state where [one needs] the artificial support to survive, [DNR orders are] a request not to continue with procedures that might be necessary to keep you alive … . (4.2.1/1)

> Cathy. [DNR orders mean] that if a person's heart stops, they're not artificially revived. … [The] heart failure … was nature's way of saying the body had had enough. … [T]hat would be a natural way that the life would be concluded. (4.2.1/2)

Nature, or a 'natural death,' was placed in rhetorical opposition to artificial, or a mechanical maintenance of life, in order to justify the identification of an appropriate and preferred time to die. This is a commonplace distinction, artificial/nature representing a comparative dyad, one invoking the other.[369] However, as noted by Stoffell and Asbhy,[369] in the context of care at the end of life the distinction between natural (good) and artificial (bad) can be seen as somewhat arbitrary: Any medical attempts to treat cancer (through chemotherapy, radiation therapy, or surgery) can be viewed as artificially interfering with the progression of the illness (and delaying death), but was presumably favourably viewed by participants, many actively undergoing such treatment—the difference perhaps lying in a predicted imminence of death. Nonetheless, viewing death as part of a 'natural' cycle of life may act to normalise it, or render it less removed from current experiences, and therefore less to be feared. Being natural, death is not to be avoided at all costs. However, the identification of a natural death rests upon the premises that there is a reality separate from and untouched by human experience (nature), and that death is part of nature, part of a natural cycle of life and death. However, these constructs—reality, death, and nature—are themselves not unproblematic. It has been asserted that 'reality' is socially constructed,[294] and therefore intrinsically and ineluctably bound to human experience, and both 'death' and 'nature' have been identified as historically and culturally situated.[370-372]

Peculiar to contemporary Western societies, the natural death is an idealised conception of what individuals think death should be—according to Charmaz,[347] "an easy death without agony, pain, lingering or undue inconvenience to self or others" (p. 70). Charmaz contended that such a conception leads individuals suffering some illness to seek medical care so that they might delay death until a "correct time." This prompts individuals to seek medical help to attain the natural death, which in turn operates to maintain medical dominance over the dying process.[373] Certainly, physicians institute the majority of DNR orders.[2, 48, 72] There are other constructions of death that do not lend themselves to the medicalisation of the dying experience: For example, according to the tenets of Indian Hindu beliefs, pain and death are opportunities to demonstrate the virtues of endurance and transcendence,[374, 375] while Jewish tradition accords the rabbi (not the doctor) authority over the dying, stipulating that medical interventions cease when death is imminent and inevitable.[376]

Discursively, within Western ideology, the construct of 'nature' is flexibly available to be used rhetorically in order to justify a particular argument,[377] as the identification of something as 'natural' operates to render it self-evident and unchallengeable, not subject to further debate.[369, 378] Within Cathy's speech above (4.2.1/2), this position is further reinforced as the rhetorical employment of the 'commonplace' understanding that it's "nature's way" functions as a socially agreed upon conclusion to debate and conversation.[379] These informants rendered non-compliance with DNR orders (instituting CPR) as contrary to 'nature', a position that, within their culture, is negatively viewed.[347, 380] Locating DNR orders within the natural serves to set a limit on the use of medical technology: to say, 'this far, and no further.' Thus, the invocation of the considerable authority of 'nature' justifies medical non-intervention in dying, with compliance with DNR orders constituted as appropriate and desirable.

Some individuals spoke of DNR orders as preventing an unnecessary prolongation of life (see also 4.1/8).

> Mike. If a person's going to die, why string it out any longer than is necessary, … why stretch it out, why try and preserve a life with agony and pain? (4.2.1/3)

> Delia. [DNR orders] mean that you don't do anything extraordinary, … anything that is going to prolong life, and keep a body alive regardless of what state it's likely to be in. (4.2.1/4)

Such terminology connotes the extension of something beyond its appropriate length, implying some form of biological limit for each human life. When constituted as a

biological entity, the individual subject typically becomes the focus of medical practice, which not only defines the subject, but how they should be treated.[298, 381] By contrast, participants here invoke a biological discourse to assert the appropriateness of limiting medical authority. With the additional consequence of rendering the indiscriminate preservation of life as inappropriate, the value of an individual's life was also defined as more than mere corporality, more than just a biological entity, as participants commented that to "keep a body alive" was not a sufficient goal in and of itself.

Many stated that medical science should not 'bring back' the patient. The following excerpts were all responses to the question "What do DNR orders mean?"

> Nigel. … if somebody was in the life-threatening situation and they were dying, or they were dead, that you don't bring them back to life. (4.2.1/9)
>
> Don. It's not bringing someone back to life again. (4.2.1/10)
>
> Elaine. … if you go into heart failure …you don't want anything done to bring life back. (4.2.1/11)
>
> Harry. … if [patients] arrest while in hospital, that there's no attempt to resuscitate them and bring them back to life… . (4.2.1/12)

If patients do not wish someone to "bring them back to life" when dying, to do so may be seen as violating individual autonomy. Given the pre-eminence of autonomy within Western society, particularly with respect to medical decision-making,[119, 382, 383] CPR is constituted negatively, as an inappropriate and unwelcome procedure, and DNR orders positively, as a preferred option. It can be argued, however, that as what follows on death remains unknown, the degree to which one can make a fully informed choice (a condition of autonomy) may be problematic.[384]

It has been argued that the development of CPR, in conjunction with advances in other life-sustaining treatments, has changed the medical definition of death from a heart-based, to a brain-centred criterion,[347, 385] although the particulars of this are still contentious.[386, 387] What has remained constant is the irreversibility of death, within current technological limits.[385, 388] These participants do not, however, seem to endorse brain-centred criteria, or the notion of irreversibility as defining death: The language they use construes death as both heart-centred, and potentially reversible. Although this may be a product of how this research was presented to them (what to do following cardiac-pulmonary arrest), the beating human heart has a symbolic importance in determining life or death status.[389]

For the lay person, this may override the centrality that medical technology has accorded to the brain.

4.2.2 Negative construal of CPR

DNR orders were also legitimated through a negative construction of CPR as both cruel and futile. Participants depicted CPR as reviving the patient to continued suffering and dying, when they would probably arrest again a short time later.

> Bettie. … there is a chance we could save their life, you know, bring them back, but only for more suffering so, do not resuscitate. (4.2.2/1)

> Cathy. … you wouldn't want a person to go through a lot more suffering just for the sake of resuscitation, to then go on suffering, for it to happen again. … [When] the heart stopped beating that would have been the end because quite obviously, they've been going through a lot of suffering … just end it. (4.2.2/2)

This argument is compelling because it draws upon dominant ideas within Western society. Patients' speech reflects and supports Western medical practice, citing medical futility as grounds for forgoing the use of CPR.[41] Nevertheless, the definition of medical futility varies significantly within and across Westernised societies.[390, 391] Determining futility involves a value judgement,[390, 391] here centred on the issue of suffering—to add to patients' suffering is negatively perceived. Incorporating a humanitarian discourse focusing on compassion, the injunction that one's actions should cause no harm to another constitutes a powerful humanistic directive enshrined in law and bioethics.[122, 392] Since CPR may lead to continued patient suffering, and DNR will forestall this, those who oppose DNR orders are positioned as uncompassionate and unethical.

It may appear axiomatic that suffering should be avoided wherever possible. However, suffering is itself culturally constructed and not universally decried.[375] As with futility, determining what constitutes intolerable levels of suffering involves a value judgement—for some patients, even within Western societies, life under any circumstances may be viewed as preferable to death.[200, 393] Notions of futility and suffering are sufficiently flexible for co-option in support of a multitude of views. Here, their invocation operates both to limit the perceived relevance of medical opinion at the end of life, and affirm the primacy of autonomy, because only the individual patient can determine what is futile, what is worth doing, or what would constitute intolerable suffering—for them.

Autonomy is also invoked by the implication that attempts to prevent a patient's death through CPR would contradict their preference.

> Felicity. ... if you have cancer ... you get to a stage of acceptance anyway that you're going to die. Just to prolong it ... [for] a few days or a few weeks, I don't believe is necessary. (4.2.2/3)

This further negatively positions CPR as a violation of patient autonomy, effectively legitimating no action to prevent death, or the instigation of and compliance with DNR orders.

It is also important to note that some patients suggested that suffering was not limited to a patient's own physical discomfort, but included patient's discomfort due to emotional stress (expressed or inferred) of their family.

> Delia. ... if heroic measures are taken to resuscitate him ... it could be very painful. ... You need to know that it's probably going to be very painful for any family or friends who are watching, ... feeling totally helpless and probably then having to make a decision to turn things off. (4.2.2/4)

> Keith. [When you suffer] and your family's suffering as well, I can't see the quality of life in continuing with it. It's just too stressful, both for the patient and for the people around you. (4.2.2/5)

Individual autonomy and the DNR decision itself are thus placed within a social context, as participants acknowledged that the emotional well-being of others is of legitimate concern to the individual (patient), with the moral implication that this should not be ignored.[163, 314] Considering the welfare of others is paramount in those cultural groups which constitute the individual as interconnected and interdependent, for example, 'Eastern' cultures,[394] including Korean,[156] Chinese,[141] and Indian.[395] This understanding provides an alternative to the dominant Western conception of the self-contained, rational, autonomous decision-maker operating free from the influence of others,[151, 396] which is fundamental to the prevailing concept of autonomy in medical decision-making.[397] The Western ideal ignores the interdependence of individuals, dismissing arguments that posit the importance of considering others, a point of view which may be particularly salient for those who have invested much of themselves in, for example, their family or friends (as noted by patients above). Although contending that the patient is responsible for the DNR decision (see 5.1) participants implied that what hurts the family hurts the patient, and what benefits the family benefits the patient, accepting that determining a course of action may involve considering the effect on others.[111, 123] Participants' suggestions that consideration of others is a required part of individuals' decision-making lend support to those models of decision-making that stress interdependence and relationships as fundamental elements of autonomy.[123, 129]

There is, however, a potential that the perceived applicability and desirability of DNR orders might be considerably widened in terms of numbers, as patients may not be suffering themselves (perhaps being moribund or comatose), yet may have relatives in psychological distress. It has been noted that this argument may be utilised to 'subtly influence' individuals to initiate DNR orders, since a patient's continued existence may be viewed as causing (psychological) harm to those around them.[119]

Participants here reproduce the dilemma inherent in the liberal ideology of individualism—that the ideal autonomous individual should possess the sensitivity to perceive and consider the welfare of others, and act on this.[398, 399] Nonetheless, these patients' identification of the relevance of emotional and social factors at the end of life, in tandem with the pre-eminence of autonomy as the determining principle in patient care, further operate to limit the jurisdiction of the medical practitioner. In practice this can lead to discrepancies between the will of the physician and that of the patient and/or surrogate.[3, 26] Critically, although none of these participants appeared to endorse CPR for the dying patient, to do so is not inconsistent with the endorsement of the value of autonomy they espoused: Prioritising autonomy operates to legitimise a variety of views and preferences of the patient, with consequent differences in outcome. Thus, determining the appropriate course of action in cases where patients request CPR when the physician believes it to be futile presents both ethical and legal dilemmas for the medical profession, many of which are yet to be resolved.[61, 98, 400-402] Considerations such as these have led to questioning of the adequacy of current models of patient autonomy within the medical profession,[37, 156] a position supported by this research.

Some participants suggested that a patient's quality of life (specifically dependency on others, and an anticipated 'vegetative' state) following resuscitation may not be acceptable. Because determining quality of life is a subjective matter, with emphasis on personal rather than medical assessments,[403] such arguments again move the DNR decision beyond the provinces of medical practice, further representing CPR as undesirable.

> Bettie. I wouldn't like to have to depend on anybody else if I was so ill that nothing else could be done then, just end it, yeah. (4.2.2/6)

> Keith. ... where I'm just laid, virtually as a vegetable or something like that ...I wouldn't think there'd be any point whatsoever in resuscitating to bring me back to the quality of life that I have got, ... a burden having doctors and nurses just virtually keeping me alive, for no reason. ... I wouldn't want it, to be resuscitated under any circumstances if you're going to be brought back to just be a vegetable. (4.2.2/7)

Participants assumed that a dependent patient would constitute a worthless 'burden' to both medical staff, and the wider community. This belief is the inevitable consequence of equating the value of a person with what that person can do for others, and frequently leads to feelings of worthlessness in patients restricted by their illness.[404, 405] If this belief is held, attempts to prolong a life self-assessed as worthless can only be negatively perceived. Further bolstering arguments against CPR are negative perceptions of dependency within Western society: It does not fit with notions of independence, integral to the Western concept of self,[399, 406] undermining our social status as adults.[383]

Patients also voiced concern regarding the value of CPR in the context of an anticipated degree of cognitive impairment. The separation of cognitive capacity from bodily functions both reflects and supports the dualist (mind/body) construct of persons, fundamental to Western culture.[407] Asserting the primacy of the former reflects the privileging of rationality in determining what it is to be human.[386, 408]

Amongst European Americans, both the fear of being a burden, or of existing in a permanently comatose state (being a 'vegetable') are the most commonly cited reasons to abjure the prolongation of life.[200] 'Vegetables' and 'burdens' have reduced social status, and their presence have been noted as factors in 'social death'—being effectively 'dead' to the world before bodily functions cease.[409k] In such circumstances, death may be viewed as preferable to life,[162, 200] and returning a person to such an abhorred state of existence may be seen as uncompassionate.

As these three constructs—futility, suffering, and quality of life—central to these arguments against CPR, are subjectively determined, the issue is construed as essentially personal, not medical; thus medical authority is nullified with intervention disapproved. This particular construction of CPR (as producing vegetables or burdens) provides a powerful warrant legitimating both the cessation of medical attempts to prolong life, and the instigation of DNR orders.

4.3 Conclusion

In this chapter I have argued that participants recognised that compliance with DNR orders will forestall CPR attempts, and a patient will die following cardiac or pulmonary arrest. This was legitimated through invocation of highly valorised discourses within Western society, namely *nature*, *autonomy*, and (the humanistic construct) *compassion*. This works

[k] By some medical definitions, 'vegetables' may be defined as dead.[386]

to negatively position non-compliance with DNR orders (instigating CPR) as violating nature, infringing autonomy, and uncompassionate. Several of these strategies overlapped, and served to reinforce each other. Their combined effect is to revoke medical authority at the time of impending death—to construct dying as a natural event which is, or should be, the concern of the individual involved and their family. Deemed to ensure medical non-intervention in the process of dying, DNR orders are thus positively construed and legitimated, as is the patient's subsequent death. Focusing on patients' construction of the DNR issue, this analysis thus provides support for those currently questioning the wisdom of a default policy of initiating CPR on any hospitalised patient, regardless of whether or not the patient is engaged in dying, and lends support to a policy of non-intervention when death is imminent and inevitable.

These participants construed DNR orders as primarily personal, with criteria for justification reflecting subjective assessments by the patient: This works to foreground the importance of patient autonomy, constructing the issue as a matter of personal choice. In the following chapter I further explore ways in which participants discussed issues of responsibility for, and timing of DNR orders. I also examine any discrepancies between their representations of these, and those implied in traditional models of decision-making, with specific questioning of the assumptions underpinning these, and specifically, the construct of autonomy.

Chapter 5. Study 1. Patients, others, and decision-making

In the previous chapter, I demonstrated that patients with cancer construed DNR orders as primarily personal, thus intimating that responsibility for the decision lies with the patient. Here, I further examine how they talked about the DNR issue, focusing on how they justified who might be assigned the DNR decision, and when it should be discussed. In determining the appropriateness of an individual to make decisions, participants informally applied what I shall call *Sanity* and *Stability* tests, assessing both an inherent ability to reason, and the presence of emotion which might impact on the decision-making process. Failure to pass the Sanity Test excludes, and failure to pass the Stability Test excuses, individuals from decision-making.

Before presenting this analysis, I will define these two tests (Sanity and Stability tests) and explain how their existence was derived. Previously (in Chapter 2) I reviewed current criticisms of many of the dominant concepts of decision-making which structure practice, in particular, the ideal of autonomous decision-making. One of these centred on the questioning of rationality as the dominant criterion for assessing the process of decision-making, the decision made, and the decider themselves. In addition to these criticisms, it has also been noted that the word *rational* is itself contested, reflecting a complex construct and possessing multiple meanings.[148, 410] These varied meanings may be differentially drawn upon in discussions about the rational in decision-making, and can result in tangible differences in who is deemed eligible to make decisions about medical treatment.[411, 412] Given this, I will examine common understandings of 'rational' in further detail below and define the ways in which I will use the term throughout this chapter.

A standard definition of 'rational' is that it is "Having or exercising the ability to reason."[413] But "having" the ability to reason is different to "exercising" it, and this distinction underpins two different operations of *rational* (and *irrational*) in the context of decision-making. This is most readily grasped through considering the sentence "He couldn't make the decision because he was irrational." There are two possible colloquial interpretations of this: "He was crazy," or, "he was emotional." The first connotes some sort of biologically-derived capacity, a "having … the ability to reason." This is critical in the assessment of 'competency,' sometimes but not always equated with decision-making or decisional capacity.[155, 414] As a default, competency in adults is presumed in law, and requires legal process based upon medical opinion to negate this presumption.[415] Competency denotes the ability to deliberate about new information and make choices in relation to one's own values and goals, and to communicate with others with regard to

these.[155, 414] It is inherent in references to "the right of the competent individual" to make medical decisions.[124] It must be acknowledged that competent individuals might make decisions that, to the observer, may be deemed non-rational—that is, 'reasoned' decisions that are based upon beliefs that are empirically non-verifiable—without jeopardising either their status as competent, or the perceived force of the decision made.[119, 416] However, those classified as 'incompetent' are typically precluded from participating in a decision-making process: persons who are intellectually retarded, deranged, or comatose. For brevity, I will refer to this as the 'Sanity test,' whether you can or cannot reason (see Table 7): To fail this is to be *excluded* from decision-making.

However, determining that someone has the ability to reason is a necessary, but not sufficient condition in determining that a rational decision has been made. There is the 'exercising' of this ability, referring more to the process followed. Thus there may be persons who theoretically can, but who do not exercise the ability to reason, and whose decision-making (and subsequent decision) cannot be said to be rational—in the sense of conforming to the critical, reflective, and reasoned process stipulated within dominant models of decision-making. It is here that the second interpretation of 'he was irrational' becomes relevant. This second version has elements of the first (in that it refers to a capacity to reason), but connotes more of a temporary, psychologically-based capacity. It assumes the individual is not inherently unable to comprehend and manipulate information, but that at this time, they do not or cannot do so due to the disruptive presence of emotion.[417]

This understanding draws upon a construction of emotions that has dominated Western thought since the eighteenth century.[151, 152] Emotions are commonly perceived as beyond volition, as a force that should be controlled by the application of rational thought (reason), but which may yet prove too strong.[152] Thus although defined as antithetical and subordinate to reason, emotion is also constructed as capable of disrupting reason, as the superior force. Both, nonetheless, represent ways to characterise and evaluate persons and their actions.[151] Emotions therefore constitute a major discursive resource to explain behaviour that cannot be accounted for by rational appraisal.[152, 417] Recently, some have asserted the integration of reason and emotion,[418-420] while others have argued for a reversal of the privileging of reason over emotion.[421] Furthermore, some have argued that, within Western societies, emotionalism is currently promoted above rationality as *the* criterion for self-hood,[153, 154] or as the essence of what it is to be human.[152] Some social constructionists have further noted the multi-faceted nature of emotions in speech—

sometimes construed as opposed to reason, sometimes not; as signifying both strength and weakness.[152, 417, 422] These developments notwithstanding, the enduring and dominant metaphor remains the master-slave concept of reason-emotion,[152, 420] the latter nonetheless deemed capable of disrupting the former. Indeed, this representation appears fundamental to arguments that the presence of emotion in patients and families at the end of life makes it unlikely that they will be able to participate in a rational decision-making process.[35, 37]

Certainly, through the pre-eminence accorded autonomy with its built-in notions of rationality,[149] it remains axiomatic that patients should make their decisions, and in a rational way.[35, 37] The possibility that a rational decision-making process may be subverted by the presence of emotion is not here well accounted for. It does, however, feature within medical practice, for example, through the attempt to establish guidelines regarding professional communication skills.[110, 181, 423, 424] Physicians holding that patients should possess relevant information may yet consider that an individual patient may receive some particular piece of information badly, and will be upset by the news. Although often phrased in terms of the bioethical precept of non-maleficence, this may also reflect a concern that, while and because they are upset, the patient will make an irrational (therefore bad) decision.[285, 425] In such circumstances, physicians may modify or delay giving such information[285, 425] and, by definition, the patient will not be able to make a rational (fully informed) decision: They will be exempt from the decision-making process. Again, for brevity, I will call this the 'Stability test,' whether you do or do not reason (see Table 7): To fail this is to be *excused* from decision-making. (Parenthetically, I note that the ethically-based criteria for research participation—coherence and emotional stability—reflect the constructs referred to by the Stability and Sanity tests.)

Table 7. *Characteristics of tests for rationality in decision-making*

The Sanity test	**The Stability test**
Due to cognitive impairment	Due to emotional impairment
Biological	Psychological
More likely to be enduring	More likely to be transitory
Failure: individual excluded from decision-making	Failure: individual excused from decision-making

For ease of comprehension of the concepts, differences between the Sanity and Stability tests shown in Table 7 are accentuated. I acknowledge, for example, that inability to make a decision due to cognitive impairment may be quite temporary, possibly due to severe

illness, or medication side-effects; whereas inability to make a decision due to the presence of emotions may be a habitual response, and therefore long-standing. Nonetheless, I contend that, for a patient to make what is deemed a rational decision, thereby fulfilling the requirements of autonomous decision-making stipulated in traditional models of decision-making, they must pass both.

But what if a patient fails? Is deemed incapable of following a rational decision-making process? Here, the decision is assigned (when the Sanity test is not passed) or falls by default (when the Stability test is not passed) to those who are rational—that is, to those who are able to reason by virtue of being neither crazy nor upset. There is some disagreement within the literature regarding who might best make decisions on the patient's behalf—some naming physicians, others family.[48, 83, 426] However, in South Australia, individuals can proactively legally appoint others (typically family) to make their decisions through establishing Medical Power of Attorney,[264] or Enduring Power of Guardianship.[265] In the absence of such formal delegation of authority, relevant legislation identifies the family (in order of spouse, parent, adult offspring, and adult sibling) as suitable 'informal' alternative decision-makers, with the physician specifically excluded. However, where these possible alternatives are unavailable or where their suitability is called into question (i.e., where family cannot be located readily, or where there is evidence of dispute within that family such that accord cannot be reached, or of dispute between family or physician regarding the welfare of the patient) then decisional authority may be legally determined and assigned by the Guardianship Board—to a specific family member, or to an independent advocate.[265] Thus, although the family's right to make decisions for the patient is enshrined in law, it is neither absolute nor unchallengeable, and may be revoked.

If the family, or sometimes "family members,"[427, 428] are nominated as proxy or surrogate decision-makers, it is assumed that they represent an extension of patient autonomy, that they will both know and support the patient's decisions, and will have that individual's best interests at heart.[55, 243, 426] These fundamental assumptions underpin the utilisation of advance directives.[240] There are, however, a number of further implicit assumptions, namely:

1. that 'family' will be rational, passing both the Sanity and Stability tests;
2. that, given the family as one entity, rather than an individual in a specific familial relationship to the patient, is nominated, family will be united in their position in relation to the patient and his/her welfare. In practice, one person

identified as 'next-of-kin'[108]—in itself an ambiguous category, particularly where there might be several potential candidates for such a position—is usually selected as proxy;

3. that family/next-of-kin will be available to make a substitute judgement for the patient, or indeed, wish to take on that responsibility; and
4. with regard to the impact of surrogate decision-making, the only position that is ethically justifiable is the presumption that family will not be negatively affected by their participation.[238]

In the following I demonstrate how participants' accounts of decision-making challenge many assumptions inherent in dominant medical models of patients' decision-making, particularly, the centrality of rationality. In discussing end-of-life decision-making, participants in this study drew upon two very different interpretative repertoires regarding the construct of the person, with certain conditions consistently associated with each.[296] Drawing on Gergen[151] these repertoires may be termed the *modernist*, and the *romanticist* concepts of the individual. The modernist repertoire construes people as "rational agents who examine the facts and decide accordingly" (p. 19). It epitomises the subject of dominant models of medical decision-making and was typically cited in response to direct questions about the DNR decision. Thus this repertoire was used in patients' accounts of how decision-making *should* occur, and usually in conjunction with the implicit application of the Sanity test. By contrast, the romanticist repertoire, which Gergen[151] proposed characterises people as guided by interior passions and personal relationships (pp. 18-27), featured in anecdotal accounts of how decision-making *had* occurred, and was usually associated with the Stability test. I also suggest that the coexistence of these two repertoires, and associated Sanity/Stability tests contributes to something of a dilemma (for participants, and ultimately for medical practitioners) in terms of determining appropriate timing of any discussions regarding the DNR decision, thus: The modernist repertoire and relevance of the Sanity test are available to support arguments for earlier rather than later discussion, whereas the romanticist repertoire and relevance of the Stability test may be drawn upon to legitimise (an indefinite) deferral of the discussion. I conclude that the absence of the romanticist repertoire in dominant models of patient decision-making has ethical implications for policy makers and medical practitioners dealing with dying patients and their families.

5.1 The patient as decision-maker

Conventional medical models of decision-making featuring the modernist repertoire were well-represented within participants' talk, particularly when they responded to a direct question about who should make the DNR decision; all but one said the patient should make their own decision. Reflecting the dominance of the discourse of autonomy in this setting, it was taken as axiomatic that the patient should have input or control over what should happen to them. For many this required no further justification than that it was 'the patient's life.' Most personalised the issue, presenting themselves as wanting to make their own decisions, suggesting the moral imperative concealed within this position.

> Alex. I feel that the most important person who is to make a decision is the patient himself. (5.1/1)

> Helen. I want to be in control of what happens to me, it has to be my decision. (5.1/2)

> Harry. Well, I personally, I would always want to know 'cos I feel like this is my life and all of this is being inflicted upon me I wanna have some input into it (laughs). (5.1/3)

These assertions constitute the decision as fundamentally personal, and work to support the notion that decisions about DNR should be determined by patients. The importance of this to the patient was indicated in the speech of some participants who specifically alluded to the default status of CPR within the hospital environment.

> Gavin. [When you have a terminal illness] you should be made aware of that earlier in the piece, while you're still able to make that decision. … And [asked] "What rights would you like to exercise" and perhaps "These are the range of options." … [A] lot of people … suppose that they always try and resuscitate you virtually no matter what. (5.1/4)

> Ivan. You wouldn't expect [doctors] to [not resuscitate] if the patient wasn't aware of that, to not resuscitate somebody without their consent basically, because everyone's intention is that if something goes wrong they're gonna try and keep you alive. So that's something that the patient needs to agree to, it's not something that can just be done without permission because it's their life, it's no-one else's and the final decision is theirs. (5.1/5)

If (at least some) patients expect that, without their agreement to the contrary, CPR will follow on their own cardiac arrest, then it arguably constitutes a breach of trust to fail to provide same without such discussions. The expectation that all attempts to prevent death will be undertaken reflects and supports the Western (medical) imperative to oppose death at all costs.[106, 174, 347] It constitutes a considerable challenge to those who hold that the DNR

decision should be made by medical staff, with no obligation to ensure patient knowledge of or acquiescence in the decision.[17, 21, 30, 57]

Despite the presumption that patients should be consulted regarding the DNR decision, participants also asserted that sometimes the patient might not be the most appropriate person to make the decision: specifically, if they failed the Sanity test.

> Cathy. Probably at that stage [of making a decision] the patient would be too ill to really be able to make an informed answer (laughing) or even to understand probably what was going on. (5.1/6)

> Gavin. There's patients with dementia and things like that and they're not capable of [making a decision], … if you're on treatment with drugs and things like that which may cloud your judgement or, you may not be able to concentrate enough to even make that decision or be fully aware of it. (5.1/7)

Such accounts seem to endorse traditional medical models of decision-making: The patient makes the decision, if they're rational. But the whole notion of rational decision-making entails the getting of information upon which to base one's decision—and this appeared problematic when participants reflected on when such information should be delivered.

5.1.1 Timing the DNR discussion

Clearly, the two limiting parameters for choosing the right time for a conversation about DNR orders are the *time of diagnosis* of a potentially fatal disease, and the *time of death*. The first is relatively easy to establish. However, determining the latter is a challenging task even for the most experienced of doctors,[429] and as death approaches there is an increasing probability that the patient will be cognitively compromised in some way and (in failing the Sanity test) will be excluded from the decision-making process.[7, 109, 183] Many participants identified the cognitive capabilities of the patient as relevant in timing, specifically in establishing a limit on how late in the disease process the DNR discussion should take place—namely, before biologically-determined factors impeded the ability to follow rational process.

> Elaine. I think it's better to discuss it while you've still got all your faculties, while you can logically think about it and you've got … all your senses there. (5.1.1/1)

> Felicity. Earlier on when … you're fully aware of everything, you know you're not being affected by pain and misery or whatever … . [E]arly in the process would be better because I think you're more objective, probably than later on. (5.1.1/2)

> Liam. [Discuss it] before it gets too late. While they still know what's going on. (5.1.1/3)

The need to have the DNR discussion before a patient was cognitively compromised represents an ever-present pressure to hold the decision earlier rather than later,[430] something of which participants were cognisant. However, other factors were also asserted as critical in determining appropriate moments for the discussion. Mentioned in connection with many potential opportunities for the discussion, these related to the patient's emotional state. Although participants typically spoke in terms of an appropriate time (too early or too late) for the discussion, I suggest that it was not time *per se* that was the relevant factor. Rather, it was the assumption that at particular times, the patient's emotional state was taken as indicating that they would be incapable of fulfilling the requirements necessary for a rational decision, and would be excused from deciding.

Along the time continuum of potential points at which a discussion might take place, the earliest possible moment—that is, when the patient has been informed of their diagnosis of cancer—was unanimously identified by participants as an inappropriate time at which to have a discussion about the DNR decision. In citing the relevance of this in decision-making, patients drew upon a romanticist repertoire to justify and make sense of their accounts of how early, or indeed whether, a DNR discussion should take place.

> Anne. When you first hear that you have cancer, you just feel as though the whole world has dropped away from you, and you need come to terms with it gradually. You need … a little time to adjust before you start talking about the end of life. … They [doctors] shouldn't [raise the issue when you're] in shock, [but] when you've learnt to accept the fact that they can do so much but it can't be cured or something like that, then you should start discussing it then. (5.1.1/4)
>
> Ben. Right at the beginning would be inappropriate because it's an immensely traumatic time and it's quite difficult enough coping with the concept without perhaps having people sort of talking about signing you off. (5.1.1/5)
>
> Delia. [It's] a case of [doctors] using intuition to find out which patients can accept the idea, and which would literally go downhill with the mere suggestion of it. … [Of] being very careful … that you don't take away a person's last thread of hope. (5.1.1/6)
>
> Nigel. It'd be too early [at diagnosis]. … [M]aybe when you're feeling all right, and you've got over the initial shock of being diagnosed with cancer. (5.1.1/7)

Participants here re-present the commonly held assumption that the impact of hearing about cancer is overwhelming.[431] The language employed is cataclysmic, with the diagnosis of cancer construed as producing an immediate, involuntary, and destabilising effect in the patient, one which is emotional in nature, and which results in an inability to rationally process information.

That this emotional reaction both arises in patients and is recognisable as legitimate and taken-for-granted by the observer may be contingent on an interaction between the views that death is to be feared and avoided at all costs, and a dominant discourse of 'cancer equals death'[432]—this despite the advent of increasingly sophisticated medical interventions designed to forestall death.[433] With cancer, mere diagnosis is equivalent to death,[347] and the normative reaction to a diagnosis is a negative one, characterised by an avoidance of, and withdrawal from situations associated with death.[329] This socially sanctioned emotional reaction thus provides justification for patients' refusal or inability to participate in the decision-making process, and legitimises, if not mandates doctors' deferral of the discussion.

There are, moreover, other implications of invoking the Stability Test in this context. First, it is presumed that a patient's doctor should aim to minimise patient anxiety or distress; and, second, that the DNR discussion is inherently distressing for a patient.

Doctors' responsibility regarding the emotional state of a patient is well-accepted within the medical profession, and has been noted as providing justification for (usually temporarily) withholding information regarding diagnosis or prognosis,[174, 285, 423] and for refraining from initiating DNR discussions.[197] Participants' accounts arguably lend support for this practice, as they construed it appropriate that, as part and parcel of the medical role, a doctor should modify their approach to the patient, based upon consideration of the patient's emotional state (e.g., see 5.1.1/4 and 5.1.1/6).

The assumption that the DNR discussion is inherently distressing for a patient may rest upon its association with death, indeed with the patient's own death. Space does not permit an adequate exploration of this issue, but, as many writers have attested, within contemporary Western culture, death has become marginalised and unacceptable, such that each death represents failure, a battle lost.[347, 434] It is almost self-evident within Western society that death is to be feared,[347, 435] but Charmaz[347] observed that this perception is culturally specific, with other cultures responding to impending death with reactions ranging from pleasure to calmness to acceptance (p. 87). However, within the Westernised (Australian) context, discussions about death, and an open acknowledgement of its imminence are negatively perceived, and do not always occur.[283, 433] I suggest that this underpins the existence of two mutually reinforcing factors which operate to justify delaying or avoiding the DNR discussion (see Figure 6).

First, the negative construal of death means doctors might be reluctant to initiate a discussion which 'speaks' the fact of the patient's demise. Indeed they can only justify doing so given the presumed prioritisation of something else—in this case, probably the importance of facilitating patient autonomy through ascertaining (and following) the patient's wishes regarding this matter. Gordon and Daugherty[176] have similarly observed that although respect for ethical principles of non-maleficence, beneficence, and compassion for patients prompts oncologists to delay discussions about death and treatment options until (too) late in the disease (to represent meaningful decision-making), respect for patient self-determination (i.e., autonomy) drives initiating discussions, with the justification that patients might direct their affairs.

Second, given this reluctance, there is the probability that, when the topic is raised, patients will assume that their own death looms large, and, given their culturalisation, experience emotional distress. And this probability operates to sanction and sustain the doctors' hesitation in broaching the issue, and so on.

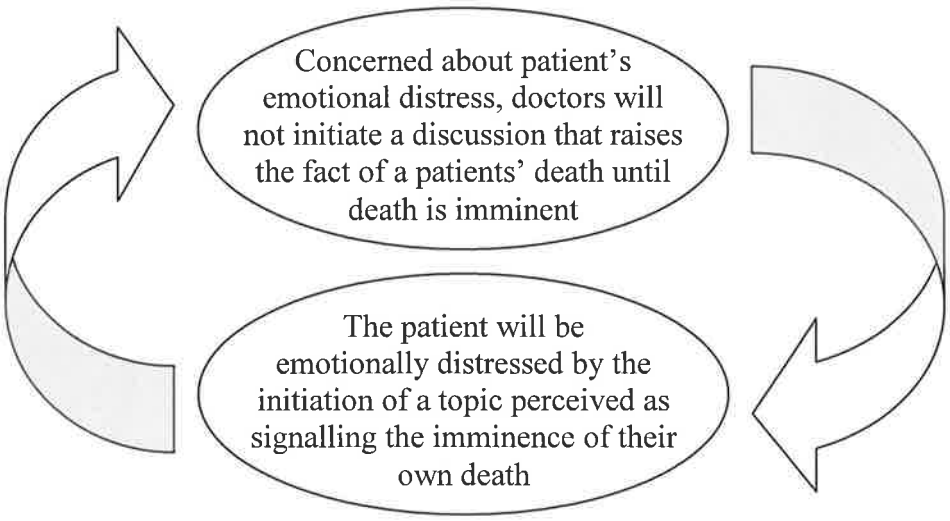


Figure 6. *The reciprocal relationship between doctor and patient construals of the DNR discussion which operate to maintain the negative construction of the DNR discussion, and to justify its deferral*

Combined, these two factors create something of a vicious circle, with the net effect that they can constitute justification for (always) delaying the discussion. Liam's speech illustrates the assumed association between death and the DNR issue, as well as how this is used as justification for holding the discussion later rather than earlier.

> Liam. Well, if you come out too early with it [the DNR discussion], they [patients] are always going to be thinking about "I'm dying, I'm dying," you know. So I wouldn't come out too early. (5.1.1/8)

To summarise, patients with cancer are construed as needing to make an emotional adjustment to their diagnosis before they can consider and make a decision about issues relating to the end of their life. This takes (varying amounts of) time, and so any discussion, preparatory to making decisions about DNR orders, is justifiably deferred—until patients can pass the Stability Test. To this extent, emotions take precedence over reason: Emotions both precede reason in terms of time-line, and dominate in terms of relative influence.

Nonetheless, although presenting the initial emotional reaction to a cancer diagnosis as reason not to discuss the DNR issue, most suggested that this reaction was transient—that, at some point, the patient might reasonably be expected to have "come to terms with it," to "adjust," "accept the fact," or "get over the initial shock" (see 5.1.1/4-7), that 'shock' is transient.[436] At this point, to claim exemption from the discussion and the decision on the grounds of disequilibrium generated by emotional distress might no longer be perceived as justifiable. This reflects the Western notion that emotions are impermanent, that they have an appropriate span, and that to continue to exhibit a specific emotion will ultimately have to be accounted for.[417] Certainly, an individual's continued avoidance of issues pertaining to their own death are negatively constructed within our society, taken as markers for moral or psychological deficiencies.[347, 436] This may go some way to explaining why participants constantly identified themselves as capable of participating in DNR discussions, even as they identified those who might not (e.g., see section 5.1.2, and excerpts 5.1.1/14-15 below). Nonetheless, their assertions that those others should be accommodated operate to endorse the value and legitimacy of emotional factors in the DNR decision-making process.

Other discernible points in the continuum from diagnosis to death are those associated with treatment received. When discussing treatment in the context of the DNR discussion, patients usually represented both as inherently stressful—that is, likely to produce a negative emotional response in the patient. Nonetheless, although treatment stress was construed as undesirable, it was not deemed something to be avoided given that the treatment could work, that is, could cure the patient. Stress associated with the DNR discussion, however, was construed as undesirable and potentially avoidable—certainly deferrable.

> Ivan. [It's] probably hard enough for the patient going through the treatment at the start, to understand and to cope with it more … [then] having to have something else [the DNR decision] to worry about or think about. Whereas if the treatment isn't working or there's something wrong, then the only other option may be to explain that. But the treatment could work so why put more pressure or stress on a person to worry about … . There's enough to worry about in the initial start with the treatment and in signing forms that says the treatment could kill you and all that sort of thing, which is reality. (5.1.1/9)

It is noteworthy that, for Ivan, the presentation to the patient of forms saying that "treatment could kill you" does not justify not providing this information about treatment. Thus it appears that a distinction is drawn between raising the subject of the patient's death as a hypothetical in association with treatment intended to work (or cure), and raising it as a predicted 'real' future with which they must engage—which is presumed to be implied in the introduction of the DNR discussion. Little and Sayers[437] have also noted a similarity between treatment and death, naming the difference as "the redeeming element of hope for cure, for life over death" (p. 1329). Thus, in the case of treatment, the anticipated and focused-upon end is cure, which would obviate the need for the DNR discussion at all, a point implied by Keith.

> Keith. I don't think it should be raised before the doctor in his own opinion and everything else, reaches a stage where any treatment is not going to do any good. 'Cos before that I think you're giving more stress to the patient. (5.1.1/10)

Such speech again represents and maintains the assumption that the DNR decision is inherently distressing, and, considering the medical bioethical directive to minimise patient distress, it follows that the default option would be to avoid it in the absence of indicators that it might be necessary: Any time is too early unless proven otherwise—unless there is perceived to be some compelling reason to hold the discussion *now*. However, given the medical imperative to cure, the overwhelming focus on aggressive treatment, and reluctance to concede what is construed as defeat, this argument can be maintained for some considerable time, as noted by others.[121, 176] This is compounded by the avoidance of discussions of death by doctors and patients alike,[174] and the possibility that patients may view any treatment as indicating that death is still not the inevitable end-point of their disease.[57, 286, 438]

The existence of the need to determine patients' wishes through initiation of the DNR discussion, concomitant with many arguments which would justify its delay poses something of a dilemma for the medical practitioner. What would constitute an appropriate time? What might serve as a marker for the optimal moment? These participants also

appeared cognisant of this problem, and for many, some change in treatment protocol was presented as a potential solution.

> Alex. It might upset many people, but once you know that there is serious possibility that [death] might occur, well then it should be discussed. … If there is no definite clue that this can happen, well then what's the use of discussing it? But once you know that there is a possibility, then that could be, or should be, cleared. (5.1.1/11)

> Gavin. I suppose it's going to be an assessment by the doctor, … perhaps if the doctor feels that you're at an advanced stage of your illness or the prognosis is not that good and you've got perhaps in his view or her view perhaps weeks or perhaps down to months left, that anything that might crop up say in the next three months or something like that, they [the patient] should be made aware of it while you're still able to make the decision. (5.1.1/12)

A change in treatment protocol was invariably associated with a worsening of the patient's condition, and taken to indicate both that continued medical intervention was likely to be ineffective in occasioning a cure, and that the patient's death was foreseeable (and imminent). At this point, the mere fact of awareness for the patient that treatment is no longer likely to be efficacious, and that their death is more of a probability than it had been during active treatment, could be cited as justification for again deferring the discussion: If the emotional stress of diagnosis, and of undergoing treatment is taken as legitimate justification for delaying the DNR discussion, it might be thought that the awareness of impending death would engender even greater emotional stress, and thus militate against the discussion. Yet some participants suggested this moment as a potentially appropriate time, echoing the judgments of many oncologists.[176] The reasons why this should be so rest, I suggest, on the presence of, and interaction between particularly Western concepts of the mind, body, and disease, specifically cancer.

In Western culture, a significant feature of contemporary metaphor about the body and illness stems from immunological discourse which sees the body as a battlefield in which a civil war is constantly in progress.[439] As Sontag[440] noted, the language employed in discussing cancer is replete with metaphors of war (pp. 64-6). Cancer is constructed as an enemy from within, which must be overcome. Within this conceptualisation, the appropriate response to the enemy cancer is the marshalling of all responses to combat and defeat it. The patient's body becomes a battleground and the eventual outcome can only involve winners (who conquer cancer) or losers (who succumb and die). At the same time, it is assumed that, through the judicious application of will, the patient can affect the progression of disease through their body. The "discourse of will" connotes a specific relationship between the body and the mind, such that the mind (or reason) can control the

body,[425] and, notwithstanding Lemon's[441] observation that "current evidence for a relationship between psychological factors and the onset or progress of cancer is highly equivocal" (p. 44), is common in lay and medical discourse. This Cartesian division of body and mind, and the privileging of the latter permeates Western notions of self, and underpins the importance placed upon controlling the body, through conscious and continual vigilance.[442] The perceived ability to do so works to confer a moral obligation on the part of the individual patient to engage in the battle to control their wayward body by 'being positive,' by maintaining an optimistic spirit, by not 'giving up.'[429, 442-444]

However, while the discourse of will couples body and *mind* (or reason) thereby nominally affirming the primacy of reason, and thus a modernist construct of self, I suggest that what is accorded agency is actually the emotional state of the individual. What is prioritised is a romanticist construct of self. Although the ostensible focus is the thought patterns of the individual (thinking positive thoughts etc.), what is valued is the production of positive or negative emotions these thoughts are construed as engendering. Negative emotions are construed as instrumental in reducing the body's ability to engage in the fight, where positive emotions are deemed to facilitate the body's struggle against cancer. These recommendations therefore reflect the relative weight accorded to the emotional state of the individual in fighting cancer process. Emotions are constituted as a resource to be drawn upon or manipulated as part of the treatment process and therefore as at least partially under the control of the individual—in contrast to the earlier construction which saw them as uncontrollable.

It is apparent that there are a number of assumptions which come to bear upon this issue, enabling us to make sense of a patient's recommendations for DNR discussions when treatment (aimed at cure) ceases, or is no longer helpful:

1. cancer is an enemy, and the battleground is the patient's body;
2. the patient is obliged to do all within their power to 'fight' against cancer;
3. the DNR discussion will imply the probability of the patient's imminent death;
4. a patient's focus on death will engender negative emotions;
5. negative emotions will impair the patient's ability to fight against cancer;
6. the doctor's role is to do everything to help stave off death, to do nothing that will harm the patient; and
7. the doctor is therefore (morally) obliged not to present information that would hinder the patient's ability to fight cancer.

Thus while treatment continues, while the battle is still engaged, raising the DNR issue is difficult to justify. As illustrated by Ben below, there is a sense of magical ideation, of superstition, in the power accorded the mere fact of a DNR discussion, in its ability to disrupt the attempt by patient and doctor to successfully treat (cure) the cancer. This attributed power resides in the network of the assumptions listed above.

> Ben. I suppose there is an argument [that] while treatment's taking place that one doesn't want to [ruin] sort of the probability of success for that treatment by being negative about it and looking at the worst outcome. … [When] a patient's had treatment and has obviously had a while to think about it all, they might indeed be more receptive later on. More, they ought to accept the possibility of coming undone. (5.1.1/13)

When the battle is deemed already lost, when available treatments are no longer likely to be efficacious, disturbing the emotional equilibrium of the patient has relatively less merit as an argument for deferring the DNR discussion. Indeed, the patient should have got used to the possibility of their death, and should accept their fate. At the point where cure cannot be achieved, the need to obtain patient wishes, critically before they exhibit cognitive impairment due to disease process (e.g., see Gavin 5.1.1/12), attains priority, has relatively more weight, and thus would be more likely to outweigh any ills associated with 'speaking the patient's death,' that is, the probable intensification of patient distress. In terms of balancing the bioethical obligations of protecting the patient (according to the precept of non-maleficence), and of determining their wishes (respecting autonomy), the scales now might be deemed to tip in favour of the latter. What is interesting here, is that these patients' construction of this balancing act perfectly mirrors that of those held responsible for their care—oncologists.[176]

The network of arguments and assumptions which legitimated selection of the point at which death is no longer a hypothetical as a potential opening for a DNR discussion were also prominent in speech referring to hope. Hope has been described as fundamental to oncologists' treatment practice.[176, 177, 285, 425] It is held to enable the cancer patient to maintain a "fighting spirit,"[445] and was described by Beste[446] as "an essential weapon for patients fighting cancer who wish to maximise their chances for recovery" (p. 224). Furthermore the need for doctors to 'preserve' or 'maintain' hope has been noted as relevant in discussing end-of-life issues, including treatment options.[83, 99, 277] Within Western societies, hope is a dominant discourse surrounding cancer.[298, 425] Because there was considerable variation in how these patients with cancer used the word *hope* and, moreover, this variation had particular implications for patients and clinical practice, I shall

examine hope in more detail in Chapter 6. However, I shall here comment briefly upon some aspects as they pertain to timing of the DNR discussion.

One position represented was that DNR discussions should occur "at the end of your life," when death was inevitable, and specifically *not* while there was still hope.

> Anne. Well, [discuss the DNR decision] at the end of your life when you are past all medical help, and there's not much that can be done for you … .At the beginning, there's still hope, but at the end when you know there's no hope then the doctor should talk to them about it. … As it [the patient's disease] progresses and there's no hope, well then it should be discussed further then. (5.1.1/14)

> Ben. [It would be best] to be working this through … when it appeared to be likely I suppose that there was probably no other outcome than death. I suppose it's not a good idea, perhaps, while there's still some hope. … [If] there is felt to be some hope, it's sort of premature (5.1.1/15)

Within the medical literature, it has been claimed that hope (and hopelessness) are crucial in delays in discussing end-of-life care,[447] that some types of 'unsafe' information are anathema to patients' necessary maintenance of hope,[448] even that truth and hope exist in an inverse linear relationship, justifying modifying the provision of information by physicians.[449, 450] In a similar vein, hope is here is invoked to legitimise deferral of any discussion about the DNR decision, until the moment where it might be unequivocally asserted that there was "no hope," equated to the time when the patient was "past all medical help," and when death was the inevitable outcome. The rationale behind this position is suggested in Gavin's speech below.

> Gavin. [The DNR discussion] could be a bit [stressful], for some people it would perhaps make them drop their bundle and really bring it home to them that perhaps they don't have any hope, and they go down to it [death] quicker. (5.1.1/16)

Here, the inference is that not only will the DNR discussion imply that a patient does not "have any hope," but that this will have deleterious consequences for them. The justification for this again rests upon the assumption that the patient can actively resist their disease, also drawing upon the common understanding that having hope is instrumental in the patient's ability to do so.[446] Thus, Gavin argues that without this hope, patients would "drop their bundle" and "go down to it [death] quicker." To "drop one's bundle" is a colloquial description of an inability to process information, which is here linked with the presumption that one is about to die, and connotes the emotional turmoil associated with this. Again, the implication is that this emotional-based reaction (precluding rational consideration of the issue) would justify deferral of the DNR decision.

Although typically represented in arguments justifying delay of the DNR discussion, hope might also be invoked as justification for holding the discussion earlier. However, both hope and the DNR discussion were again associated with the imminence and inevitability of death.

> Harry. I'd like to have been told [about the DNR issue] sort of a long time in advance of the actual possibility of it happens … . [Maybe discuss DNR issues when] it's obviously becoming more of a possibility that that [death] could be an outcome, but before all hope's taken away so at least the patient can still realise the situation but feel like they can still go on, and there is something left for them to hang on to (laughs). (5.1.1/17)

Harry's contention that if the discussion was held while there was still hope (of successful treatment) the patient would have something to "hang on to" construes the presence of hope as enabling the patient to deal with the turmoil engendered by the intimation of imminent death. Although this might be seen to recommend an earlier time for these discussions, there is, however, something of a balancing act implied here, as Harry also suggests an appropriate moment might be when death was "more of a possibility." This implies a need to establish that death is indeed imminent, and mandates against discussions prior to this determination.

To summarise, the DNR discussion was construed by these participants as capable of engendering distress or harm in the patient, and as contra-indicated while there was still hope, that is, while treatment was still in process and aimed at a cure. However, the implication was that once this hope was removed—that treatment could no longer prevail against the disease—this reason for delaying the discussion no longer existed. Nonetheless, the multiple aspects of hope discernable in these participants' talk contribute to the difficulty of identifying an optimal and appropriate time to initiate the DNR discussion.

Further attesting to this difficulty, some participants appeared ambivalent about timing, whether information should be obtained early or late. However, the determining factor was primarily the emotional state of the patient: If the patient would not "handle" the discussion or it "would frighten" them, then that constituted reason, at that time, to excuse them from it. However, as illustrated below in Elaine's recount of her "mother's case," this state of affairs might persist, even to death, such that discussions might never take place. Thus the romanticist outranked the modernist repertoire. What was at issue was not whether patients would pass the Sanity test, but whether they would pass the Stability test.

> Elaine. I'd say early, although you'd scare them, … but by raising it early it gives them a chance to think on, rather than sort of get down and then sort of be

> frightened by the fact that "Hey, I mightn't be getting better" or something. … Some people probably can handle it, others probably can't. I know in my mother's case, she didn't handle it at all. She just didn't want to know about it. She just never discussed it, never talked about it. (5.1.1/14)

> Harry. I think it would frighten me more towards the end, 'cos I think then that you know that the end is imminent. … But [the beginning is] such a stressful time for yourself and for a lot of people around you that, that would almost be a last straw, … [to] contemplate the end before you've even started the treatment, and I think that that wouldn't be very useful. (5.1.1/15)

Overall, it appears that in considering timing, participants consistently represented and re-presented the commonly held views that receiving the diagnosis of cancer, and intimations that death is imminent (sometimes achieved through determination that there was no hope) have an emotional impact. Although typically constituted as appropriately time-limited, while it is operative this reaction is taken to render a discussion about end-of-life issues inappropriate for patients so affected. This position reflects and reinforces the well-developed and commonly accepted binary opposition between thought and feeling, with the latter deemed capable of disrupting the former.[420] In short, participants invoked the Stability test, drawing on the romanticist repertoire to establish that some persons may choose not to participate in discussions, nor to make the decision, and should be actively sheltered from these. Decision-making entails that patients pass both the Sanity and the Stability tests; to fail is to be excluded or excused, respectively.

This is not without potential benefits for the patient. They may choose not to participate in (difficult) DNR discussions, or not to make a decision with the unspoken knowledge that this will be understood in the light of an inferred disqualification: To wit, a rational decision is precluded because the necessary conditions that enable a rational decision-making process to occur are not present. Thus, a patient's emotional state may be cited and accepted as legitimate grounds for failing to make a decision, as represented in the following excerpts (see also Elaine at 5.1.1/14). With the romanticist repertoire ready to hand, the appeal to the emotions constitutes a resource for absolution of responsibility.[417]

> Alex. Yes, I suppose generally speaking [the decision is the patient's] unless someone doesn't want to know. I suppose there are people who are afraid of knowing the truth. They would prefer not to know the actual situation, there are some people like that. (5.1.1/16)

> Ben. I suppose it depends very much on the patient, the way they react. I would feel that I could make a decision about that now, and it wouldn't be too upsetting, but for other people it might be upsetting. I guess it does depend on the individual, to some extent. (5.1.1/17)

The implication in these excerpts is that the presence of emotion (being afraid or upset), constitutes grounds for not making a decision, and thus excuses the patient from the decision-making process. Again, this gives priority to a romanticist concept of self, rather than the modernist self pre-supposed by traditional models of decision-making. Either way, however, the patient is accorded the right to make a decision not to make the decision, constituting one of the paradoxes inherent in the construct of autonomy (see 5.1.2).

In point of fact, only three patients (all female, all non-curable) had actually made and formalised their decision, with only one having this noted within their file.[1] This was despite the assertion of the majority of participants that they were capable of making these decisions, and denial of any problems with so doing—they were not, for example, those 'others' who could not because they were too emotional. Overall, in discussing this issue, as can be seen in many of the above excerpts, the majority spoke in the third-person of "the patient," sometimes, as shown below, using the hypothetical "if." Both these features suggest that they considered the issue neither personal nor pressing.

> Alex. If, let's say that there is a major operation then before me, then the doctor will inform me of the possibilities, well, I would like to make the decision then. If there is no definite clue that this can happen, well then what's the use of discussing it. (5.1.1/18)
>
> Bettie. If I knew I was going to get to a stage where no more could be done, then discuss it … . (5.1.1/19)
>
> Elaine. I don't really know, (laughing) I haven't even thought [about it], I haven't got to that sort of stage. (5.1.1/20)
>
> Frank. I was never faced with that option [of discussing DNR issues], we never had to face that, it was always a curable type and we were told we were always in the 90% category of patients that were curable for the type I had, so personally I don't think we were ever looking down the barrel of that type of thing. (5.1.1/21)

Despite asserting the desirability of the patient making the DNR decision, most participants identified themselves as not at "that stage," not at the point where a decision was appropriate or necessary—they were curable, or not close enough to death. This further works to reinforce the aforementioned links between the DNR discussion and death. In tandem with the previously discussed emotional disturbances presumed incumbent on the DNR discussion, it also functions to justify (both in theory and in practice for each patient) the (potentially indefinite) deferral of both the DNR discussion and decision.

[1] One further patient (also female and non-curable) informally filled in a sample advance care plan shown to her for comment, but this was not disseminated and thus had no bearing beyond the study.

5.1.2 The paradox of autonomy

Although patients' rights to make decisions (i.e., patient autonomy) were consistently alluded to by participants, other aspects of their speech revealed a number of paradoxical elements inherent in this. When actualised, autonomy (as conceived in dominant models of decision-making) becomes problematic, as evident in participants' discussions regarding patients' refusing to make the DNR decision, their attribution of responsibility for timing for the DNR discussion to the doctor, and their consideration of familial obligations.

5.1.2.1 Deciding not to decide

Some participants suggested that a patient could refuse to make a decision, either nominating someone to make the decision for them, or implicitly leaving it to others by default.

> Alex. If he is capable of making a decision but doesn't want to make a decision, well then the matter is again open, as possibly several [specialists'] opinions should be taken into account. (5.1.2.1/1)
>
> Bettie. I think everybody is individual. I would like to be involved with it, myself, personally, but somebody else might not. (5.1.2.1/2)
>
> Eric. I think for some people though, that they'd rather not think about it. … A lot of people are very much the ostrich, but I think I'd like to know. … I'd like to be asked, and then I would like to make my own decision. (5.1.2.1/3)

Choosing not to make a decision was thus constituted as equivalent to making a decision. Although equally justifiable through appeal to the patient's right to do as they choose (autonomy), there are several aspects of participants' speech that suggest that the preferred option was that the patient neither assign nor leave the decision to others, but actively make it themselves. First, this latter option was mentioned more often and presented first, features which, Potter[294] noted, identify it as the dominant, preferred choice (pp. 58-60). Second, participants tended to attribute to others the tendency to avoid the issue, with the potential invocation of the Stability test (citing the presence of emotion) as explanatory (e.g., see 5.1.1/17 and 5.1.2.1/2-3), but to assert their own ability and desire to make the decision. This identifies the latter option as the morally superior course of action.[451]

It must be noted, however, that a patient may pass both the Sanity and Stability tests, yet consider that they lack the expertise needed to make a decision, and rationally choose to delegate it to their doctor. Such an option is permissible within Ivan's talk below.

> Ivan. The final decision is theirs, and if that decision can't be made from them, then they should be given the option to ask someone or allot somebody to do that

> for them, 'cos that's still their ultimate decision, but it's just coming from somebody else. (5.1.2/4)

One of the paradoxes of autonomy—the right of the individual to make their own decisions—is that one can argue that an individual can decide not to decide. Although this is contested within the literature,[37] these participants seemed to find refusal to make a decision both understandable and acceptable. In presuming the right to decide not to decide they both challenge and reinforce the dominance of autonomy in patient decision-making. For some patients, refusal may be due to a perceived lack of expertise with this decision, falling within the realm of rational choice; for others, what may operate to render their refusal legitimate and understandable are the inferred emotional connotations of making difficult decisions, thus effectively precluding a rational process. Such patients, understood within a romanticist repertoire of persons, would fail the Stability test.

5.1.2.2 Doctors determine timing of DNR discussions

One of the common features of participants' talk presented above was the presumption that discussions about DNR orders, and particularly, the timing of these should be tailored to each individual patient. In this, I suggest that the role of the doctor is construed as pre-eminent, whether it was (1) through their capacity to identify particular medical parameters presented as potential markers for the DNR discussion (e.g., presence of cognitive capacity, see 5.1.1/1-3; phases of treatment, or proximity to death, see 5.1.1/11, 12, 15, 16); (2) their obligation to consider the patient's emotional state (e.g., see 5.1.1/4, 6, 14); or (3) some combination of both (e.g., stress of treatment, see 5.1.1/9, 10, 13). Whilst maintaining that patients should (preferably) make their own DNR decision, these participants tacitly assigned to their doctors the responsibility of determining an appropriate moment for discussion of these issues, with the assumption that this would be specific to the circumstances of each individual. This assignment was sometimes made more explicit.

> Ingrid. I would hope … that [DNR orders] would be raised by medicos rather than patients because I think some patients go into shock. … I know nobody can be specific about what's gonna happen in a terminally ill patient, but … an oncologist knows, has all this information at their fingertips. … You need the knowledge to reach, to form your own ideas and to know what's going on, and, let's face it, it's your body. (5.1.2.2/1)

> Keith. A doctor should be able to know, in my opinion, whether it's worthwhile going to all the trouble and the expense and everything of doing this sort of thing, for the patient. … I think [doctors] should learn to be able to discuss it with [the patient], it's something [they're] involved in, and they should be able to talk to the patient about that sort of issue. … It should be easier for the doctor than the patient really to raise the subject. … [Doctors] should be in a

> better position than the normal lay person, to be able to approach the subject. (5.1.2.2/2)

Doctors' clinical (and cognitively-based, or rational) skills were here deemed to render them appropriate persons to initiate the DNR discussion. Many participants anticipated that, during a DNR discussion, patients would access medical information possessed by doctors as medical expert, an assumption that fits neatly within the modernist repertoire and traditional models of decision-making: It presents the doctor as the rational and knowledgeable expert who correctly interprets a range of medical facts, and thus can facilitate the enactment of patient autonomy through the provision of relevant information needed for the patient to make their own decision.[84]

But, as I have repeatedly argued, participants also required that the doctor consider the patient's emotional state. The assessment of patient's emotional state is, strictly speaking, outside the specific medical skills nominated by Ingrid and Keith as justification for why doctors should initiate the discussion, yet most participants assumed that doctors would have the skills to determine the optimum time and manner in which to approach the patient. What appeared to be needed was that doctors use their intuition about, or sensitivity to patients—as specifically stated by Delia (see also 5.1.1/6).

> Delia. I think there are probably some patients, and again, it's probably intuition largely, on the part of people looking after the patient, that some people probably would tend to, as they say, to drop their bundles, if they knew that there is a finite suggestion. … Yeah, I think it's not the sort of thing you can just go in and say "Well, I want to ask you about this," bang, bang, bang. I think it's got to be done very sensitively in most cases. … I think probably again it's sussing out the patient, and using intuition and instinct very largely. (5.1.2.2/3)

Good and Good[452] have noted that these two sets of skills—what they've called "competence" and "caring"—are integral to Western medicine, with both defined as essential to the role of physician (pp. 91-4). They observed that where competence is construed as primary and as a skill that can be learnt (as might be expected given its fit within the dominant modernist repertoire), caring is presented as indispensable, but as innate within each individual doctor (which fits within the romanticist repertoire). Here, Delia locates both doctor and patient within a romanticist repertoire, highlighting emotional aspects of both—something that is marginalised through the emphasis on rationality inherent within the modernist repertoire that dominates models of decision-making. Locating doctors within a romanticist repertoire, requiring that they both display and consider "the emotional self" (see Lupton[152] for a comprehensive discussion on this construct of self), has implications regarding assignment of responsibility for the DNR

decision: Although participants overwhelmingly asserted that rights to and responsibility for a DNR decision rested with the individual concerned, they also held that responsibility for appropriately eliciting patients' views lay with the doctor. As a result, one could argue that responsibility for the DNR decision was re-assigned to the doctor.

5.1.2.3 Patients' familial obligations

Both the romanticist repertoire and the importance of emotion in decision-making were particularly discernable when participants spoke about rights and responsibilities. For example, in addition to speaking of patients' *rights* to make the DNR decision, participants sometimes spoke in terms of the desirability of patients acting to relieve others (usually "family") of the *responsibility* for a difficult decision. The language used was evaluative and emotion-centred, both in terms of the decision itself and its potential effect on individuals (patients or others). The decision was construed as a "burden" that could be put on others, as a "pressure" to be relieved.

> Elaine. My family have asked me not to put them in a position where they've got to make the decision. … You can't put too much pressure on your family. (5.1.2.3/1)

> Felicity. [If the patient's wishes are] very clear earlier on then that's a responsibility that's probably taken away from [the family], a burden that they may not have to bear. (5.1.2.3/2)

> Liam. I think [patients who make their own decision] are taking control of their life. It would be a lot worse if their relatives had to make the decision, at least it's them making the decision. It's not so hard on the family then. (5.1.2.3/3)

The implication was that the decision is emotionally difficult to make, with participants asserting that it would be "better" for the patient to make the decision, and "unfair" or "worse" to leave it to others. These others, located within the romanticist repertoire, were presented as persons who would be emotionally affected by the (in)action of the patient, and their welfare as a factor to be considered by the patient. Thus, although the decision is construed as personal, this speech also illustrates, on several levels, a social aspect to it: The decision is made by an individual located within a reciprocal network of social relations; as such, this individual is enjoined to consider the real or anticipated reactions and perceptions of others—which further works to identify the decision as moral. There is a reciprocity of effect between patient and carers, that acts to modify any conception of the isolated individual (patient), independently coming to a decision, as also argued by many feminist writers.[35, 123, 129] As I have previously observed (see 4.2.2), this offers a challenge to traditional models of decision-making, premised upon the independent autonomy ideal,

but lends support to those models of autonomy that propose a notion of social responsibility[392] or the importance of relational ties.[35, 123, 131, 132]

In addition, however, notwithstanding that patients may, through invocation of the Stability test, legitimately be excused from the DNR decision, such accounts suggests that those who are so excused (thereby leaving the decision to others) are liable to be negatively perceived. This is an inevitable consequence of equating autonomy to the active making of decisions and construing this as the ideal. Patients become subject to the twin forces of patients' rights (with the moral obligation to make their decision) and responsibilities (with the moral obligation to save others from the burden of the decision). In this instance, participants concluded that "family" (as opposed to patient) should be excused from the decision-making process, and that the individual patient must preemptively shoulder the burden. Thus it is not only preferable that patients make their decision, but there is considerable (moral) pressure upon them to do so, regardless of whether or not they want to. The discourse of autonomy, ostensibly advantaging the patient, enabling them to attain their desires, can work to effect the converse.

5.2 The Family as surrogate decision-makers

Participants' accounts that involve considering the obligations inherent in their rights and responsibilities contradict many of the assumptions within medical models that underpin the nomination of family as surrogate decision-makers. For example, construed as responsibilities, family are not necessarily a source of support, but may be a potential burden for the patient (see 5.1.2/8-11). In addition, family might not want to make decisions in lieu of the patient (see 5.1.2/8).

To further investigate notions of surrogate decision-making, participants were specifically asked "If the patient cannot or will not make the decision, then who should?" Participants usually nominated family members, but sometimes the patient's doctor was seen as providing guidance.

> Anne. The family should be guided by the surgeon's opinions ... and perhaps another doctor's opinion as well. (5.2/1)
>
> Bettie. [It should be] their spouse. Yeah, if you're close .... I've told my husband what I want so (laughs), so, yeah. (5.2/2)
>
> Harry. Someone who's close or has a particular relationship with the patient, ... in my case my brother. ... [M]y closest confidante. (5.2/3)

> Mike. I think the next-of-kin has the say, because they should know how that person would feel about that sort of thing. (5.2/4)

The surrogate nomination was typically predicated on the basis of a close (emotional, rather than familial) relationship with the patient. The emotional closeness established over time between patient and nominated surrogate were arguably as, if not more, important than the interpersonal knowledge gained through physical proximity over time. Although presuming knowledge of patients' wishes (see 5.2/1, 3) might imply a modernist repertoire whereby surrogates weigh this in their decision-making, when featuring a notion of trust and understanding (see 5.2/1-2, 5, 6) it also draws upon a romanticist repertoire. Indeed, where patients alternated between recommending the doctor and the family as surrogates, the family nomination was invariably based upon this emotional connection—which lies outside the purview of the modernist repertoire and dominant models of decision-making.

> Alex. If [the patient is] beyond making decisions then the doctors should make the decision. … Just the close family I suppose, but, but mainly wife. … The person really who can be trusted completely is my wife. (5.2/5)

> Eric. Our understanding between [me and my wife] is that each would make the decision but the doctors … must make the decision, because they know that the patient has not got long to live. … Well, if it's the wish of the patient, … their immediate family would have that decision. (5.2/6)

Separately, or in tandem, conceptions of the family as providing support (being close, being trusted), or relaying the patient's wishes (they were told, or they would know) operated to justify their nomination as surrogate decision-makers, standing in for the patient who is not rational, by virtue of failing either the Sanity or the Stability test. But are family rational? Specifically, will they adhere to some rational process in decision-making? Given the default position that persons are presumed competent unless formally assessed otherwise,[155] thus passing the Sanity test, the critical question becomes 'Will they pass the Stability test?' Frank found this problematic, saying

> If the people were not wanting to make a clear and justified decision then [the doctor] should step in with some power as a doctor to say 'I don't think that's correct' or whatever, but if everybody seems to be making a rational decision then allow the general flow of the decision to come from the family or the person themselves, rather than try and direct it, unless they're not making a very clear or good decision, yeah. (5.2/7)

My aim is not to endorse Frank's speech, but to point out, first, that it is conceivable that family might not be operating according to some rational process, and second, that rationality is being employed as the marker for suitability for decision-making: Frank invoked the Stability test—if family do not proceed rationally, then the doctor should take

over. This position functions to legitimise both the removal of the decision from the irrational, that is to say, emotional family or patient, and the co-option of the supposedly rational, less emotional doctor. Perhaps many mentioned the doctor in this context because of their understanding that the impact of emotion on patient and family should excuse them from the decision-making process. Certainly, Bramstedt[240] has suggested that evidence of strong emotions in the decision-making of surrogates is indicative of "questionable decision-making capacity," and may mandate the re-assignation of the decision elsewhere.

In discussing responsibility for the DNR decision, these participants employed two different repertoires under different circumstances to different effect.[296] They used a modernist repertoire when asserting the appropriateness of someone making a decision, yet drew upon a romanticist repertoire to account for the identification of either patient or family as ineligible to make the decision. I find it noteworthy that, in response to a direct question about surrogate decision-makers, participants employed the modernist repertoire, and tended to reflect dominant models of decision-making and assumptions embedded within them. Yet many such assumptions were belied when participants gave spontaneous accounts of their experiences with cancer to date, drawing on the romanticist repertoire in characterising family as actually or potentially emotionally disturbed by what was happening for the patient.

> Glenda. [My husband] would know what I'd think anyway. Although … a few things that I've said, I don't think he wants to take it in, but my daughter knows, because I think she's a little bit clearer thinking at the moment. (5.2/8)

> Nigel. [Just after my diagnosis] I had a bit of feeling sorry for meself and a bit of a cry, and then … I seemed to come to terms with it. … Then me wife came in, and she were very upset, … she started abusing me because she said I didn't care. But it was just that I'd sorted me head out. (5.2/9)

Family were here presented as failing the Stability test, as potentially more emotional than the patient, and as demanding some attention from the patient. At times, moreover, the person who was ostensibly nominated was not always the most clear-thinking (see 5.2/8, 10, 11). Again, the inference was that the determining factor rendering someone appropriate or inappropriate surrogates was the presence of emotion. Parenthetically, I note potential difficulties in assuming that an individual in a particular relationship to the patient (often the spouse or parent) will be either the preferred or most appropriate choice (compare 5.2/3-4, and 5.2/8).

Some participants' anecdotes about deaths of other family members further suggested that events at the end of life were characterised by the presence of emotional factors, and that these had impacted negatively upon the patient's welfare.

> Don. [When my father-in-law was in a coma] my mother-in-law, she kept saying, "No, he'll be right" and the rest of the family kept saying "No, he's going to die, and the sooner the better" because … he was in a lot of pain. … [He] did suffer. Nobody, no-one said anything about it. I would have liked my mother-in-law to make the decision. I mean her [three] daughters, … they did push her, [saying] "Look Mum, Dad's gone, it's no good saying he's coming back" so he actually laid around for another week while he suffered badly, where I kept saying you know "Isn't it better to end it?" and nobody would wanna listen to me. So, I say [it should be] up to the family but it's, I don't know, I don't know … . (5.2/10)

Don's account of his experiences as a family member draws upon a romanticist repertoire, culminating in his questioning of the appropriateness of his nomination of family as surrogate decision-makers. The person nominally responsible for making a surrogate decision (wife) was reluctant to face the patient's impending death, that is, was not making decisions via a reasoned appraisal of the situation. Here, the romanticist supplanted the modernist repertoire, as this reluctance, or denial, which has its origin in the emotional difficulties of facing death,[453] precludes rational decision-making. It also appears that the opinions of the nominated surrogate were not shared by other family members, thus increasing the level of emotional distress. The potential for disagreement may be exacerbated in dysfunctional families.[111] In Don's case, even accepting 'family' as inclusive of other family members (children), given the discord within the family unit, with all concerned dealing with emotions engendered both by the patient's situation, and the one that they found themselves in (disagreeing as to what to do), it seems likely that adherence to the rational decision-making process prescribed by dominant models of decision-making was, at this time, improbable. Decision-making, and decisions, are construed, as previously discussed, as difficult.

Similar issues are evident in Cathy's account of the death of her brother-in-law.

> [My] husband's brother was involved in an accident and was on life support systems, on two occasions [and he died the second time. After the first time] … we probably waited for him to initiate talking about his experience, and so it was never brought up. And we didn't ever talk about it, … it was just sort of, "Oh, it's so wonderful that he's well again, and let's try and forget it" sort of attitude, which in a way wasn't really responsible. … And my sister-in-law … sort of virtually went into shock. … But as a family it would, it should have been talked about. … He could have talked about it with his two adult children, and his wife, and even if she wasn't able to grasp the whole issue, the children would have been able to. … You tend to leave these things for the person concerned, or his wife, to do something about it, but they didn't act quite quickly enough, and I guess this is

> what happens when you're right in the thick of things, quite often other issues cloud it, and you try to sort of, maybe it's human nature to sort of think "if I don't think about it, it'll go away" (laughing), and sometimes it's not the best way of dealing an issue, it doesn't go away. (5.2/11)

According to Cathy, the nominal surrogate (wife) went into "shock," an emotional state that prevented her grasping the issue. Furthermore, although Cathy tacitly acknowledged the force of the modernist repertoire through assertion of the obligation to ascertain the patient's wishes (they *should* have), and conceded the opportunity (they *could* have), the family as a whole chose to avoid the issue. Although stating that this might not be "the best way" to proceed, Cathy nonetheless found it explicable, as "human nature," using this commonplace understanding to account for her family's behaviour. Such an understanding follows from a romanticist repertoire, the construction of persons as emotional, and therefore not always rational. Paradoxically, those most likely to be in the best position to know the patient's wishes are those most likely to be emotionally affected by the possibility of impending death. Indeed, Loewy[113] has suggested that families accorded the DNR decision will be "frightened" (i.e., negatively emotionally affected) by the implied responsibility for outcome. Thus, the conditions that constitute patient autonomy in decision-making are inherently contradictory in this instance. While patient autonomy may be best represented by those who are close to them, this very closeness and consequent emotional attachment may render them less likely to wish to deal with issues pertaining to the patient's death, as well as unlikely to be able to follow a rational decision-making process as it approaches. Families will fail the Stability test. Critically, this failure legitimises their non-participation in a decision-making process.

Such accounts exemplify what is often happening for families and patients at this time, illustrating Schneider's[37] contention that in situations involving decision-making at the end of life, we will encounter people "in their least rational moments, in their most emotional travails, in their most contextual complexity" (p. xvii). Family were depicted as far from the rational entity presupposed in notions of surrogacy within dominant models of decision-making, but rather, as beset by emotional factors that preclude adherence to a rational decision-making process. Their lack of unity also contradicts the assumption of homogeneity, that they will act as one. Further, this analysis challenges assumptions that family's actions will always represent the patient's best interests, that they will know, agree with, and relay the patient's wishes—and this applies even when one person within the family is nominated within advance directives.[240] It also supports research and arguments indicating that families are negatively affected by their experiences as

surrogates,[121, 438, 454, 455] and challenges the ethical criterion of no harm presumed in assigning surrogacy.

5.3 Resolution of the modernist and romanticist repertoires

The romanticist repertoire drawn upon by participants represents a version of self that is not accounted for in models of decision-making that are premised upon the modernist self, that constitute either the decider, the decision-making process, or the decision as solely determined by rational principles. Indeed, to the extent that the impact of emotion on either the patient, or the family was perceived as critical in determining whether or not they should be faced with the decision at all, the romanticist repertoire might be said to trump the modernist. A resolution of these two opposing repertoires was evident, however, especially with regard to the patient: Holding both that the patient should make the decision, yet should not be confronted with it if it was perceived as too emotionally challenging, participants resorted to what Potter and Wetherell[296] have termed both a "common rhetorical device" (p. 155), and a "particular interpretative device" (p. 171). This is a rhetorical strategy used to resolve contradictions produced by the presence of two incompatible interpretative repertoires. Here, participants invoked a discourse of individualism to assert that *it's up to the individual,* claiming that *everyone's different and should be treated accordingly.* This emerged most clearly in accounts of when discussions about DNR issues should take place.

> Delia. There's no absolutely hard and fast rule there, it's a case of being very sensitive to the individuals. ... Probably the earlier the better for a lot of people, and then again for other people, it would be "I don't want to think about it yet." ... Again, I think it's very much up to each individual. (5.3/1)

> Ivan. [When to raise the DNR issue] comes down to the person, how the person feels and what their choice is .... I suppose it depends on the individual as well as how they're coping with the treatments as how you would jump on them and say "Look, this is an option, what do you think we should do?" (5.3/2)

Although Gergen[151] has suggested that the modernist and romanticist conceptions of persons are oppositional, there is some potential for common ground within the concepts themselves, specifically with respect to decision-making, thus: The modernist repertoire would posit the responsible autonomous adult undertaking the (reproducible) measured deliberation of facts, free from the influence of others, leading to an inevitable (and reproducible) conclusion. By contrast the decision-making of persons as depicted within the romanticist repertoire would be spontaneous, intimately bound up with the lives of others, and emotional in nature, with the decision potentially forever opaque to others. However, within the modernist repertoire, as noted earlier, lie the terms for its negation:

Individuals may not decide, justifying this as their autonomous right, or their rational decision to leave it to others (for whatever reason). Ironically, this mirrors the position available within the romanticist repertoire: Individuals may not decide because beset by emotion, or may decline to follow a measured process which is easily discernible by others. Both conceptions of self draw upon the ideological position that affirms the individual as the sole arbiter of what is right.[383] Decisions are above all else, personal, individual. Thus it becomes intelligible that the same phrase *it's up to the individual* can be used to evade recognition of inconsistencies or even to justify the differences conveyed in participants' accounts of the behaviour of individuals faced with a (DNR) decision—inconsistencies that arise as they selectively draw upon these two concepts of persons.

Thus, in these accounts, the rhetorical employment of the commonplace understanding that *everyone's different and should be treated accordingly* operated to reconcile the modernist and romanticist repertoires. Critically, given the importance of the discourses of autonomy and of individualism within the modernist repertoire, it works to re-establish the dominance of this repertoire (cf. Potter and Wetherell,[296] p. 155). Tending to occur at the end of participants' deliberation over the issues (see 5.1.1/17, 5.1.2.1/3, 5.3/1, 2)) it seems likely too that *everyone's different* further functioned as a conversational device to elide differences and create similarities, and thereby end discussion with minimal potential for dissent, proving a socially acceptable conclusion to debate on dilemmatic issues.[379] I note, however, that in asserting the need for doctors to respond uniquely to each patient, participants drew on the romanticist repertoire, talking of how individuals felt, of the need to be sensitive, and not upset the patient. This further underscores the importance of this repertoire in patients' decision-making.

5.4 Conclusion

In this chapter I have demonstrated that participants' initial responses to direct questions about decision-making drew upon a modernist repertoire, reflecting what might be called an 'official version,' imbued with notions of autonomy and rationality: Patients make rational decisions, and family act as surrogate decision-makers as needed. But when addressing issues of timing of discussion needed in order to obtain information upon which to base these rational decisions, or when giving accounts of actual events (off-the-record as it were), a different picture emerged. Participants augmented the modernist repertoire with the romanticist, construing patient and family as interconnected, interdependent, and emotional beings, all features that shaped the decision-making process—thereby lending support to alternative constructions of autonomy, including feminist and post-structuralist,

that promote precisely these qualities. Furthermore, the use of the romanticist repertoire in patients' accounts of decision-making was associated with excusing either patients or families from the decision-making itself—either before or after the fact.

Participants agreed that patients had to pass the Sanity test, and were excluded from decision-making if they did not, but also held that patients had to pass the Stability test, being excused if they did not. Because DNR discussions that were a precursor to the decision were construed as inherently distressing, the invocation of the Stability test operated to justify delaying holding such discussion, representing a force to make decisions later. Some patients similarly justified delay until 'hope' (deemed influential to patients' emotional state) was assessed as absent. However, factors supporting delaying DNR discussions were countered by the need to obtain decisions while patients (being mentally competent) were able to pass the Sanity test, this representing a push to hold discussions and make decisions earlier. Nonetheless, the ever-present negative emotional connotations of confronting the DNR decision operated to justify patients' continual deferral of (and effective refusal to make) the decision, with the consequence that it would pass to surrogate decision-makers. Surrogate decisions are problematic, however, in that surrogates and patients are presumed to meet the same criteria for decision-making. Yet the prediction of future values and preferences regarding a decision without experience of the intervening conditions that necessitate that decision is questionable even for patients.[55, 168, 270] Without that experiential knowledge, surrogate decision-making cannot meet the criteria for rational decision-making that pertain to the reasoned deliberation of relevant information. Moreover, decision-making may place a burden, potentially ongoing, upon the nominated surrogate—one that family may be reluctant or fearful to undertake.[113]

Several features of participants' speech suggest that at times delegation to the doctor may be appropriate, including their construal of the DNR decision as difficult, their concern regarding its effect on their family, and their accounts of their own experiences of the death of a close relative. Participants' recourse to the rhetorical device *it's up to the individual, everyone's different and should be treated accordingly* also works to validate the clinical practice of modifying the provision of information according to the emotional state of the patients, as patients appear to find this both understandable and acceptable.

I conclude that the presence and importance of the romanticist repertoire is not well accounted for in dominant medical models of decision-making, and argue that these models are deficient, assuming a limited, abstracted, and idealised notion of patients and families. Participants hold both that patients should make decisions, but do not have to.

Paradoxically, although the modernist self was presented as preferred, the romanticist often prevailed—but not without a cost, given the associated negative moral judgement. Consequently, patients or families may be left feeling inadequate, as moral failures if they do not make the mark according to a model that takes rationality as the gold-mark for decision-making, and obliges them to live up to it. Perhaps rationality need not be the sole criteria for assessing the worth of a decision. Pragmatically, perhaps an emotion-based decision might be good enough.

In this chapter I also briefly commented upon how 'hope' featured in participants' speech about end-of-life decision-making. In the next I further explore some of the implications of their speech regarding hope. I also examine how hope is constructed within the medical literature, and consider some implications for medical practice of discrepancies between medical and these participants' constructions of hope.

Chapter 6. Study 1. The discursive properties of hope in cancer patients' talk

One of the advantages of employing qualitative (in this case, discursive) analysis is that it confers upon the researcher the opportunity to pursue issues within the data that were not identified as important at the beginning of the research endeavour. Although not a specific focus of the interviews, during my multiple readings of the interview transcripts, *hope,* as part of the end-of-life decision-making process, appeared to be important yet was characterised by some variability of use, as previously (but briefly) commented upon in Chapter 5. In this chapter, I examine hope as it is constructed within medical discourse, turning then to analyse its discursive properties within participants' speech. I shall demonstrate how hope was variously construed by participants as objective or subjective, as a burden or a resource, how it represented an evaluation of an empirical state of affairs or the wish for a desired outcome, and operated as a warrant for action or an excuse for inaction. Hope was additionally attributed to both patient and caregiver, an individual or a situation, was present- or future-oriented, and deemed to be both vulnerable and enduring. I conclude that hope can incorporate, but is not limited to, those versions dominant within the medical literature.

6.1 The medical literature on hope

Medical research into 'hope' has been set predominantly within an empirico-realist paradigm. This presupposes that reality exists independently of the observer, to be discovered by an objective researcher, unfettered by any culturally or historically situated subjectivity. Such an approach takes it as given that there is such a thing as 'hope,' and attempts to define and operationalise it. In 1995 Farran, Herth, and Popovich[456] observed that there existed at least eleven different scales designed to measure 'hope,' and three purporting to measure 'hopelessness.' Since then, Snyder and colleagues have published three more hope scales,[457-459] and an Australian scale claiming to measure personal hopefulness has been developed by Nunn and colleagues.[460]

The development of instruments to assess hope has been viewed as a priority in medical research into hope, and the ability to identify a patient's hope is considered a precursor to effective intervention in assisting patients to maintain or modify hope.[456, 461, 462] According to Dufault and Martocchio,[463] intervention is often seen as the domain of nursing staff, who are assigned the role of "maintaining, sustaining, … restoring" (p. 379), "assessing … and therapeutically influencing hope" (p. 391), and presumably adjusting patients' hope to

what is considered appropriate.[464-466] The physician is also accredited with the ability and sometimes the responsibility to influence, harness, or adjust patients' hope.[177, 285, 467-469]

However, precisely what 'hope' is remains problematic, with many definitions, models, and conceptual frameworks proffered that are not always interchangeable. Elsewhere I have noted that the flurry of hope-based research during the last part of the twentieth century (involving different research paradigms and tools) has rendered hope a multi-faceted construct, leading to increased opportunity for different aspects of hope to come into conflict.[470] For example, hope has been referred to as a multidimensional dynamic life force,[463] a unique personal experience,[471] an inner power,[472] a process of anticipation,[473] the cognitive energy and pathways for goals,[474] an emotional attitude,[475] the most robust resource one can possess,[476] and a means of maintaining a fighting spirit.[445] Somewhat justifiably Kylma and Vehvilainen-Julkunen[477] concluded that there was a lack of precision about hope, Lohne[478] observed a lack of ontological precision within the medical (with focus on nursing) writings on hope, and Stephenson[473] noted that hope as presented within academic literature is not a singular entity, being at once a part of human development, a process, a theory, and a source of meaning in life.

Many researchers have acknowledged the complexity of meanings ascribed to the concept of hope, and attempted various manoeuvres to dissect and identify its various components. Consensus is rare. Table 8 shows a selected review of recent dissections of hope, said to be composed of between two and seven elements, which are identified as subscales, factors, attributes, dimensions, components, and categories, among others. There appears to be no single feature all authors identify as intrinsic. Although most mention some kind of inner resource of the individual, as well as an interpersonal or relational aspect, some include a spiritual aspect, some a temporal, and so on. The suggested components seem to be variously describing a process, a state, or a source. The diversity of definitions and conceptual frameworks has been identified as causing confusion in terminology, hindering a consistent approach to hope, and limiting actual clinical application across populations.[456, 479]

The origin of hope is similarly contested. Some identify the source as primarily external to the individual—for example, Klenow[480] named religion, medical science, fallibilism, self-discipline and renewal, and deception by others. Salander et al.,[481] however, located it within the self, citing the body, helpful relationships, cognitive schemata, and the handling of information as sources of hope. Erikson[482] identified hope as formed within the infant to endure throughout life, and this, although compatible with the notion of hope as an inner

resource, might render attempts to alter levels of hope somewhat futile. More recently, some have noted that hope is both a state and a trait, and claimed that the former is amenable to influence.[457, 459, 463]

Table 8. *Selected review of published papers delineating elements of hope*

Author/s	Number & name of elements	Specific elements
Snyder[474]	2 Components	Agency (goal directed determination) Pathways (planning of ways to meet goals)
Godfrey[483]	2/3 Kinds (3 Aspects)	Ultimate (focused) Fundamental (unfocused) Absolute (an extreme form of fundamental) (with 3 aspects: Cognitional, Conative, and Affective)
Herth[484] Herth[485]	3 Subscales 3 Factors	Temporality and future Positive readiness and expectancy Interconnectedness
Jakobsson, Segesten, Nordholm, & Oresland[486]	3 Factors	Satisfaction with self, others, and life Avoidance of hope threats Ability and capacity to influence the outcome in life
Nekolaichuk, Jevne, & Maguire[479]	3 Factors (or Dimensions)	Personal spirit (Personal dimension) Risk (Situational dimension) Authentic caring (Interpersonal dimension)
Stephenson[473]	4 Attributes	A process involving thoughts, feelings, behaviours and relationships The element of anticipation A positive future orientation An object which is meaningful to the individual
Farran, Herth, & Popovich[456]	4 Attributes	Experiential A relational process A rational process Spiritual or transcendent
Cutcliffe[487]	4 Themes	Hope relative to help Hope as coping resources Hope interwoven with caring The presence of hope as synonymous with a personal future

Table 8 cont'd. *Selected review of published papers delineating elements of hope*

Author/s	Number & name of elements	Specific elements
Benzein & Saveman[488]	5 Subthemes	Inner strength and energy Significant events Support from relatives and/or a familiar environment Confidence in treatment Nursing actions and treatment
Owen[471]	6 Subthemes	Goal setting Positive personal attributes Future redefinition Meaning in life Peace Energy
Dufault & Martocchio[463]	6 Dimensions within 2 Spheres	Affective Cognitive Behavioural Affiliative Temporal Contextual (within 2 spheres: Generalised and Particular)
Nowotny[489]	6 Subscales	Confidence Relating to others Spiritual beliefs Active involvement Belief that the future is possible Hope from within the individual
Herth[472]	7 Categories	Interconnectedness Attainable aims A spiritual base Personal attributes Light-heartedness Uplifting memories Affirmation
Morse & Doberneck[490]	7 Components	Realistic initial assessment of the predicament or threat Envisioning of alternatives and the setting of goals Bracing for negative outcomes Realistic assessment of personal resources and of external conditions and resources Solicitation of mutually supportive relationships Continuous evaluation for signs that reinforce the selected goals A determination to endure

Despite the lack of unanimity among medical researchers regarding hope, the number of existing tools to assess it suggests certain features of the medical construction of hope, specifically, the hope of interest to scale devisers and users: First, hope is perceived as a valuable entity that can be measured and objectively assessed. Second, a person can possess hope to varying degrees. Third, hope can be modified, even created or destroyed. Finally, it is legitimately within the purview of the healthcare profession to stipulate appropriate amounts of hope for an individual, determine a patient's hope, and then take action to reduce any discrepancies between these two amounts.

It has been suggested that hope remains elusive in part because the word itself functions as a noun, a verb, and an adjective (hopeful),[456, 473] to which I would add, as an adverb (hopefully). It seems curious therefore that, in purporting to measure hope, scale devisers and users reify it, focusing on its 'noun-ness' and ignoring the verb aspect. Other writers have examined how hope is employed rhetorically to justify certain actions or beliefs within the medical profession,[177, 285, 425, 491] how it is informed by cultural myths,[492] how it comprises part of the dominant discourse on cancer,[229, 425] is emerging as dominant within genetics, and is integral to the scientific endeavour in general.[493, 494] These writers access and deconstruct another version of hope as constituted by the medical profession—that is, the possibility, probability, or availability of treatment resulting in cure or remission of disease. Whilst it is the prerogative of the medical profession to determine this hope, attempts to define and measure hope are confined to the 'hope' defined in the previous paragraph.

6.2 Finding hope within the speech of patients with cancer

I now present an analysis of hope as it featured in this study. Other research into linguistic features of hope has not examined hope, as it were, 'in action,' as part of spontaneous speech. For example, Godfrey's[483] discriminating treatise considered the philosophical and linguistic implications of hope, whereas Averill et al.[495] analysed hope through its metaphors, or their predetermined categories. In applying discursive analytic techniques, I specifically considered whether medical constructions of hope were represented by patients, what other constructions were manifest, the clinical implications of discrepancies between different versions, and the context and implications of noun or verb usage.

In order to identify all instances of the word hope, I used a feature of the N6 software, namely, I performed a string-pattern-search for hop[e | ed | es | eless | eful | efully | ing]. This collected all instances of the word *hope* (and derivatives thereof), with surrounding

context. Each of these items of speech was initially coded into instances of noun or verb use, with further analysis focusing on the discursive features of hope (see Figure 7). At this latter level, I examined the consistency or diversity of use of hope within and between individual speakers, the functions and consequences of hope for these patients, how its employment and function varied with the aims of the speaker, and ultimately, how hope was constructed and shaped discursively.[296]

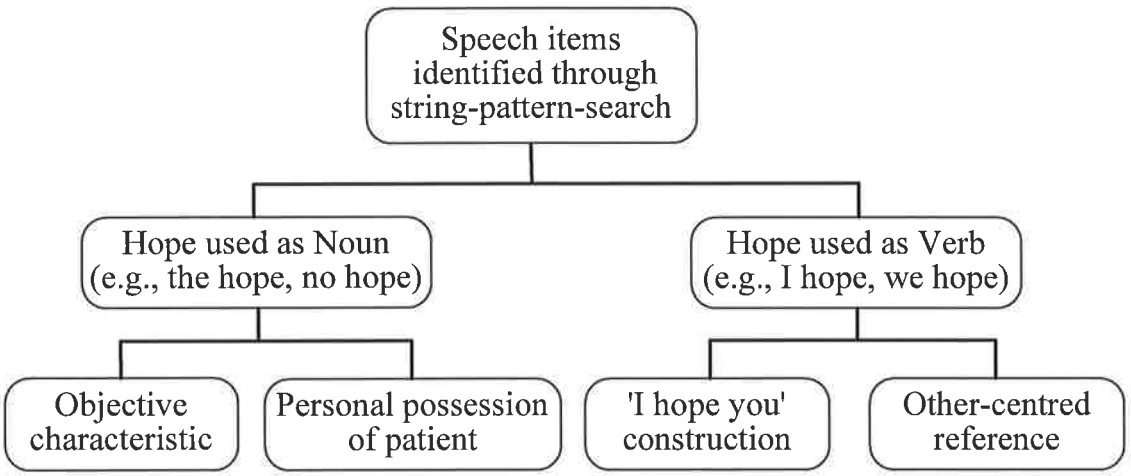


Figure 7. *Detail of hierarchical tree structure showing how hope was coded in N6**

*The third level had many more categories

To summarise statistically, in the absence of specific prompting, when talking about DNR decision-making, 12 patients used the word hope, or a derivative thereof, 64 times collectively.[m] It was employed as a noun/adjective (*hope/s, hopeless, hopeful*) 46 times, and as verb/adverb (*hope/d, hoping, hopefully*) 18 times. Although hope as a noun and hope as a verb are somewhat interchangeable in that "I have a hope that …" and "I am hoping that …" are functionally equivalent, in practice participants usually employed them differently with associated differences in implications for the patient.

6.2.1 Hope-as-a-noun

The immediate consequence of employing hope-as-a-noun (HN) is the inherent depiction of hope as a 'thing,' as an object, with attendant properties. This was the most common rendition of hope within these interviews.

[m] One patient used the word 'hopefully' twice in a row.

6.2.1.1 Hope exists independently

In representing hope as an entity with many properties of an object, some participants suggested that hope existed independently—that there is, or there is not *hope*—and that determining this was up to the doctor.

> Alex. If there is hope … is an open question which could be answered better by medical professions than the patient.…[As] a patient, I would like to know that the doctors would clearly state to me that there is no hope … . (6.2.1.1/1)

> Anne. Well, [discuss the DNR decision] at the end of your life when you are past all medical help, and there's not much that can be done for you except for quality of life. … [The patient] would want to know how bad they are, and [that] there's no hope, if there's no hope, not to be resuscitated. … [When] you know there's no hope, the doctor should talk to them about it. (6.2.1.1/2)

"No hope" emerged as a recurring phrase, but in using this, participants appeared to take for granted precisely what "no hope" meant. As do medical writers on hope, they seemed to assume that hope (at least as noun) just is. However, as Godfrey[483] observed, hope must have an object—there has to be hope for, or of, something—although this object may not be a "thing," but rather a "state of affairs" (p. 11). Here, the object of hope is implied by Anne's statement regarding the limits of medical help. For participants, hope was usually directed towards the existence of treatment/s that would ensure that they would not die (constituting cure) or, at the very least, ensure long-term reasonable health (constituting remission). Anne and Alex expected doctors to report on this, to relay an empirical 'fact,' expressed in terms of the presence or absence of an 'objective' hope. This tendency to couple hope with a cure, even to equate the two, reflects prevalent medical attitudes.[434] Within the illness/disease paradigm, hope is often linked, even limited to, curative treatment,[446, 462] and based upon clinical advances,[496] a practice which can isolate the patient who has reached the limits of medical help.[492] Nuland[497] suggested that patients and physicians need to refocus the aim of hope to outcomes other than cure or remission, but acknowledged that this is difficult in a high-tech biomedical era which offers a possibility of attaining a cure. The effect of this hope is to maintain medical authority, and patient reliance on and expectation of medical intervention towards the end of their life.[425, 446, 468]

This construction of HN was also invoked as both a warrant for action, and an excuse for inaction, in that its presence or absence determined future outcomes and current choices (including, as noted in 5.1.1, when or whether to have the DNR discussion). As such, the function of this hope for participants was similar to that observed within oncology,[425] namely, as a rhetorical justification for various actions or beliefs. Participants represented

"hope" (or "no hope") in terms of absolutes, with a sense of an inexorable predestined chain of events that merely unfold with the progression of the illness or the passing of time (see also Anne at 5.1.1/14):

> Elaine. If there was no hope of a productive life, just please do not resuscitate, and do not try and prolong a life. (6.2.1.1/3)
>
> Ingrid. "Do not resuscitate" means …do not prolong my life …when it reaches the stage of no hope. (6.2.1.1/4)
>
> Mike. [If] I ever get to the stage where there is no hope, I would like somebody to put me to sleep …[If] it comes down to …no hope, finish it. (6.2.1.1/5)

These patients reified hope: The abstract concept of hope was perceived of and dealt with as if it were a concrete entity, and this practice had associated consequences. The absence of hope was equated with the imminent end of life (as noted in 5.1.1), and this was understood to legitimise a range of medical options, often centred on abstaining from treatment. I suggest that the reification of HN can act to obscure the facts that (1) hope, in this instance, represents an evaluation by medical staff of how successfully medical science can delay a death that is determined to be inappropriate, and (2) any evaluation is a probability, based upon statistical aggregates and therefore not inevitably predictive for a given individual. Reification of hope functions to obscure the subjective component of the evaluation made, and can operate to distance medical staff from the evaluation. Thus hope may be readily invoked to provide justification for particular actions or outcomes, as these actions are rendered an invariant and obligatory response to an objectively verifiable reality, which can in turn act to reduce responsibility for any actions that follow (see Potter,[294] pp. 115-6, 150-5 on the function and status of 'reality' in empiricism).

6.2.1.2 Hope can vary in degree and resilience

Although when speaking about DNR decision-making, participants often presented HN as an all-or-nothing entity determined by the doctor, hope sometimes appeared to fluctuate in amount. In such cases, hope was perceived as a possession of the individual patient, and as subjectively held, rather than objectively present. Although not determined by the doctor, this subjective hope could be increased or diminished through the doctor's actions or, more specifically, by patients' perceptions of these. This subjective hope also had varying degrees of resilience. It was frequently construed as vulnerable and in need of protection, thus requiring some discretion on the part of the doctor when dealing with the patient (see also 5.1.1/15).

> Delia. Some people … would literally go downhill with the mere suggestion of [DNR orders]. It would be a case of really being very careful in those cases that you don't take away a person's last thread of hope … . If they're told "Look there is nothing more we can do, it's just a waiting game now," some people really, I know, go downhill very quickly. (6.2.1.2/1)
>
> Gavin. For some people [a DNR discussion] would perhaps … really bring it home to them that perhaps they don't have any hope, and they go down to it [death] quicker … . (6.2.1.2/2)

This version of hope can represent the focus of medical concern regarding the impact of diagnostic and prognostic disclosure, but is also accessible in order to justify practices of information control regarding these,[285, 449, 450] re-establishing the physician as responsible for patients' hope.[446] Some participants supported this understanding, offering the possible loss of the patient's hope as justification for avoiding or delaying a DNR discussion, concluding that the patient would be adversely affected if they knew there was "no hope" or that "there is nothing more [medical science] can do." Although this argument suggests that hope is vulnerable, it represents two different medical constructions of hope, playing one form against another: *objective* hope determined by medical science against *subjective* (vulnerable) hope held by the individual patient.

The logical inverse of an understanding that "no hope" (objective) means that there is nothing more that doctors can provide, that death is imminent and inevitable, and that the patient will lose hope (subjective) in these circumstances, is that the mere fact of doctors doing something, the mere provision of treatment, can imply the presence of hope (objective) and consequent delay of death. Some medical writers have noted that, for patients and their families, treatment implies cure, sometimes linking this with the hope of either.[179, 438] A treatment/cure/hope link certainly seems to be inferred by Harry and by Keith and his companion who commented that a visit to their doctor resulted in an increase of their (subjective) hope, arguably because they saw treatment as demonstrating that there was (objective) hope:

> Harry. I think the thing that I appreciated most with Dr Smith … [was that] he explained things to you in a positive way. You always felt walking out of … his room that there's a next challenge, that you can go ahead and there's really some hope at the end. (6.2.1.2/3)
>
> Keith. Up to the stage where [doctors] know that any further treatment is no longer doing any good, they're all hopeful that they're going to control it … .
> Companion. We always think of the worst, and then when … we see Dr Jones, he puts our hopes up again you know, because he's seen so many patients and makes you feel better.
> Keith. Each time I come in for an interview, or an examination, he says "I'll see

> you in a month's time" and I think "Oh well, if he's going to see me in a month's time that's a month I've got to make sure I'm here," do you see? If he came in one day and says "There's nothing more we can do, don't bother coming back," that's the time to worry. ... [If] we're going to get in control, which is what he's hoping to do, this [treatment] is what's going to do it. (6.2.1.2/4)

Importantly, for both Keith and Harry, the origin of hope appeared to lie (in part) in something more than just treatment available—but in the doctor's positive manner, even his expertise in the field. Thus patients can derive hope from non-verbal aspects of the consultation, and possibly when it was not intended: Hope is engendered in the interaction, as doctors inadvertently communicate hope to the patient. This supports the observation that patients can gain hope from any aspect of any interaction with their healthcare workers,[487] legitimising articles directed at advising healthcare workers regarding their (caring, supportive) attitude to patients. However, it indicates that patients' hope cannot be entirely amenable to professional control—a point implicit in research reporting that behaviours exhibited by oncologists were found to be hope-giving by some patients, but experienced as the opposite by others.[273]

Keith's use of the words *hopeful* and *hoping* reveals another aspect of how hope is construed by patients. Although patients can possess hope, it can also be attributed to their caregivers. This hope may not necessarily be identical with the objective evaluation of the probability of successful treatment, as medical staff are not immune to the subjective desiring of a favourable outcome. Some have suggested that without this hope doctors and other medical staff would find it difficult to continue to practice.[175, 425] However, the hope of medical practitioners may also represent the *expectation* that some particular event will eventuate. Thus, medical staff might have the hope (subjective desire) that treatment will be successful, and the hope (subjective expectation) that it will be, but believe that there is little hope (objective evaluation) for their patient's long-term survival.

Because subjective hope is the possession of the individual, it may be maintained independent of objective hope. Thus, although hope was identified as vulnerable, it could also be enduring. Some participants linked the presence of hope with the occurrence of miracles.

> Ben. In people's minds, there'll always be a glimmer of hope, and some have pulled through it all. ... I guess there's always some hope. [It's] difficult too, because the patient will always be hoping and a miracle might occur. (6.2.1.2/5)

> Ingrid. ... so many people say "Where there's life, there's hope," "Miracles do happen" and all that .... (6.2.1.2/6)

If we take a patient's knowledge of miracles to equate to knowledge of instances wherein individuals have lived far beyond medical predictions, it follows that hope may be sustained despite the most pessimistic of medical opinion. Certainly, media interest ensures continued access to such anecdotal 'evidence' of the power of hope. Thus, aspects of hope denoting the miraculous lie beyond the domain of the rational, contradicting claims that hope should be rational and based on the possible.[483, 498, 499] One further implication behind Ingrid's (above) quote is that hope is rendered invincible up to the point of death. This is consistent with research suggesting that hope (even of cure) remains present in patients regardless of proximity to death.[499, 500] Hope can prove surprisingly resilient, with doctors unable to remove patients' hope, even if that hope does not concur with medical opinion. It must be noted, however, that not all health professionals hold that hope based upon the knowledge of the miracle cure is necessarily to be decried.[277]

Hope has previously been identified as a coping resource[471, 476, 487] and was similarly construed by these participants:

> Gavin. … while there's still hope, some people will cling on. (6.2.1.2/7)

> Harry. [Maybe raise DNR issues when] it's obviously becoming more of a possibility that [death] could be an outcome, but before all hope's taken away, so at least the patient can still realise the situation but feel like they can still go on, and there is something left for them to hang on to. (6.2.1.2/8)

Far from a vulnerable burden, hope was understood to enable patients to cope with present and anticipated difficulties associated with the experience of having cancer. This appeared to apply regardless of the real or objective status of hope. The enabling aspect of hope may also be perceived in cases wherein individuals profess a belief in a life hereafter. For example, Debbie said,

> As a Christian, [dying] wouldn't hold any terror, it would be just moving to a better life. … For me, the Christian hope is the all-important thing. (6.2.1.2/9)

This "Christian hope," though located externally to the individual, is presented as contributing positively to their current and anticipated experiences and as enduring throughout all circumstance. Furthermore, its ontological status appears to be a moot point given the benefits associated with its presence. In this guise, hope, equated with faith in a higher power, is further constituted as beyond the jurisdiction of medical control.[177] Hope as a resource which endures, whether grounded in a specific religious faith or not, may be similar in concept and function to the "generalised hope" postulated by Dufault and Martocchio[463] and the "fundamental hope" proposed by Godfrey.[483]

6.2.1.3 "Unrealistic" (or "false") hope

Because hope can vary both between and within individuals, the potential exists for incongruence and conflict between patients and others (including healthcare workers) with regard to orientation to hope, a point which has been made elsewhere.[437, 468, 470, 480] This affects medical perception and treatment of individual patients. For example, although hope is usually perceived as a necessary positive quality for a patient to possess, their hope that they will get better that is in defiance of the majority of medical opinion, is labelled *false* or *unrealistic* hope,[n] and decried by many medical writers who suggest it should be dismantled and replaced with *realistic* hope.[462, 484, 501] However, there are a number of factors suggesting that this process is unnecessary, even counterproductive.

First, the distinction between "realistic" and "unrealistic" hope rests on an assumption of shared and objective reality,[466] which is itself problematic.[294] Second, hope can only be proven to be false or unrealistic only after the fact,[437] in this case, when the patient has died. Should they survive, their hope is unlikely to be so labelled. This calls into question the merits of insisting that patients acquiesce with medical opinion on whether or not their hope is realistic. Third, Hall[465] noted that the hope to continue living is common to all humans even though all will die and asked why someone with a terminal illness should be expected to be different. She further observed that patients usually die as they have lived, and if they have tended to focus on the positive, even avoiding the negative, the dying process is no time to try to change this. Finally, unrealistic hope is not the sole prerogative of the dying, has not been proven to be detrimental to patient well-being, may have some beneficial aspects, and often alters when the individual has the resources to cope with the situation.[466, 502, 503]

The motivation behind efforts to alter a patient's hope may be the societal pre-eminence placed upon autonomy.[285, 431, 504] Patients and medical staff alike hold that individuals should possess all information pertaining to their condition in order to make an autonomous and rational decision. Yet, patients and doctors may differ in their perceptions of what is considered rational.[465] Should a patient's behaviour following the provision of "bad news" not accord with medical expectations, medical staff may conclude that the patient has failed to understand the information provided, has unrealistic hopes regarding the disease, and needs to have the information repeated. I do not suggest that doctors abdicate their responsibility to inform patients of how or whether medical science can

[n] Klenow,[480] however, defined "false" hope as generated through deception by (medical) others. He acknowledged that it may have beneficial aspects, but also that, by his definition, "false" hope is based upon the patient's relative lack of power.

benefit them, particularly because these participants considered this mandatory.[339] However, it seems probable that the identification of 'unrealistic' hope in a patient may represent a mismatch of types of hope, rather than the patient's failure to act rationally or comprehend given information: For example, the patient's hope may consist of their (not unreasonable) desire to survive, but hope as employed by medical staff might express their evaluation of the likelihood of that occurring. It may, therefore, be useful for all healthcare professionals to consider precisely the justification for acting to remove a hope they consider to be false, particularly since there exists some debate regarding the ethical implications of such a course of action.[502, 505]

6.2.2 Hope-as-a-verb

One consequence of using hope as a verb is that a subject is introduced—*someone* hopes that something will occur. Hope-as-a-verb (HV) is inherently subjective; one cannot objectively hope. Hope is thus immediately personalised, and the object of hope is determined by the individual (patient) requiring no legitimisation by medical staff. This contrasts with what can occur when HN is employed, where, as noted earlier, hope is more easily perceived as objective, divorced from human volition, and merely assessed by the doctor who then informs the patient of its presence or absence. Where HV is employed, it is not for medical science to determine if there is or there is not hope.

6.2.2.1 Hope is the active desiring of a possible positive future outcome

Where HN was often associated with an inexorably predestined outcome beyond the control of the patient, HV appeared to lend itself to the expression of a possible positive outcome, with the patient engaged in their own circumstances, both medical and social. This may be in part because to hope is to undertake an active process of doing something, rather than being a helpless victim of circumstance. Thus, even when anticipating their death, Delia and Felicity were focused on something associated with their lives, with the process of living:

> Delia. What I do hope most sincerely is that the path leading up to [my death] is one of dignity. … I hope it doesn't get to [being a "write-off" and considering euthanasia] but I believe in it. … [I] just think "Well really you're a tiny little speck and you're here for a while, and make the most of it and hope that when the time comes you can go out with dignity, and maybe leave something behind."(6.2.2.1/1)

> Felicity. Now [I've prepared a DNR document] I don't have to worry about that, I can just go ahead with my life. Hopefully I won't have to call on it for a long time but at least it's done, it's there and it's one less thing to have to worry about. (6.2.2.1/2)

HV introduces both chance and positivity. Thus, it appeared that, in contrast to the case with HN, participants were unlikely to define their situation as overwhelmingly negative, as one requiring a definitive (often centred on ending their life) response. HV facilitates the envisaging of a possible future outcome. Although this may involve a cognitive, assessing component, it may reference the social, the emotional, and the simply unknown.

> Keith. So I'm [OK], and that's after 8 weeks [of chemotherapy]. I think I've learnt to live with it. I just hope I can live with it for a lot longer. And not deteriorate too rapidly. (6.2.2.1/3)

> Mike. After having this operation and recovering so well, the best I hoped for was a few more years of a reasonable life. (6.2.2.1/4)

> Gavin. Hopefully [my family would] respect [my wishes] or if they were able to, carry them out … . (6.2.2.1/5)

Because this hope is not limited to that which is cognitively driven, as per Snyder's[474, 499] theory of hope, I suggest that hope in speech is more akin to Morse and Doberneck's[490] conceptualisation of hope, emphasising both the "doing" of hope, and possible benefits to the individual. The active, positive voices of these participants contrast markedly with the absolute solutions demonstrated with the noun version ("if there's no hope, finish it").

HV also encompassed a desire for the future that might not be the patient's own:

> Gavin. [Some] people will cling on 'til the bitter end, and hopefully they can make an informed decision. (6.2.2.1/6)

> Ingrid. I would hope that [DNR orders] would be raised by medicos rather than patients because I think some patients go into shock… (6.2.2.1/7)

As noted by many researchers,[463, 471, 477] HV implies an active occupation in the present time, but the focus might be on another time, or another life. Given that their own current situations might be perceived as somewhat negative, this use of the word *hope* might encourage a moment of positivity for the patient, ameliorating the arduous vicissitudes of cancer and associated treatment.

6.3 The consequences of (multiple versions of) hope

Because *hope* encapsulates a number of different meanings, participants could switch between different versions of *hope*, depending upon what point they were endeavouring to make. The tendency to exhibit variation about a particular topic, even endorsing contradictory views, is common in unstructured speech,[296, 314] but interactions between particular versions of hope often carried with it specific consequences for the projected

well-being of the patient. Although I have earlier noted some of these in 6.2.1.2, the following discussion further articulates how culturally specific notions of hope and the relationship between mind and body informed these patients' experience of cancer and its treatment.

6.3.1 Hope and the progression of cancer: the discourse of will

These participants suggested that if doctors (perhaps through raising a discussion on DNR issues) implied that there was no hope (noun, objective) for the patient, the patient would lose hope (noun, subjective), and then cease to hope (verb, subjective) for a positive outcome. Therefore, they would "drop their bundle" and "go downhill" or "go down [to death] quicker." The absence of hope (noun, objective) was understood to impact negatively upon the physical well-being of the patient such that they would move more quickly towards death, which itself would contribute to a poor prognosis. Hope, patient health, and prognosis are locked within a reciprocal relationship (see Figure 8). The implication is that, conversely, the presence of hope (noun, objective) would help the patient to maintain hope (noun, subjective) and continue to hope (verb, subjective) for a positive outcome. This would enable them not only to face the present and future with some degree of equanimity, but would actually positively alter the physical progression of the disease within their body, resulting in an improved prognosis (see Figure 9).

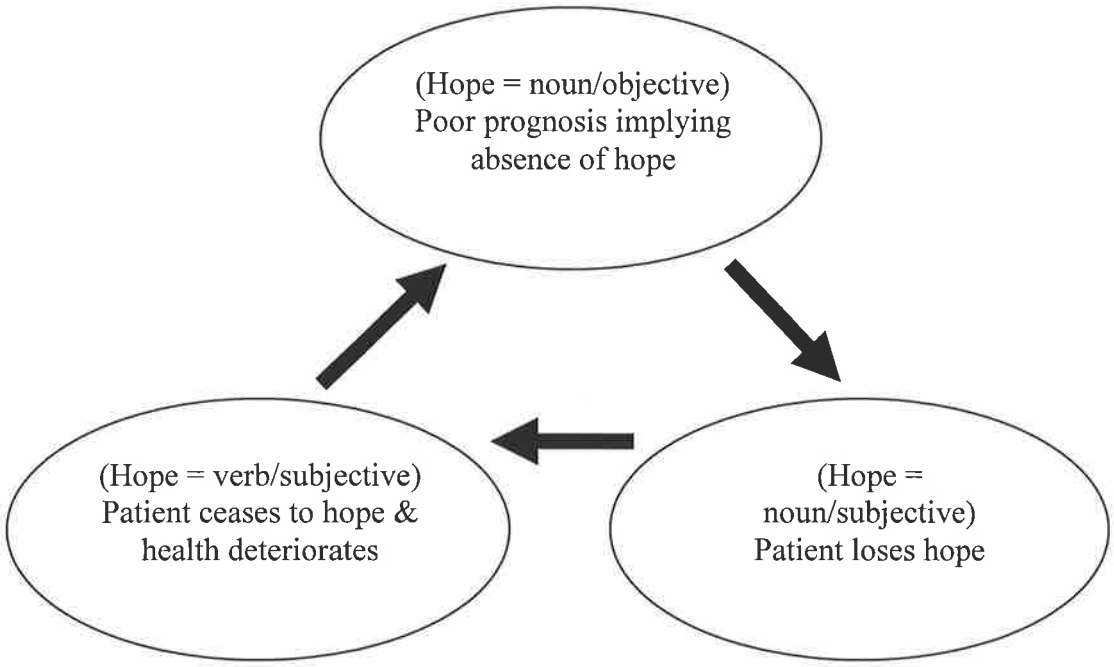


Figure 8. *Reciprocal relationship between three specific versions of hope and patient health: Poor prognosis*

The perceived reciprocal relationship between the three versions of hope shown in Figures 8 and 9 is based upon an assumption that the mind can influence the body. In making this assumption, participants drew upon what Good and colleagues[425] identified as a discourse of "will." This discourse incorporates Western concepts of the individual as responsible for their own life, and the relationship between psyche and soma, suggesting that "if one has enough hope, one may *will* a change in the course of the disease in the *body*" (p. 61, italics theirs). As Good and colleagues do not define the precise nature of this hope, it is difficult to discern its nature. Nonetheless, although the meaning of the word *hope* is still contested within medical circles, it remains a fundamental principle in medical practice that one of the primary duties of a doctor is to preserve hope, a view which was shared by these participants. Doctors, however, may have other reasons for perceiving hope as a valued possession for the patient, including the observation that a patient with hope is less demanding and more compliant clinically than one without hope.[174, 175, 425, 480, 506, 507]

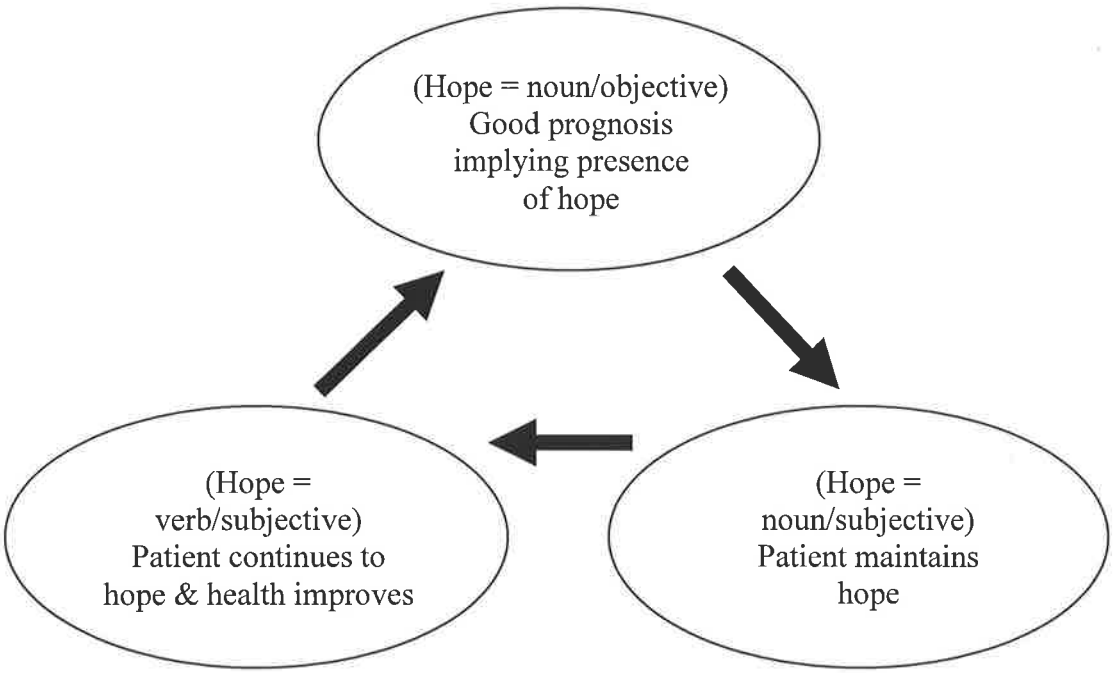


Figure 9. *Reciprocal relationship between three specific versions of hope and patient health: Good prognosis*

Nevertheless, this understanding of the "real" effect of hope in influencing the course of a disease may account in part for the medical emphasis on detecting and increasing a patient's hope. Certainly, some doctors appear to hold the view that the presence of hope might enable a patient to "will" a change in the progression of their disease, thus delaying their death.[425, 480, 508] Some have claimed that without hope a patient will die,[473, 489] but it would seem indisputable that many patients with cancer have died with or without hope. There are few conclusive studies regarding the impact or mode of operation of hope upon

the body,[425, 441] although hope has been positively linked to survival time in some patients with cancer.[509, 510] More recently, in investigating the "cerebral neurobiology of hope and hopelessness," Gottschalk and colleagues[511] attested to the 'real' effect of hope. Jenkins[512] and Snyder with others[513] have suggested that the positive (and well-documented) effect of the placebo is essentially the effect of hope. It is somewhat surprising, therefore, that Snyder[499] remained unconvinced by correlational studies indicating that higher hope is related to positive health outcomes. Regardless of the empirical evidence for the power of hope, I suggest that its effect is real inasmuch as the presence or absence of hope is utilised to justify or explain a range of behaviours and outcomes within the medical setting, for both patients and medical staff.

6.4 Conclusion

The medical construction of hope predominantly rendered hope as independently existing, objectively assessable, and either (a) representing the availability of treatment resulting in cure or remission or (b) as an attribute of the individual, mutable and valuable; it further stipulated that it was for the medical profession to determine appropriate levels of hope, measure the level possessed by a patient, and attempt to reduce any discrepancies between these two amounts. I suggest, rather, that hope is constituted in the ways that individuals talk about it, and that this medical construction coexists amongst many potential others. Participants understood the word *hope* in a variety of ways—sometimes, but not always, in accordance with aspects of the dominant medical construction. For example, when participants viewed hope as objectively determined and measurable, measuring a patient's hope was not focused on; rather, hope was considered an attribute not of the patient but of the situation as assessed by medical staff. Although participants often agreed that medical staff had the power to influence a patient's hope, they also considered that hope could endure regardless of medical opinion. They did, nonetheless, hold that hope (in some guise) was integral to the making of medical decisions, many citing hope as justification (or not) for either holding the DNR discussion, or making the DNR decision. Finally, although some medical writers identify hope as realistic or unrealistic, true or false, these participants appeared to perceive hope as beneficial, considering that regardless of its ontological status hope enabled the patient to endure a trying situation.

Chapter 7. Study 2. Constructing DNR orders

The previous analytical chapters presented talk about the DNR decision with patients facing a serious illness—cancer. However, none were considered to be imminently dying. None of them currently had DNR orders recorded in their file, and despite agreement that stipulating your preferences for future treatment was desirable, only three had actually done so (see 5.1.1). Most of the 23 participants in this first study identified the DNR decision as specifically relevant when patients were close (or at least closer) to death. Indeed, when discussing the issue, most spoke in the third-person, or used the hypothetical 'if,' thereby implicitly positioning themselves outside the category of persons for whom this issue would be relevant. Accordingly, in the next study, 28 patients who *were* close to death were interviewed to determine how they spoke about the DNR decision. Assessed by their carers as within weeks of their death, half of these patients currently had DNR orders recorded on file, and a sizable minority (8) had formally stipulated their future preferences for future treatment. In this, and the following three chapters, I present and discuss their responses (with additional talk provided by family or friends present at 14 of the interviews) to questions focused on the DNR decision.

Data presented in this chapter were prompted by questions about the meanings or understandings of DNR orders for these (dying) patients. Generally, the institution of DNR orders was positively construed, through a number of different strategies. Many of these coexisted serving to reinforce each other, but all share the understanding that the establishment of DNR orders would mean that no action was taken to prevent the patient's death. To summarise, participants variously gave a medical definition of DNR orders, focused on anticipated outcomes of CPR, equated DNR orders with treatment refusal, or the practice of euthanasia, and understood them as entailing some form of documentation. A few claimed unfamiliarity with the term. Although the dominant construal of the DNR decision was that it was personal, participants also identified it as medical, legal, social, and moral. These different construals were differentially available to participants in order to justify a range of represented positions regarding DNR orders. Not all such positions were congruent with normative medical practice.

7.1 The medical definition

When asked what "What do you understand about the meaning of DNR orders" (or a variation thereof), four participants gave a description that accurately reflected the medical definition provided in the Information Form, namely, "a decision not to attempt to restart the heart if it stops which is otherwise routine in a medical setting" (see Appendices I & J).

This terminology, referencing an abstract "heart" in a "medical setting," works to construe the decision as primarily medical.

> Ruth. No intervention, no measures to restart the heart, no measures to restart the breathing, just simple comfort measures only. Yeah. (7.1/1)
>
> Wendy. I just, if my heart stops, just leave it. (7.1/2)
>
> Una. I would say that if your heart goes into an arrest, it means that they don't try and bring your beat back to carry on. (7.1/3)
>
> Yves. If it's in the medical notes or something or another, that the person is not to be resuscitated once their bodily functions stop, like their heart stops or something along the lines of that … . (7.1/4)

The information and consent form was signed by all participants, yet few gave the definition available within it. Those who did identified themselves as previously occupying positions that involve some experience with the "medical setting." Two of these were medical professionals—Ruth, a General Practitioner, and Wendy, a Registered Nurse in a General Hospital, who would be conversant in, and comfortable with, employing medical terminology. Una volunteered information that she had worked as an unpaid helper in a hospital, and similarly, Yves said he had worked in a children's hospital (as Manager of Supplies). This indicates a familiarity with the hospital environment that was independent of the patient role, and possible identification with it, manifested through their use of medicalised language. By contrast, patients who did not mention any prior exposure to the hospital environment, other than as a patient, did not use such medicalised terms to define DNR orders. Neither participants' exposure to the medical system (inherent in the condition of being a patient) nor their participation in the process of consent means that the medical version of a situation will predominate. Indeed, the medical construal of DNR orders was only one of several alternatives evident in participants' speech. For the most part, participants (including these four) used non-medical language to speak in terms of an anticipated outcome for the patient—thus construing the decision as rather more personal than medical.

7.2 Medical intervention, and a natural death

One of the most consistent responses to the question suggests an understanding that if DNR orders were instantiated, the patient would die and, furthermore, that this was desirable. Eschewing medical discourse, many used common euphemisms to denote death or dying, for example, those pertaining to sleep, of slipping away, and being left in peace. Dying was thus construed as an unobtrusive and gentle experience, and death as a positive

outcome or place to be. The use of colloquialisms worked to construe the process of dying as essentially non-medical, as something which will happen easily of its own accord—naturally. This set of meanings accorded death, also present in Study 1 (see 4.2.1), re-presents an idealised notion of how death should occur, and draws upon the discourse of 'a natural death,' which Charmaz[347] noted is a dominant discourse in Western society (p. 70).

> Sally. If I was to have a heart attack, and I actually stopped breathing, that is it. Not to, to try to awaken me again. (7.2/1)
>
> Tina. Well if there's not much hope sort of thing, just let me go. … Let me go to sleep. (7.2/2)
>
> Uri. If I feel that the time has come, that I'm going to slip away, then I do not want to be brought back … . (7.2/3)

When speaking of the death that would happen in the absence of intervention—the natural death—most participants used the first-person pronoun, usually indicating that this was what they wanted. This works to construe the issue as personal, something to be directed by the patient themselves. Some specifically used the words "die" or "dead," in association with either an injunction to "let" it occur, or an expressed wish to die. Thus, preventing a death was presented as preventing the patient from achieving their desires which, given the background cultural positive value accorded autonomy, is liable to be assessed negatively.

> June. They just want to go. They just want to, to die. (7.2/4)
>
> Pete. Do not resuscitate means that I've made a decision that if I had a stroke, and there was a chance that I'd die from it … because of my condition, don't try to save me. … I think I should be allowed to die with dignity, to just pass, without resuscitation. …
> Wife Kristen. Let them die if they [want to] … . (7.2/5)

In using words such as "allowed," and "let," participants construed not preventing death as a deviation from the norm, as something which, in some sense, requires permission for it to occur. Someone, and the implication is that it is the medical profession, is enjoined to allow death to occur, with the associated if hidden assumption that they could, if they chose, prevent it. However, and notwithstanding the medical imperative and obligation do something to forestall death (not to leave the patient to die), in this construal, being left is seen as appropriate, doing nothing to prevent death is sanctioned, and death is seen as natural and desirable. The DNR decision, construed as the patient choice to die, is thus patient-directed but medically effected, insofar as the medical default must be countermanded.

While some participants drew on a discourse of 'a natural death,' locating DNR orders within the passive framework of simply allowing the patient to die, others contrasted this with an alternative set of available active medical procedures which they deemed unwelcome. These procedures were typically interventions aimed at preventing death at the time of arrest (that is, CPR), or measures to sustain life that might be instituted should resuscitation be successful.

Talk about the first of these featured quite violent imagery—being "electrocuted," having "volts," "paddles" and "electro-shock" applied. The language used was dehumanised or impersonal, depicting mechanistic or electrical processes. This works to reduce any sense of human, interpersonal caring. Interventions were depicted as unwelcome 'things' that might be 'done' to the body, and often, to the patient's body. Given this as the alternative, leaving the patient in peace to die an easy, natural death was further rendered a more desirable, even more humane, option.

> Lois. Well that means that if you die, or you stop breathing or you ... [get] sort of technically dead, then you want to be left. You don't want to be, you know, electrocuted. ... You've had enough, and if that's happened, then you're quite happy with that outcome. (7.2/6)
>
> Otis. I wouldn't want nobody jumping around, and pumping and giving me 240 volts, and the jumper leads out of the car, like in Dr Bean, or Mr. Bean. ... Jumping up and down on it and giving it volts and things .... (7.2/7)
>
> Yves. Left to die. Left in peace, left. I don't think there's anything more terrible than seeing a person getting resuscitated and they're out with these, the paddles for electro-shock or whatever, I don't think there's anything more nasty than seeing a person jump around (laughing) with those things on. (7.2/8)

By contrasting violent medical intervention with the natural death, these patients positively construed DNR orders as allowing the latter to occur. They simultaneously construed them as reflecting or effecting the patient's wishes, and limiting medical intervention. This sees DNR orders as primarily personal, rather than medical.

This was also evident when participants spoke of medical procedures that might be required to sustain life should resuscitation be successful, some explicitly stating that instituting DNR orders signalled that they would not want to be brought back to live under such circumstances. The focus was on the impaired physical body and the medical procedures associated with it after resuscitation.

> Yves. I don't want to be left sitting around like a vegetable, just sitting there with tubes coming out of me, I just don't want that, … getting dosed up with morphine, just to keep me comfortable for a while. That's not me.
>
> Paul. If I'm clinically dead, don't sort of waste your time bringing me back. It seems quite pointless to be brought back to life, to lie in bed and have tubes feeding me, and people wiping my bottom, I don't want that, thank you.

Here, participants defined conditions under which life was deemed acceptable. The life depicted following on resuscitation was equated with a state of high physical dependency, and low agency, neither of which are compatible with the image of the autonomous adult valued in Western cultures (see 4.2.2). DNR orders were thus effectively sanctioned as preventing an unacceptable outcome—as enabling participants to control what is often referred to as 'quality of life.' This argument often featured in talk about potential reasons for instigating DNR orders, and will be discussed further at 8.1.3.

There are a number of taken-for-granted assumptions within these excerpts, and indeed, throughout much of the interviews. One is that the action dictated or desired by the patient is *the* appropriate course of action to follow, a relatively new, if well-entrenched feature, and dominant discourse of Western medical practice. As discussed in terms of patients' wants, DNR orders were conceived as reflecting patient autonomy, as patient-directed, a position more explicitly stated when patients discussed issues of responsibility for instigation of DNR orders (see 9.1).

In speaking of being left to die, or circumventing life-support, these patients also appeared to assume that, if initiated, cardiopulmonary resuscitation (CPR) would be successful in restarting the heart, and thereby in restoring life (albeit of an unacceptable quality) to the patient. CPR is rarely successful in restoring life in this population,[19, 21, 26] yet both doctors and patients overestimate the extent to which life can be restored in patients who suffer cardiac arrest.[73, 514] These patients appeared to have no notion that CPR simply might not work, something observed in other dying patients.[121] This deficit may be attributable in part to the very terminology employed: *Do Not Resuscitate* implies that resuscitation is an option available which may be renounced. The DNR decision is thus construed as a decision between life and death, a choice that does not exist.[14, 21, 121] It may be argued that, by using the term the medical profession does little to correct this misapprehension, thereby contributing to the assumption that, more than merely being obliged to try to, the medical profession would actually be able to avert death in this instance. Without a perception that medical intervention could act to prevent death, the injunction to desist from such action would be meaningless, and redundant. By extension, this perception

works to support the right of the medical profession to dictate the terms under which death is allowed to happen. This may have implications beyond the construct of DNR orders to issues of euthanasia (see 7.4).

7.3 Treatment refusal

Some patients also construed DNR orders (as their decision to forgo CPR) as equivalent to any other decision a patient might make regarding treatment options. It is considered axiomatic in Western cultures that patients should have the right to refuse treatments, even treatments that might prolong their life,[119, 515, 516] and the framing of DNR orders in these terms works to make them appear unproblematic.

> Interviewer. That term do not resuscitate, could you give me your thoughts =
> Xavier. Well I could have pneumonia for example, which untreated might take me in a few days, so if I had pneumonia and I was at the terminal end of it, I wouldn't want to be treated … . I'd know I wasn't being treated, I could say my goodbyes and go. And that would be a good way to go, if I had a choice, but you don't always get a choice (laughing) of course. … [DNR] means no medical treatment. Treatment or pills, so palliative care only. (7.3/1)

> Vera. I don't want anything other than palliative care. No resuscitation or anything like that, because … I just want to just let it take its course, basically.
> … All I wanted was palliative care, which is just … make me as comfortable as possible. Other than that, just let nature take its course. (7.3/2)

It was not treatment *per se*, however, that was deemed unwelcome, but treatments designed to interfere with a dying process—palliative care at that time was specifically contrasted as appropriate and preferred. This works both to restrict and to reinforce the medicalisation of death: Although the medical profession is denied the right to take action to prevent death, it is attributed responsibility for enabling death to occur under conditions acceptable to the patient. What is foregrounded is choice—the right of the patient to determine how (and preferably when) they should die.

However, as well as affirming patients' rights to choose options that will result in their death, these participants positively evaluated a decision based on an assessment that a life is no longer worth living. This works to reinforce the notion that assessment of worth constitutes legitimate grounds for making decisions that result in death. Again, this may have consequences beyond the construct of DNR orders (see 7.4).

7.4 Euthanasia

DNR orders were sometimes equated with a request on the part of the patient for an active medical intervention to end life, commonly and medically referred to as 'voluntary

euthanasia.'[517, 518] This was nonetheless viewed positively. Two women completely confused the two terms throughout their interview. In justifying medical intervention aimed at ending life, they used language similar to that used by patients to justify medical non-intervention aimed at ensuring life was not prolonged.

> Maud. Well, [the term DNR orders] means isn't it, if you want your life taken before … . If you get so ill that you're suffering, and you don't want to suffer any more, that I should be able to be taken (crying) … . The doctor he should come and give you a needle or a tablet, you don't know anything. It's just like giving you a sleeping tablet only a bit stronger, and you go to sleep. (7.4/1)

> Opal. I don't want to be put on life-support or anything … .When you the stage where you can no longer do for yourself you know, then, go to sleep and not wake up (laughs).
> Interviewer. Have you heard of the term do not resuscitate before =
> Opal. Oh yes, yeah. And I've heard of Mr. Nitschke[o] and all the rest of it, and I'm all in favour of it if it's done the right way. (7.4/2)

Intervention to end the patient's life—euthanasia—was deemed by these participants as in accord with patients' wishes, it averted an unacceptable anticipated quality of life, was appropriate when there was "no hope," was medically effected, and was associated with a positive construal of death. Thus, in positively construing the active intervention to end life, these patients drew on discourses of autonomy (patient's wishes carried out by doctors), compassion (relieving suffering), hope (its absence used to justify particular actions resulting in death), and of a natural death (dying as going to sleep), identified in my analysis of the first study as operating to legitimate DNR orders. When construed as patient-directed, but medically effected, DNR orders and euthanasia have some conceptual similarities—they both represent ways to manage death, with doctors enjoined to take actions to ensure that patients die on their own terms, under medically directed and sanctioned conditions. It is possible that the increased attention paid to ensuring that DNR orders are patient-directed may have helped to create a climate in which (1) for patients to attempt to organise the manner of their death is not only acceptable, but preferred, and (2) clinicians are deemed obliged to effect patients' wishes, even when this results in the patient's death (cf. [519-523]). Construed thus, euthanasia appears to be merely a logical extension of current practice.

[o] Referring to Phillip Nitschke, a prominent and active promoter of legalised euthanasia within Australia

7.5 Documentation

Some participants also spoke of DNR orders as a form of documentation to ensure that resuscitation was not commenced. Most perceived these as patient-initiated, and therefore as operating to effect patient autonomy (see also 9.1/9-12 and discussion).

> June. They [patients] have signed a form which tells others and their family and medical staff that they don't want to be resuscitated .... (7.5/1)

> Nina's husband Ray. We each have a Medical Power of Attorney over the other ... [and] our wish is not to be put on life-support systems, when there is no chance of resuscitation later on. Nina's agreed to that a long while ago, and so did I. (7.5/2)

Here, DNR orders are construed as legal (forms signed), as personal (patient-directed), and medical (instruction to medical staff, or reference to medical procedures). There are a number of consequences of the legal construal: As the existence of forms indicates an established normative practice, this may work to both legitimise and mandate patient-directed death. Medical practitioners may feel obliged to present patients with such forms in order to clarify their own legal obligations. Indeed, Bartley[515] observed that the 1995 legislation in South Australia[264] appears to intend that patients wishing to leave "advance directions must now comply with the formalities of the legislation" (p. 156). There is, furthermore, potential for a bureaucratisation of the process of dying, whereby completion of appropriate forms becomes just another task to be completed before death.[67, 270]

In addition, participants presumed the operational force of such a document, assuming that medical staff will know of, and be bound by it. But medical compliance with patient wishes is not guaranteed.[62] Within this study, at the time of interview, eight patients had completed Medical Power of Attorney (see Table 5). However, although four of these had DNR orders written in their file, the presence of their Medical Power of Attorney was noted within the case-notes of only one. The others did not have a current DNR order on file. The patient may make a decision about what should happen to them, but actualisation of their preferences is dependent on their decision being noted and respected by the medical profession.

7.6 Unfamiliarity with DNR orders

In the first study, all participants indicated some familiarity with DNR orders, notwithstanding some variation in the precise details of their descriptions of what was entailed. In this second study, although the majority of these terminally ill cancer patients claimed familiarity with the term DNR orders, four—all males, all older than 65 years

(demographic characteristics of patients that others have reported associated with increased desire to leave decision-making to their doctors[212, 213, 215, 217, 218])—did not.

> Interviewer. What do you understand by do not resuscitate orders? =
> Rex. I know nothing about them whatsoever. (7.6/1)

> Interviewer. Have you heard of the term do not resuscitate orders?
> Vern. I don't know what it means. (7.6/2)

> Interviewer. Do not resuscitate? Have you heard of that at all =
> Sean. No. (7.6/3)

> Interviewer. What do you understand by do not resuscitate orders? Have you heard of that term before?
> Oliver. No, I haven't. (7.6/4)

These four males went on to talk about and thus construe DNR orders in specific, though different, ways. However, all effectively construed the issue as of no specific relevance to themselves right now, either through identifying the DNR decision as the responsibility of another person, or as appropriately dealt with at some later time. In this interview situation where patient knowledge about DNR orders was presumed (as implied by the question itself), such arguments functioned to justify their lack of knowledge, but more generally, constitute resources for repudiation of responsibility for the decision itself.

7.6.1 It's not for me to decide because doctors should decide

It has been previously reported that some patients prefer that doctors make decisions regarding CPR,[38, 126, 212, 213, 215, 217, 218] and in this study, two participants presented the DNR as a medical issue—as something to be determined by the doctor, somewhat irrelevant to them, and not something that they should direct. Indeed, although both had current DNR orders stating that their doctor had discussed resuscitation with them, and that they had indicated that they "did not wish" to be resuscitated, during the interview both positioned the doctor as the expert, and appropriate authority in determining their DNR status, thus establishing themselves as not responsible for it.

> Rex. I think that should be up to the profession meself, because they know a lot more than anyone else does, and they react I suppose. They're trained to do that sort of thing. And who is anyone else to come and in tell them what to do. (7.6.1/1)

> Vern. I don't feel it's a question that needs asking. Doctors, the doctor knows … . Well in my case I don't think the doctor would want to restart my heart, would he? (7.6.1/2)

However, there were differences between their accounts. Rex construed the whole decision as somewhat irrelevant given the inevitability of his death, and inability of anyone to prevent it: In such circumstances a decision about (not) attempting CPR is a moot point.

> Rex. I've got an uncurable [sic] disease, doesn't matter what you do, you're not going to stop it. So I'm prepared for that. ... The person in charge at the time [should decide] I suppose. That's what I think. If he's that you've got no chance, well, just let me go. ... I don't care who has the say, you've got to die and that's it. (7.6.1/3)

Drought and Koenig[121] have argued that this circumstance is typical of patients deemed likely candidates for DNR orders: CPR will not prevent death, so the choice is more fiction than fact. Here, the role of the doctor was to affirm that death was inevitable, that there was no chance (of restoring life), and then to let the patient go. While this minimises the significance of this action in terms of outcome (the patient will die regardless), it accords the doctor the responsibility of making the appropriate decision in response to the biological circumstances.

Where Rex did not contemplate the possibility of life after CPR, Vern did, citing (as many others did) a life that was "worse off" than the present one as justification for refraining from CPR. As did Rex, Vern assigned the doctor the responsibility for making the right decision, rendering any discussion with the patient unnecessary. However, he drew on a discourse of compassion to negatively construe any attempt to raise the issue with the patient. This was framed as confronting the patient with equally unpalatable options: the prospect of dying from a "massive heart attack," or being brought back "worse off."

> Interviewer. Normally if your heart stops within a hospital it's routine to restart it.
> Vern. I don't think that's going to be necessary. ... It shouldn't be. ... Because if my heart stops now, what's the use of bringing it back? I could have a stroke. Could be worse off than I am now (getting upset). ... For a doctor just to come up to you and say, "You're going to have a massive heart attack, do you want your heart restarted?" That'd just scare the shit out of you. Excuse my language. ... If it didn't happen you're lying there waiting for it to happen, and it doesn't happen. Why? Why put that on a person?
> Interviewer. You don't think that the doctor should discuss it with the patient?
> Vern. No. ... Why come and ask if they should get it started when he should know that starting is of no value? (7.6.1/4)

Rather than terming the decision faced by the patient in the abstract or hypothetical, Vern bluntly personalised it, using graphic and colloquial language to draw attention to the probable negative emotional consequences for the patient. Given the inevitability of death anyway, the DNR discussion is construed as both redundant, and inhumane. Citing his own experiences as an illustrative example, Vern then said that it would have been "better if

there was nothing said." He further buttressed his argument that the patient should not be consulted by implying that for the doctor to do so is to fail to exercise their God-given abilities. Thus, as well as construing the decision as a medical one that the doctor is best qualified to make, Vern infused it with moral or ethical connotations that work to oblige the doctor to make it.

> Vern. I would've preferred [the doctor] not to [tell me] in the manner he did. ... Well, it didn't seem right to me in that he said ... that I was gonna have a massive heart attack ... and did I want him to try and restart my heart? I said no. Just let me go. ... For me, in my opinion, it would have been better if there was nothing said. ... So it would have been left to the doctor. So I would lived (...)
> Interviewer. Without knowing? And that would have been better?
> Vern. (Nods) ... I've always believed that God has given the doctor a brain to be able to be a doctor and He's made him clever enough to (...) people. And that's how it should stay. (7.6.1/5)

Vern's position may be readily understood as prioritising the bioethical principle of non-maleficence over autonomy, suggesting that to do so is considered appropriate by some patients, as it is for some medical writers.[450, 524] His account offers additional challenges to the dominant model of patient-doctor interaction, and of patient decision-making, providing some support for what is normally perceived as paternalism. Vern held that making decisions in order to spare patients an emotionally distressing conversation is part of the doctor's job description, as well as their moral obligation. Further, the patient's emotional state was taken as sufficient justification for excusing the patient from the decision-making process (should they fail the Stability test, see Chapter 5). This contravenes the presumption of an autonomy in patient decision-making that is premised upon the provision of information, and (as noted in Study 1) points to the significance that may be accorded to emotional factors, one that is absent from many medical accounts of decision-making. The ultimate effect is to undermine the position that dictates that patients should always be involved in making medical decisions, even those that have very tangible effects on what happens to them personally—specifically the DNR decision.

7.6.2 It's not for me to decide because I'm not ready

In contrast to Rex and Vern, the other two patients who disavowed knowledge of DNR orders did not then distance themselves from it on the basis of assignation of responsibility elsewhere. Rather, they deferred the decision to another time (not another person), thus construing it as irrelevant to them right now, and themselves as currently justifiably ignorant of it. For example, immediately following on his initial response of ignorance, Sean accounted for not having thought about DNR orders through representing himself as

preoccupied with the fight against cancer. This engagement in a highly valued and requisite set of behaviours for the cancer patient[298, 442] allowed him to present himself positively as meeting his obligations, rather then as avoiding one, a conclusion that may be implied by my question.

> Sean. No I haven't thought about that at all, no. ... My main thoughts now are what I've been saying. Yeah, I'm going to fight it. I'm going to put myself through a test, and I'm going to try and do better than what I can do now. ... I don't like the idea of, I know I need them, or will need them, all these other things, and it's gratifying to know that people are so interested in one's health, and well-being after they sort of get to this old age. But, I don't like the thought. I mean, I'm an independent person, I like to be on my own, my own two feet (getting upset) ... . (7.6.2/1)

This account also carries an implication that the discussion of DNR orders signals the end of the fight against cancer, a conclusion which appeared to be disturbing to Sean. This is possibly because it implies increasing dependency, something incompatible with his avowed identification of himself as an independent person. On returning to the topic of DNR orders, Sean appeared to further distance himself from it: He shifted from the personal and present tense ("I know I need them"), first to the future ("I will need them"), and then to the third-person (speaking of "one's health"), only to return to the present and personal tense to reject the topic ("I don't like the thought"). Interestingly, he cited his feelings about, or emotional response to it ("I don't like" said twice) as justification for focusing his attention elsewhere. That he exhibited signs of distress suggests that even considering this issue was emotionally challenging for him, as it was for Vern above. This contradicts claims that patients will not be distressed by discussions about resuscitation,[82] rather confirming the affirmation of participants in Study 1 that some patients might be, and studies showing that some are.[197, 199] As noted in 5.1.1, the DNR discussion is ultimately about a patient's death, and readiness to discuss this cannot be presumed to correspond with the severity of their disease or proximity to death,[196] as not all dying patients will wish, or be able to accept this.[433]

Oliver explicitly denied the doctor the right to make the DNR decision, construed as terminating a person's life. Based on the assumption that the application of CPR would save the patient's life, the decision had great significance (see also 7.7). It was in effect too important for the doctor to make, and, enacting the discourse of patient autonomy, Oliver here assigned it to the patient. (Subsequently, he held that only God should make such life or death decisions: see 8.3.2.2/1).

> Interviewer. Who do you think should make [the DNR decision]?
> Oliver. Well, the person concerned I suppose. ... Yeah, I don't think it's the

> doctor's right to say whether or not it's, to terminate somebody's life. ... If a person is anxious about it, and wants to know about what their immediate future's going to be and, but I definitely don't think it's up to the doctor to decide. ... I think it's up to the patient to decide [when he wants to discuss the issue], and if he wants that information, he should ask the doctor what information he wants, to be told truthfully about it. (7.6.2/2)

Consistent with the consumer-model of doctor/patient interaction,[35, 84] Oliver construed doctors as providers of information requested by the patient. However, although he reiterated the right of the patient to dictate the play of events, Oliver had apparently neither made, nor even thought about this decision. His suggestion that the patient (prompted by some anxiety over an immediate future) determines the appropriate time for a discussion about DNR orders, lends itself to the conclusion that Oliver did not consider that apposite moment to be upon him.

By virtue of his inclusion in this study, Oliver had been assessed by his medical carers as within weeks of his death, and in fact died less than four weeks after his interview. Despite this, he located himself outside that category of patients for whom a DNR discussion, and—as he held that determining DNR orders is the patient's prerogative—for whom institution of DNR orders, might be deemed appropriate. In part, this may be because for Oliver to have done otherwise may have entailed his identification as "anxious about ... [an] immediate future." Although this anxiety was presented as instrumental in prompting the patient to take action, thereby embodying notions of patient autonomy, to be anxious connotes a state of emotional distress, of indecision, and dependence on another (here the doctor) for help, conditions not compatible with such notions. Thus, while his position might be taken as avoidance or denial of the reality of the situation and failure to meet the ideal of the responsible autonomous adult, Oliver's speech allows for the explanation that he had not addressed DNR issues because he was not yet anxious over his immediate future, thereby maintaining a presentation of himself as an autonomous self-reliant adult.

His account also points to problems with assuming that the medical assessment that death is nigh corresponds to a patient readiness to discuss the issue: Patients may always be able to position themselves as not meeting criteria for a discussion, thus identifying the discussion as appropriately deferred to a later date. Because that date can only be identified by the patient, the automatic introduction of the issue by medical staff at a time convenient to or designated by them is thus contra-indicated.

7.7 The choice of life and death

Common assumptions underpinning participants' discussion of DNR orders were that the application of CPR will save a life, and that a DNR order represents the decision that this should not occur because the saved life is deemed unacceptable. The DNR decision is thus construed as a life and death decision, and I want to explore some consequences of this construal evident in the speech of one patient—Sean.

Responding to a question about when resuscitation might be deemed inappropriate, Sean began by locating the decision somewhat jokingly within both an interpersonal and moral domain. In this account, the provision (or not) of resuscitation is determined by the assessment (positive or negative) of others of a person's life, not on physical, but on moral grounds.

> Sean. I think it depends on your friends and how much you owe them (laughter). ... I haven't got any debts (laughter). ... It does depend on the person themselves. In other words, if they were normal sort of people enjoying a good life, and got good friends and company, and helping somebody where they can, and not hindering them, and living a good and honest life, been a real good type of bloke, like myself (laughter), and yeah, I can, I've got everything to live for, I'd say go for it. And yet, if it was the other way, then the world'd probably be a better place without him or her. (7.7/1)

Resuscitation, as the opportunity for life, was identified by Sean as the appropriate reward of someone who deserves it. Not surprisingly, he considered himself a "good type of bloke" with "everything to live for," therefore leading to the conclusion that he is an appropriate candidate for resuscitation. As a contrast, Sean then proposed a hypothetical "him" who is "the other way," whose demise would leave the world a better place, with the implication that resuscitation for such persons would be inappropriate. Thus an understanding that DNR orders mandate against resuscitation may be interpreted as implying some moral judgment about the patient on the part of the decider—an interpretation that is only available if resuscitation is deemed likely to succeed.

In further speech, this version appeared to present a dilemma to Sean, particularly since he assigned responsibility for the decision to his relatives.

> Interviewer. Would there be any circumstances where you would want not to be resuscitated if your heart stops?
> Sean. No, not really. I go back to what I said. I think it's up to my relatives to do what they feel like doing. And that's it. I've got no, I was going to say non-wish (laughter) to come back into this world again, if I'm wanted back. So you know, if I had something to hide, or something I didn't want, I mean that'd be a different answer maybe. But, no, I'd have it done, if they wanted to resuscitate me, that

> shows they want me. But by the same token, if they didn't resuscitate me, and let me go, I shouldn't be thinking they didn't want me (laughter). (7.7/2)

Previously, Sean had distanced himself from the DNR decision, implying that he was preoccupied with his fight against cancer (see 7.6.2/1). Here, Sean reiterated this position, professing his neutrality regarding resuscitation ("No, not really"): If his family (relatives) want him back, he's agreeable. This position of neutrality was further achieved through the use of double negatives: "I've got no … non-wish … to come back." Thus Sean managed to avoid saying that he does want to be resuscitated (which would undercut his assignment of the decision to the family), while still presenting himself as worthy of resuscitation. However, the moral connotations of his earlier account of CPR mean that the relatives' decision to resuscitate or not to resuscitate had implications both for Sean (is he worth it?), and his relatives (do they want him?). To not choose resuscitation implies a negative assessment, either of Sean because he is not worthy of resuscitation, or of his family because they do not want him around. This may lead to guilt or resentment within the family who takes on the responsibility for the DNR decision. These negative consequences, however, rest upon the assumption that the DNR decision (and thus the decider) determines whether the patient lives (however briefly or badly) or dies—an assumption that ineluctably construes the decision as moral. Although this is a common assumption,[21] the documented inefficacy of CPR in this population suggests that it is incorrect. Based on this analysis of Sean's speech, I suggest that it is certainly not useful, and should perhaps be abandoned.[306] Some writers have called for increased education of both patients and doctors regarding the efficacy of CPR,[30] which has been shown to decrease rates of preference for CPR.[73, 525] However, some patients maintain a preference for CPR, a position which seems inevitable given the moral connotations of making choices regarding its provision.

As a further point, it seems likely the proliferation of and promotion of different terminologies for these orders, including "No-CPR,"[184, 252, 526, 527] "DNAR" (Do Not Attempt Resuscitation),[528-530] "AND" (Allow Natural Death),[531, 532] "NFR" (Not For Resuscitation),[13, 533, 534] or "GPC" (Good Palliative Care),[99, 535, 536] typically with a rationale that these (1) do not presume that resuscitation will succeed; (2) thereby avoid an implicit and emotionally difficult choice between life and death; (3) promote a focus on a positive provision of care; and (4) are consequently more compassionate, are likely to founder upon the same moral dilemma as DNR orders—particularly where patients or families are asked to direct the outcome. Where a choice about CPR is construed by individuals as equivalent to a choice between life and death, where CPR is infused with moral connotations beyond

the medical parameters, debates over terminology appear petty at worst, redundant at best (see also [270, 537]).

7.8 Conclusion

In this chapter, I have suggested the dominance of the assumption by participants that initiating DNR orders ensured that a patient would die without undergoing medical intervention to prevent this, this being positively presented as an appropriate outcome. Nonetheless, participants construed DNR orders in several different ways, including medical, legal, social, moral, and personal—the last predominating. There was, moreover, variation within each construal, and juxtaposition with selected others to different effect. For example, for some the medical construal lent itself to assignation of responsibility (sometimes moral) for the decision to the doctor; for others, DNR orders were deemed to be medically effected, but personally directed; many saw them as indicating the possible, or appropriate limits of medical intervention. Construing DNR orders as legal attested to normative social practices involving multiple parties (including the doctor, the patient, and others cited as, for example, Medical Power of Attorney). For the majority of participants, the dominant construal was personal: DNR orders were depicted as encoding and actualising patients' wishes (to limit medical intervention, to ensure a natural death, to choose how they wanted to die). A prevalent view was that DNR orders represented a choice between life and death, which imbues the issue with moral implications, both for the subject of such orders, and for others implicated in the making of them. In addition, some participants implied that DNR orders are relevant only for certain persons at certain times, which, should patients not identify themselves within this category, permits justification for not having made, or not having considered the issue. Thus, even though DNR orders are considered personal, patients (even dying patients) may be able to provide legitimate reasons for not having personally considered them. In the following chapter I shall further explore how participants justified the institution of DNR orders, examining what factors were deemed relevant in this, and considering some implications of what they presented as appropriate grounds for making DNR decisions, both for the patient, and for medical practice.

Chapter 8. Study 2. Justifying DNR orders

In the previous chapter I examined participants' responses to a question about the meaning of DNR orders, demonstrating how they variously (and favourably) construed DNR orders, with the common premise that these would preclude any intervention to prevent the patient's death. Within the interview format, the next question was intended to enable identification of factors patients considered relevant in making a decision to institute DNR orders—making the decision that some patient should not receive CPR following cardiopulmonary arrest. The question took various forms, including: "What sorts of things are important to think about when making this decision?" "Why might someone make the decision?" or, "What might persons consider in making it?" Where participants had indicated that they had made the decision, or had been involved in discussions about it, the question was personalised, for example, "What sorts of things did you think about when making this decision?"

I wish to emphasise that the following (and indeed the previous) analysis involves a somewhat arbitrary and artificial division of patients' speech. Patients rarely cited one particular reason but rather constructed a network of arguments to justify the institution of DNR orders. Nonetheless particular recurring phrases, metaphors, and themes can be detected. I will consider data within three overarching categories: Patient-centred (or personal), Other-centred (or social), and Fatalistic (or philosophical). All support the conclusion that in this population of patients in the final stage of terminal cancer, death is the appropriate outcome following a cardiac arrest. Collectively the reasons proffered can be deemed to characterise a category of persons for whom DNR orders are appropriate—which I have called 'the DNR category.' Some patients located themselves outside this category, being thus able to justify either not having considered DNR orders, or a preference for receiving CPR.

8.1 Person-centred (personal) arguments

As was the case in Study 1, in justifying the institution of DNR orders, participants presented both the current state of the patient, and an envisaged prognosis after CPR as relevant. Most delineated conditions under which they would not want to live, many speaking about 'quality of life,' often centred on an ability to participate in valued activities. A few represented DNR orders as part of an appropriate preparation for death.

8.1.1 Patients' pain and suffering before an arrest occurs

One common reason given was based upon an assessment of the value of the patient's life at the time of deciding upon DNR orders. Participants implied or asserted that some conditions indicated that life was not worth living, presuming that DNR orders would ensure that such a life would not be extended. Several patients mentioned physical pain as a factor, describing it as something to face, to be released from, to go through, and as unbearable. Such language works to construe pain as an ordeal or as an overwhelmingly negative experience, thus legitimising measures presented as likely to end it.

> June. … I say to [my husband] "Don't you let them let me go through will you?" "No." "You promise me," like that, "I can't go through this pain, you know that." (8.1.1/1)

> Interviewer. So why do you think a patient would make a DNR decision?
> Kate. Because they just want to be released from the pain they've got and they don't want to be dragged back to life to face that pain again if they specifically asked not to be, really. (8.1.1/2)

> Otis. I would rather have two or three weeks of non-pain than six or seven weeks of with the pain. … That's not living, that's not being good for me. (8.1.1/3)

These participants associated pain with being alive yet close to death, assuming that this pain would be ended only by death. The implication was that a DNR order would ensure that this unpleasant experience would be either avoided, or ended. As a solution to the problem of pain, a DNR order was thus positively presented.

Others spoke more generally in terms of suffering, similarly implying that the DNR decision would mean they would not have to put up with, or go through this. Suffering is typically understood as an unpleasant state that includes, but is not limited to, physical pain, and incorporates emotional distress.[524, 538, 539] Although some have claimed that suffering may have some merit, enabling persons to find meaning in life, even ennobling their death[540, 541] (see also Maud at 8.1.1/6 and 8.2.1), here participants construed it as unnecessary, as having no worth when the patient was dying. Consequently, options deemed likely to end suffering were cast as legitimate.

> Pam. Well I was so relieved to think that I didn't have to put up with what I've put up with, for the last eight weeks, that, I think it's marvellous that I don't have to go through this same thing over and over and over and over, for weeks on end. That awful endless nights, yeah. I think it'd be a great relief meself. (8.1.1/4)

> Yves. I can't see the sense in bringing someone back to suffer more, when they've already suffered long enough. … I mean, you probably don't know you're going

> through it, but I wouldn't want to go through it, and I don't know how many people would want to go through it. (8.1.1/5)
>
> Maud. I don't want to be a coward, and yet, why should we have to suffer if we don't have to? Like that. I don't say a person should never suffer, you've got to suffer to know what life's about, but why, what? (8.1.1/6)

Because what constitutes 'suffering' is subjectively determined, these arguments work to locate the authority for determining appropriateness of instituting DNR orders within the patient, and thus strengthen the construal of the decision as personal.

8.1.1.1 When you get to that stage … you've had enough

Two phrases regularly used in this context were variations on 'You've had enough,' and 'When you get to that stage.' Both were based on an assessment of the patient's life, and often they co-occurred.

> June. It doesn't come in to say that "I've had enough, I just wanna go now," but I think sometimes, when it has got to that stage it will be … that, yeah I have had enough (laughs). (8.1.1.1/1)
>
> Una. I would like to think that when the time comes I'll have my faculties together enough to say "my body's had enough." (8.1.1.1/2)
>
> Yves. If you get to the stage where you had, where your heart stops, then you're obviously at a fairly advanced level of the illness … . If I'm at that stage anyway, … if the ticker stops ticking, that's it. So they leave me as I lie. (8.1.1.1/3)

'You've (I've) had enough' functions very similarly to 'don't prolong things' earlier discussed (see 4.2.1). It implies a limit that should not be exceeded, beyond which is too much, beyond which it is unreasonable to expect someone to go, leading to the conclusion that things should stop here. It works to construe alternatives (e.g., failing to ensure the limit is not exceeded) as violating patients' wishes, and, to the extent that 'enough' is associated with an optimal amount, as potentially harmful to the patient. Participants thus established that the decision that a patient's heart should remain stopped respects patient autonomy, and is a compassionate and appropriate decision.

This decision was also presented as rational, through use of language such as "obviously," and "I would like to think … I'll have my faculties together enough to say … ." Thus the decision is deemed, not only preferred by the patient but a logical option dictated by the situation, only requiring that the patient recognise and bring it into effect. As a result, the decision is normalised and the extent of individual responsibility for it is minimised.[294] This effect was also achieved through the use of the phrase "when it gets to that stage."

Using the metaphor of the disease as a journey with recognisable signposts (cf. Frank[542] and "quest" narratives of cancer), this connotes a place in the journey, one that is well defined, with an accepted vision of how it is, and where the next logical place is to go. The decision to let a patient die is thus positively construed, being presented as rather more objective than subjective, as an obvious next step in a progression, and part of a recognised and unproblematic order of events.

8.1.2 Quality of life before an arrest occurs

A further justification for the DNR decision centred around a predicted inability to participate in desired activities, due to physical-based factors such as fatigue, pain, misery, or other consequences of a patient's illness. Although these consequences were referred to, what appeared to be important in the following excerpts was the impact these had on patients' abilities to do things. Without such abilities, life was deemed as worth less, and, again, a decision that would ensure its surcease was correspondingly rendered both reasonable and compassionate. Such issues are often subsumed under the term 'quality of life,' and some used this phrase, usually in tandem with some specific things that they themselves wanted to be able to do, and the negative effects associated with their lack.

> June. So yeah, [I thought about DNR orders] before [we] got pain under control. … It gives you that quality of life and that, the ability to do something, you know. Yes, it makes quite a lot of difference in, just being able to sit, really. (8.1.2/1)

> Interviewer. [You said] one of the issues would be quality of life?
> Pete. Oh, quality of life to me, is just that I've got some dignity and I've got some quality really for what I've really got left to (…) and that time I've got left I could spend with my family, my grandsons, my daughters, that sort of thing. (8.1.2/2)

> Ruth. [It's] quality of life, not quantity, and I'm after the quality. I was in recently for a pleurodesis and I was utterly miserable, and everybody around was utterly miserable, and no, I don't want that. That's not what it's about. And it may mean that my time is shorter, but if I am able to be coherent with my children, and sane and lucid, and me, that's what I want. (8.1.2/3)

The varied and arguably idiosyncratic nature of what constitutes 'quality of life' points to the subjectivity inherent in the construct. As judgments of the value of their life are attributed to the patient, calling for a compassionate assent by the observer, the term is endowed with considerable rhetorical power, invoking discourses of autonomy and compassion without necessity of further definition. The consequent flexibility of this construct makes arguments predicated upon it both difficult to predict, and to refute.

Participants certainly seemed to value activity, assessing an inability to be active as reducing the value of their life, and thus providing reason to institute DNR orders. One implication of this is that human life has value, or quality, by virtue of the ability to do. The emphasis on quality, as contrasted implicitly or explicitly with quantity, works to conceal the extent to which there is an implied quantity of activities that are progressively restricted by illness. A lesser number of things one can do (relating to quantity) is associated with a diminished quality of life, and therefore, a lessened value on that life. In fact, this is one of the major premises underpinning scales purporting to measure quality of life: How many activities are deemed restricted, and to what extent?

For many, valued activities involved some interaction with significant others, whether family or friends. It seems probable that this has significance on several levels. Interaction with others may be one of the few activities left to a terminally ill patient, other more active occupations likely to have been curtailed sometime previously.[347] Thus this remaining activity may have immense symbolic value. Furthermore, as social interaction is commonly recognised as fundamental to the establishment and maintenance of identity and agency, a diminution in one's ability to interact with those fundamental to one's own sense of self may lead to a diminished sense of self.[123, 143]

Another consequence of the emphasis on physical activity in determining the value of life is that the ability to participate in activities is rendered, not just a desirable part of life but a constant and invariant part of life, one that should be maintained up to the very point of death—more, that when this ability is diminished then death is appropriate. What is dismissed here are notions that dying may itself be a valued activity, or that the cessation of normally valued activities might provide time to explore other activities not dependent on physical expenditure, or even that just being, rather than doing, may be valued by self and others.[405] The gradual cessation of participation in life's activities is part of dying, but here appears to function as justification for death. This may have other consequences: Raising similar arguments, Brescia[543] cautioned that the inevitability of death should not function as reason to end lives (to kill). But if quality of life is accepted as a legitimate ground for justifying the DNR decision (when conceptualised as a life or death decision), this may lend itself to the conclusion by persons other than individuals concerned that some lives are rather more worthy than others. This may function as justification to end such lesser lives, constituting legitimate arguments for euthanasia, or as a coercive pressure in favour of euthanasia upon those who may be deemed unable to participate in valued activities.

Nonetheless, as the particular activities that will count in determining quality of life is taken to be subjectively determined, this allows for the possibility that patients may point to the value of some particular activity as a counterargument, weighing that against potential claims that their life is not worth living. This appears to be Xavier's argument below. He stated that he supported both the practice of DNR orders, and euthanasia, not only hypothetically, but personally, but then implied that the time for their enforcement might not be right now.

> Xavier. I wanted to be very clear, that if it's terminal, and I'm (...) near the end of that terminal end, I mean minor infections just on the way now, it's a different question, because I've still got a reasonable quality, but as you get to the terminal end, then it's got to be fast, and if I could euthanase [sic], I would euthanase [sic]at the point. Now I know that's not legal and allowed but once the quality of life's gone and you can't do much, then I would want to be as quick as possible, since I can't euthanase [sic], I don't want resuscitation, or any assistance. ... It depends on their [the patient's] wishes obviously. And there's only one thing that might change my view, because what I've got is mesothelioma, and that's almost always compensatable [sic] and I'm now starting the compensation process, it may be something that'd gives me incentive to not allow termination until that 'cos I'll fight down to the wire if I have to ... . So I might in fact have to change me mind, ... sort of don't terminate me, yet, if my quality of life is still reasonable. Because I'm fighting a case and I want to sue before (laughing) I go, so there are other things that can intervene in this, that give you a different time scale, ... for example compensation ... . You've got to be flexible I guess to change for the realities of the situation, but given that that wasn't the case, then I would want to go sooner rather than later, once the quality of life's [gone]. (8.1.2/4)

Xavier continually referred to what he wanted, establishing his desires as the principal factor in determining outcome, a position reinforced by his assertion that "it depends on their [the patient's] wishes obviously." Patient autonomy was thus established as self-evident authority for determining outcome. However, Xavier also invoked the umbrella term "quality of life" as justification for preferring both life ("my quality of life is still reasonable"), and death ("once the quality of life's [gone]") and named his participation in the valued activity of suing, or fighting for compensation, as his incentive to stay alive. Indeed, the suggestion that if he was not so engaged ("given that that wasn't the case") his preference was for death, contains within it the implication that this activity was his justification to keep living, and that this was justification enough to ensure that he be so kept alive. Which activities may be so valued by the patient is infinitely variable, but the operative force of them is taken to be incontestable. This achieves (at least) three things: It reasserts patient autonomy as a dominant value, and establishes that life has a worth that can be assessed in terms of participation in activities that are desired by the patient. It also

enables the patient to justify and defend their right to CPR regardless of what others' opinion regarding its efficacy might be.

8.1.3 Quality of life after CPR is performed

Quality of life also featured prominently in a further set of personal reasons given, pertaining to an anticipated prognosis after CPR was initiated. Life after CPR was predicted as lacking quality, and thus as worthless. For some quality of life was tied to a concept of dignity, both typically undefined, but presented as conclusive arguments.

> Pete. [Some people say] yes, I want to be resuscitated at all costs, but have they thought about what does resuscitation really mean, what's the point of being resuscitated if you've got no dignity or quality of life? (8.1.3/1)

> Ross. Well I just see it [CPR] as prolonging the inevitable. … When you get down to that low, I just don't think the quality would be there. You would have deteriorated in quite a lot of areas.
> Wife Margie. We're concerned about quality of life. How much quality would be there? …
> Ross. I'm probably at the poor end of the quality scale now, but at least I can converse with Margie and the children. Friends too. So I just think that it's deteriorating too much further than that. (8.1.3/2)

> Wendy. Yeah, I think the decision was probably made even before I was diagnosed, so. That if we were in that situation, that we don't want to be resuscitated unless it's going to add to our quality in life, there's no point in trying. (8.1.3/3)

Again, there were several allusions to a quantification of quality (e.g., "poor end of the quality scale," "how much quality," and "to add" to quality of life) with the implications that a lesser quality of life contra-indicated CPR. Ironically, although what constitutes quality is presented as subjective and individually determined, this language works to construct it as an objective entity that can be potentially reliably and consistently measured, thus reinforcing the legitimacy of decisions based upon a measurement of quality of life. Quality of life, as a marker for the value of life, thus has endorsement from both the objective and subjective domains, which may go some way to explaining the proliferation of quality of life measurements. Regardless, there may be negative consequences attendant upon taking ambiguous terms (including quality of life, dignity, pain, and suffering) as defining criteria for decisions construed as having life and death import (cf. Chapter 10 on hope). The lack of definition makes these terms highly flexible categories with considerable rhetorical appeal, but leaves them always open to contestation, and as such, problematic in terms of establishing or defining practice or policy with regard to end of life decision-making.

8.1.3.1 Being less than human

In addition to the invocation of these rather ambiguous criteria of pain, suffering, quality of life, and dignity, some participants also implied that DNR orders would avert a very specific unwanted potential outcome of CPR: being less than human, phrased primarily as being a "vegetable." As previously noted in Study 1, this connotes an absence of cognition and rational capacity, with the negative judgement reflecting the value accorded these within Western culture. I have also commented previously on how this is privileged in determining what it is to be human, clearly discernible in the following excerpts (see also Yves' at 7.2/8).

> Tina's daughter-in law Alicia. We did discuss about resuscitation, and that was what mum said, that if, she did not want to become a vegetable. (8.1.3.1/1)

> Wayne. I wouldn't want my life to go on like me being just a vegetable .... (8.1.3.1/2)

To identify humans as vegetables is to reduce the degree to which they will be considered human. One other patient used different language to similar effect, designating a resuscitated human as "half-dead."

> Maud. No they shouldn't [resuscitate]. They should not. For the simple reason is, you're still come around as a half-dead person. So while you're going in peace, let you go. (8.1.3.1/2)

Within Western culture, being "half-dead" is associated with a figure of mindless abhorrence, with zombies—again, as with the less-than-human.[544] The construal of the DNR decision as operating to prevent such de-humanising outcomes thus renders it as a preferred option. However, definitions of a human who lacks cognitive capacity as essentially non-human may also be drawn upon to construct a category of humans for whom actions normally deemed appropriate are rendered inappropriate, and conversely, to normalise actions on humans normally deemed inappropriate to the category human.

8.1.4 Preparation for death

DNR orders were also considered by some to be part of appropriate preparation for death. Completion of this task by the patient was taken to achieve several positive things: It relieved the individual of having to make the decision, and the difficulties attendant upon that (attesting to the difficult nature of the decision); it guaranteed that no-one else would have to deal with the consequences of the patient not making the decision (simultaneously establishing the moral obligation of the patient to make the decision); it ensured that the

patient's wishes were noted (with the implication that this would determine what happened); and, it effectively demonstrated that the patient was fulfilling their obligations as a responsible and considerate adult.

> Pete. The other thing's that important to me at this point is peace of mind, and peace of mind knowing that I can relax in my religious beliefs. … And that [is] what is my concern. That I've done it to the best of my ability, dotted the Is and crossed the Ts. And that is good. …
> Wife Kristen. He likes everything organised and sorted out. …
> Pete. Yeah, you don't leave things to other people if you can do it yourself. (8.1.4/1)

> Vera. Basically I think I don't want anyone to have to actually say "Well now turn it off because there's no point." I just, I don't want anyone to have that responsibility, be it family or staff or medicos or. … But as I say there still are times when you think "Well, gee whiz, life's pretty good" (laughter). Yeah, no, yes. So that there are confusing times, but not as many as there were.
> Interviewer. So it's settling down now?
> Vera. Yes, yes, yeah. But yeah, it took a while. To really decide definitely, and like we got the papers and signed and everything. … So that decision has been made. … Somebody has to say stop sooner or later for somebody, and that's hard. Especially if it has be a family member or something, that's dreadful. … It makes it hard on medical staff as well. To have to say, "We will turn that switch off." (8.1.4/2)

Pete and Vera both seemed to suggest a sense of relief that the decision was made, a finding reported elsewhere.[545] Although this may represent a benefit of finalising such decisions, it also points to the existence of some pressure to make the decision, one which may not always contribute positively to the patient's overall experiences at this time. Certainly, Vera's speech here ("Yeah, no, yes") displays some ambivalences regarding the decision, even when she has been able to "decide definitely." Both she and Pete also indicated that part of the impetus towards their making the decision was to ensure that others would not have to. To construe the DNR decision as a task undertaken to relieve others of the necessity for a future decision is to implicate others in the decision, thus establishing the decision as having social aspects, a point now explored.

8.2 Other-centred (social) arguments

Most patients mentioned others as figuring in the DNR decision. These others had various degrees of personal connection with the patient, including those most intimately connected with them (their family), those caring for them (clinical staff), and a more abstract notion of the society or community within which they lived. Specifically, patients spoke of avoiding others' suffering, and of not burdening others, both their immediate family, and the medical system.

8.2.1 Avoid or end others' suffering

Most participants spoke about the effects of their dying upon others. Two persons, Maud and Yves, spoke of the difficulties they had faced in watching their mothers die, citing this as explanation for their own desire to ensure first, that they would not die similarly, and second, that others would not have to watch them so die. Both alternated between consideration of the dying patient, and of those observing this, intermingling the suffering of patient and observer to the point where sometimes it becomes difficult to ascertain whose suffering is under discussion. In addition they defined the experience as lacking value for both the patient ("you're no good to yourself," "there's not a life"), and the watcher ("you're no good to your family," "it's not right," "it's not a nice thing to see," "not something to go through").

> Maud. I had my mother went [died from cancer], and my sister (crying) and it's cruel to watch it, and you can't do nothing to help them. This is why I think that you should have a choice too. I've been there, I've seen it, and it's cruel (crying). ... Yet we had to go and face her too, we were hurting and she didn't know us, and there was nothing we could do about it. That's not right (crying). It's hard on the person, it's hard on everybody that's got to sit back and watch. ... Because you're no good to the world, you're no good to yourself, you're no good to your family. So why should you want to go on and suffer for nothing? For one thing, you don't know them. ... I don't know whether I sound a coward or, do I want to run away from responsibilities. It's not that at all. It's not only me, it's everybody around me that's got to suffer too. And that's not right. (8.2.1/1)

> Yves. Partly through what I saw my mother go through [helped me decide about DNR orders]. She died of cancer ten years ago, and I saw what she went through. ... I saw a lot of people in [the hospice], and all the suffering, and there's not a life, ... why continue it? And seeing them die, to go through that, and I'm virtually (laughs) going through the same thing at the moment, I wouldn't want that ... for me. ... And she wasn't in the hospice very long before she passed away, which was good because she was in a bad state at that stage, and I said to the people out there that I don't want to go through all that. ... I did see people [unconscious with tubes attached], and, it wasn't, it's not a nice thing to see, and particularly when your mother's dying in a room down the corridor, and you see someone else you know with one (...) hanging off them, and it's not something to go through really. (8.2.1/2)

As the experience of the patient's dying was defined in terms of suffering and worthlessness, avoiding it, or rather, ensuring that it is curtailed, was established as a reasonable, humane, and thus obvious, conclusion. More than this, the patient's choice to avert this situation could be seen as altruistic, as other-centred, rather than self-centred. Choosing to avoid one's own suffering may be deemed cowardly, as Maud said, wanting "to run away from responsibilities"; choosing to avoid suffering for others is more readily seen as noble and considerate. Either way, suffering is presented as a compelling

justification for desiring the patient's death. As the DNR decision is taken as operating to curtail such suffering through ensuring the patient's death, it may be further positively evaluated.

However, the merit of terminating the suffering of others also lends itself to arguments for ensuring that a patient dies earlier rather than later. Maud's mother, for example, contributed to five years of suffering for her family, something which Maud (who consistently equated DNR orders with euthanasia) assessed as wrong, and as something about which there should have been a choice—presumably to end it.

The juxtaposition of the suffering of patients and observers (commonly family, but sometimes carers), was evident in others' speech. So too was the conclusion that the experience should be ended.

> June. I think I'd rather have the order than someone just revive me, and keep me going for a couple of weeks, and putting everyone else through it too (crying).. That's the worst thing of it, putting everyone else through it as well (crying). (8.2.1/3)

> Otis. [Living with pain is] not living, that's not being good for me, and oh I don't know maybe just from being here people have got to know me, and probably don't like to see me like it is, because they can't do anything about it either. (8.2.1/4)

> Tom. The best all round would be to not be resuscitated. I mean, Viv (wife) was saying the other night when I was admitted back here to hospital that the agony and the pain, the trauma, that, not only me, but that we were both going through, and it's just that. (8.2.1/5)

> Wendy. [My children] don't need to, they don't need to see me that bad … . If I could die quickly like that, that'd be probably a good thing. (8.2.1/6)

Many patients appeared to presume that to see suffering is to suffer. This sets up a cycle of suffering (See Figure 10). The patient suffers from watching others suffering from watching the patient suffering; and, as suffering (though rarely defined) is bad, actions to end or avoid it can only be positively evaluated.

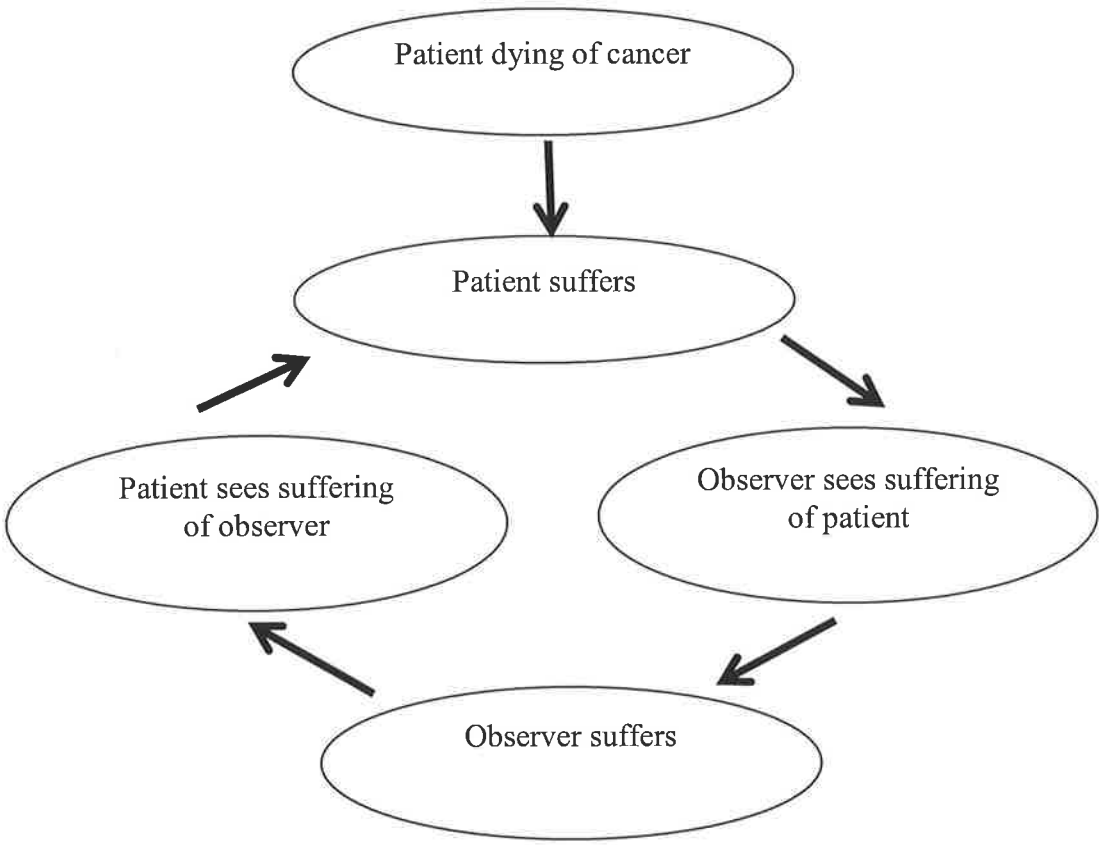


Figure 10. *Relationships between patient's and observer's suffering*

This conclusion in favour of action is further strengthened as the observers are construed as helpless, unable to do anything positive to change the situation (e.g., see 8.2.1/1 and 8.2.1/4). Given a culture where agency is prioritised over passivity,[546] any action to end this helplessness (and suffering) has considerable appeal—both in the actual taking of action (doing something), and in terminating a period of extreme enforced subjection to circumstance. Where death is perceived as something to be resisted, yet as fundamentally uncontrollable, action to effect the circumstances of death may be deemed as indicative of control over it,[547] and thus positively construed.

Several patients appeared both to anticipate and fear a painful or protracted death (see 8.1.1/1-6 above). Often, this was based upon their observations of a death that followed periods of reduced cognitive capacity, and that they deemed shocking or unsightly (see 8.2.1/1-2, 7), or extrapolated from their own previous experiences of pain (see 8.2.1/4-5).

> Ross. I guess you always make decisions based on what you experience in life. And I remember seeing my father. He died of cancer, that was smoking-related. But yeah, it wasn't a pretty sight towards the end. … I just draw on that experience … . I don't think I would have liked to have laid in bed under drug-induced comas for the length of time that he did. … And in the end he looked shocking.

> Wife Margie. It was because of the drugs he was on. He hardly knew us sometimes. … He wouldn't have wanted us to see him like that.
> Ross. No, he wouldn't have. (8.2.1/7)

As observed above, in the context of anticipated pain, compromised cognition, or unacceptable dependency, the DNR decision is favourably construed: It curbs medical intervention that might prolong these states, and, in ensuring the patient's death, minimises the amount of suffering to be endured (by all). These collectively constitute a convincing and compelling argument. What is not featured here are the possibilities that suffering may have benefit to patients (see 8.1.1), or to the watchers—perhaps through the opportunity to provide comfort and support in another's dying, or to gain an enhanced awareness of humans' intrinsic mortality.[548, 549]

In addition, the presumed association of suffering with death need not be axiomatic: Pain may be minimal or alleviated (at least theoretically), measures to prolong life may not be instituted, and both patient and watcher may view death as appropriate and welcome, and therefore not as a cause for suffering. Certainly the latter point features in some religious teachings and has been dominant at other times in Western history.[550] It was particularly evident in the speech of Sally, the most overtly religious of all participants (see 8.3.2.2/2). Nonetheless, even for Sally, the anticipation of pain and suffering for all, though not as yet experienced by her, was taken as further justification for the DNR decision.

> Sally. I feel that by making this decision, I am not then prolonging the agony that perhaps we have to go through then. Although I must honestly say that there hasn't been agony I suppose as far as I'm concerned, with my treatment that I've been getting … . (8.2.1/8)

However, not all the suffering anticipated for family was consequent upon observation of the patient's suffering. Several persons spoke of the negative experiences the family might "go through" when the patient was unconscious, and therefore, not actually suffering themselves. Here suffering is construed again as inherent in the watching of someone (a family member) die. Thus, the patient's death was positively construed as ending the suffering for the family, and DNR orders as ensuring this.

> Scott. I don't think a lot of people think about it, take time to really think about things because if you're in a vegetable type state, it's what your family's got to go through. (8.2.1/9)

> Xavier. I don't think that [resuscitation] is good for the patient or for the doctors either probably. … Because what are you keeping prolonging life for, who are you doing it for, not the person, because they've got no life. … You're running heaps of medical staff, you're running the family into the ground because they're around,

> hanging around visiting every day, sitting by the bedsides whatever, so you're running everybody into the ground, for what? What? (8.2.1/10)

Family were again depicted as helpless, and, as was the case when discussing patients' pain and suffering at the end of life, the language used defined the experience as inescapably and overwhelmingly negative. This further worked to define the DNR decision as choosing between two contrasting alternatives: either, a choice to inflict suffering on others (and self), or to ensure that suffering was minimised. No choice really.

8.2.2 Avoid burdening others

Another other-centred justification for favouring DNR orders, often associated with the notion of sparing the family negative emotional stress, was that of minimising the disruption to family life, typically phrased as 'not being a burden.' As I have noted previously (see 4.2.2), this negative interpretation of a reliance on others for care, re-presents the Western valorisation of independence, and constitutes a powerful (and oft-cited) argument in support of actions to prevent outcomes of dependency.

> Pam. Oh, that the family are in agreeance [sic] with [DNR orders], you know. Yeah, that we're not going to keep on suffering and suffering and suffering. It's gonna be a shock to the people, but, no. I think it'll be relief to everybody, the family can get on and live their own life, and, you know. (8.2.2/1)

> Pete. I don't want to be a burden. I don't want to be in the situation that, because of my illness, that I'm stopping or stalling anybody round me, doing what they need, or daily routines or what they want to do in the future. … I don't want to be a burden, I don't want to be because later on when I'm not around, I worry about how people will feel about that, that they could have done so and so and so and so. But they couldn't because they were committed to me. And I don't want that burden to be put on them … . (8.2.2/2)

> Sally. Because although I had [moved to Adelaide] to be a help to my family, which has been very important to me all my life, it still is that I'm also a burden to them. Or perhaps they wouldn't call it a burden, but that I am on their hands all the time, and that they have to help. (8.2.2/3)

Citing dependency (being a burden) as justification for DNR orders works to achieve several outcomes for the patient. It establishes the patient's own position as the socially responsible adult, cognisant and considerate of the impact of their situation upon relevant others.[314, 399] As an expression of altruism, it is a difficult argument to dismiss, particularly given the relatively low status accorded those in a position of dependency, and onus placed upon avoiding such a state. Precisely what constituted a burden was often left unstated, but for many it seemed to entail any kind of commitment to the patient, as the burdening effect of interrupting other potential activities the family might undertake was depicted as only

relieved by death. Thus, a patient may always identify themselves as a burden—Sally, for example, construed herself as a burden upon her family, even while acknowledging that they might not see it that way—and if the patient's appraisal of themselves as a burden is accepted as legitimate grounds for a decision, the decision will be difficult to dispute or reject.

These accounts reinforce the notion that family attendance upon their dying relative has no positive outcome for family itself. Rather it constitutes an interruption in their own life, and causes them emotional stress—such that only the patient's death would provide "relief" enabling them to "get on with their own life." In contrast to Victorian mores,[550] the time and effort spent was not seen as participation in a pleasurable and mutually beneficial interaction between individuals (particularly in a familial relationship) or, as suggested by others,[540] as affording opportunities for emotional or spiritual growth. Rather, it was depicted as depleting family resources to no gain, as the patient has "no life" and is just a "vegetable" and thus cannot benefit.

Given that this argument foregrounds the importance of social ties, it is ironic that it works to devalue the importance of the individual patient in the lives of others. It presumes that, in dying, patients' contribution to their loved ones' lives is at best trivial, such that their demise will enable life to resume as normal, and at worst, negative, such that they represent a draining presence in these others' lives. Furthermore, patients are construed as using resources to which they are not entitled, and thereby depriving others of the use of these resources. With this as a background assumption, any notion of a positive contribution to be made by the dying is marginalised.

8.2.3 Don't take up useful beds

An implicit evaluation of the worth of the dying patient was also discernible when participants spoke about the appropriateness of committing medical resources to a terminally ill patient post cardiac arrest. This was typically phrased as 'not taking up a [hospital] bed' that might otherwise be allocated to another (not terminally ill) patient, many participants labelling this as a "waste."

> Scott. I don't want to be put on life-support systems. … What's the good of just laying there, like a vegetable? So I might as well go, and [let them] try to help somebody else … . Well why take up a bed, someone could come in with a trauma accident and keep going for another twenty thirty years afterwards. Where I won't be, I'll be just taking up a bed. (8.2.3/1)

> Vera. It just doesn't seem right to me, to bring anybody, or keep anybody alive that's terminally ill. If they are, that's silly. Save the ones that can be saved, and who are healthy … .(8.2.3/2)
>
> Xavier. It's a waste but, it's a burden on the medical system at all frankly, I mean why should people hang around for an extra few weeks in hospital system with scarce beds, when they shouldn't be there, and, and the same for me as for everyone else so at the point you shouldn't be there, you shouldn't be there, so why do you want to take up this bed, spend public money and waste my time, waste my family's time, (…) for another two weeks or three weeks when it's totally unnecessary. (8.2.3/3)

This category of talk displays similarities to the previously discussed injunction to avoid burdening others, with the patient under consideration for DNR orders construed as depleting resources—which is construed as wrong. It sees patients as competing for resources, and takes as normative the following: (1) that medical resources are not (and need not be) infinite, and (2) that they be legitimately preferentially allocated upon the basis of (3) the probability that the potential recipient will benefit (i.e., "be saved") from the use of medical resources. Further that (4) patients who are terminally ill will not so benefit, and (5) are not automatically entitled to resources required to keep them alive, and that (6) their use of "beds," "life-support systems," "time," and "public money," is a waste of said resources, and therefore wrong.

These participants do not presume that life should be extended at all costs, but view cost as relevant in establishing the appropriateness of establishing DNR orders. Establishing comparative entitlement to resources as relevant to the DNR decision constructs it as social, economic, and moral, and may work as a counterpoint to claims rooted in assertions of autonomy. Patients cannot expect to claim access to all and any resources they wish without potentially incurring some moral judgement, and similarly, those wishing to commit resources to all patients, regardless of their prognosis or the economic consequences of doing so, may, within this discourse, justifiably be held to account (see 8.2.3/3-4).

This argument appears compelling and reasonable—given limited resources, surely they should be best spent on those who would best benefit from them? However, asserting the merits of particular treatment decisions for particular populations based upon economic cost is a contentious issue. While some claim that Western communities cannot continue to provide expensive treatments deemed to have little benefit to the patient,[61, 551] others (including patients) have expressed concern or anxiety regarding potential undesirable consequences for individual patients of an implicit or explicit policy that might be seen to

prioritise money over care.[58, 200, 552, 553] Terminally ill patients within the hospital are always taking up resources that could be used by those who are not terminally ill. They may thus be construed as constituting a burden upon society, with the available conclusion that they should be denied said resources. Patients are therefore implicitly required to justify their entitlement to use of resources. For example, in speaking of why he favoured DNR orders, Paul (below) used the 'burden' argument, but also acknowledged that he was, even at that time, taking up a bed that might be better given elsewhere.

> Paul. I really cannot see that I would be making much contribution to society, I would be a burden on it. I know I'm taking up a bed that could be used by some idiot that crashed his car into a tree or something, but I quite enjoy myself, enjoy myself at home better of course. But, I, that's how I feel. (8.2.3/4)

Paul's rejection of the available conclusion that he might not be entitled to the use of these resources was achieved through invoking arguments based on quality of life ("I quite enjoy myself"), and autonomy ("that's how I feel"). Although this points to the flexible nature of these discursive resources, it also demonstrates that the need to address the issue of 'inappropriate' use of resources may feature in patients' decision-making.

Other consequences of such arguments can be surmised from Xavier's speech at 8.2.3/3. In justifying institution of DNR orders, Xavier particularly focused on waste, asserting that people should not "hang around for a few extra weeks … when it's totally unnecessary." Here, the use of the imperative "should" construes the DNR decision as a moral imperative: Persons should choose not to be resuscitated, and those choosing to be resuscitated are morally culpable, because this leads to a waste of resources, that is, deprives others. The phrase "hanging around" further works to construe these patients as inappropriately utilising resources, and as an unwelcome drain on society and others, again establishing the DNR decision as of moral, social, and economic import. Xavier repeatedly argued that CPR for the terminally ill constituted a wasting of resources, and presented the conclusion in favour of institution of DNR orders as the only reasonable option. Although this appears to contradict his other assertions that the choice for resuscitation might be justified if the patient could present convincing evidence that there would be benefit accruing from their continued existence (see 8.1.2/4), this latter position is, nonetheless, entirely compatible with the 'waste' argument. Finally, arguably realising the fears of many anti-euthanasia exponents, immediately following his talk shown at 8.2.3/3, Xavier continued with speech about the merits and necessity of euthanasia, demonstrating that these arguments in support of DNR orders can be seamlessly transferred to discussions on euthanasia.

8.3 Fatalistic (philosophical) arguments

The final category of arguments put forward to justify instituting DNR orders represented some form of fatalistic assertion, or philosophical acceptance, that death was inevitable, and could not be gainsaid. For many, this justified the conclusion that resuscitation was pointless. Other reasons were centred around a symbolic significance accorded a cardiac arrest: For some, the heart stopping symbolised life's end, identifying that moment as the appropriate time for death to occur; for a few, it represented God's call to them.

8.3.1 Death's inevitable ...

In speaking of the inevitability of death, most patients specifically referred to their own circumstances. There was variation on the theme, with references both to the limits of medical science, and of the human body.

8.3.1.1 ... because I've got (non-curable) cancer

Several persons mentioned their medical prognosis—not only cancer, but terminal (or non-curable)—as self-evident justification for rejecting resuscitation. This often took the form *I've got cancer, they cannot cure it, so resuscitation is pointless*. This account, in defining the patient in terms of biological status, both asserts and challenges the dominance of medical discourse in this setting. Medical science determines the diagnosis, naming the biological condition and trajectory for the patient, but in doing so specifies its inability to cure the patient. Thus the limits of medical science featured as justification for limiting medical practice, with the specific practice of CPR construed as 'pointless' (see also 8.3.1.4). The construction of the patient through medical and biological discourse, most commonly used to establish medical authority, here serves to limit medical authority (see also 4.2.1).

> Opal. No, in a case like this, knowing that there is no cure for the cancer, then I can see no point in resuscitation or anything, if your heart stops it stops and it's over and done with. (8.3.1.1/1)

> Scott. When I go, I don't want to be resuscitated because I've got a terminal cancer, there's no good bringing me back. (8.3.1.1/2)

This construal sees not just cancer, but the failure of medical science to cure it, as salient. Otis, for example, in discussing the appropriateness of DNR orders, repeatedly said there was no cure available for him, taking this as an unassailable 'bottom-line' argument for DNR orders. Pam also referred to the failure of medical efforts to help, concluding this signalled a time to die.

> Otis. The medical part of it can only do so much, your body can only do so much, and then in the end there's not a cure for it, it's basically what it comes to. There's no cure... they can't cure me, there's no cure from them, and the bottom-line is there is no cure for me, I've learnt, I've coping [sic] with that. We all come to an end sometime. (8.3.1.1/3)
>
> Pam. When they told me that there was nothing else they could do for me, I thought, well, what's the good of hanging on. You know, going on and on and on. They can't help, the medication has failed, they haven't got anything else to take its place, so it's time to get out. (8.3.1.1/4)

The predicament (and decision) of the patient is thus defined, at least in part, as consequent upon the limits of medical science. At the same time, the inability of medicine to cure is construed as failure, thus reaffirming that the role of medicine is to provide a cure for illnesses, to maintain life. Death, in this construal, is a consequence of a failure of medical knowledge (as opposed to the 'natural death' discussed in 4.2.1 and 7.2.2), and, as an external force that overcomes the individual (see Charmaz,[347] p. 92), as opposed to inherent in the condition of being human, discussed in 8.3.1.3 below.

8.3.1.2 ... because resuscitation just prolongs things

The limits of medical science were also implicated when participants anticipated the consequences of resuscitation. They did not impute value to the life that might be restored if resuscitation was instituted, noting that their situation would be unchanged, that not "much could be done," and there was no "chance of any improvement." Thus, without possibility of cure, resuscitation was negatively construed as "prolonging things," with the connotations of exceeding some form of appropriate limit (see 4.2.2).

> June. I think in my situation, it's not a case with me where, if they resuscitated me, much could be done anyway. It would just be prolonging things for a couple of weeks if that. (8.3.1.2/1)
>
> Nina's husband Ray. Nina's decision was that [CPR] wasn't worth it if there was no chance of anything [improving]. ... If there was any chance of any improvement, all right, they would do that as a last resort, but if it was virtually final, and they couldn't give her a decent life in the future, then don't worry about it. Is that right Nina?
> Nina. That's right, I think that if it's inevitable, if it's going to prove nothing, there's no point in going on any further with it. (8.3.1.2/2)

This does not construe life *per se* as intrinsically valuable, as participants intimated that any life that would be gained following resuscitation would be of short duration, or impaired quality, taking this as grounds for rejecting resuscitation attempts. However, resuscitation was also deemed unacceptable because the inevitability of death meant that the patient would just die again later. This was negatively construed as futile ("what's the

use"), cruel for patients ("don't make me hang around ... [in] pain") and family ("give the family real grief"), and unjust ("a travesty of justice"), all of which work to further denigrate this unwanted resuscitation. Parenthetically, Dennis' speech (8.3.1.2/4) also alludes to the possibility that presenting the DNR discussion to the patient may also been deemed inappropriate. Echoing Vern's intimation that DNR orders require the patient to choose between two unpalatable options (see 7.6.1/4 and discussion), this again construes resuscitation (and thus DNR orders) as a moral issue.[9]

> Scott. It's very simple, I've got terminal cancer. I'm going to go anyway. And, why bring me back (...), I'd only be there another week or a fortnight or a couple of days, and I'd be gone again. I could go again, so what's the use. There's no use in it. (8.3.1.2/3)
>
> Wendy's husband Dennis. [The DNR discussion] is about [saying], "You're dead right now, do you want to stay that way, or do you want us to bring you back and then make you decide all over again whether you want to die later?" That's really what [it means] because ... at the end of terminal circumstances, it's absolutely pointless, other than to give the family real grief basically in my opinion. The [DNR] in that respect is, "I am at the end of the line, don't make me hang around any longer," basically. That's because ... there is nothing after that, except pain and bed-ridden pain. (8.3.1.2/4)
>
> Xavier. I think it would be a travesty of justice if people make that decision and then they're resuscitated, and they didn't want it. And they live another three days and then they go through it again, you know. (8.3.1.2/5)

The language in several of these excerpts works to construe resuscitation under these circumstances as an imposition upon the patient. For example, phrases like "make me hang around," and "they didn't want it" connote actions performed on someone against their will. As earlier commented upon (see 4.2.1), resuscitation is thus construed as violating patients' autonomy, a position more strongly established when patients directly asserted their desire not to be resuscitated, as many did.

8.3.1.3 ... because humans die

Although the inevitability of death was sometimes construed as a consequence of patients' incurable cancer, death was also deemed simply inevitable (see also Otis at 8.3.1.1/3).

> Sally. I think in the long run, I know that I'm going to die. Because I am getting older every day. Yes, all of us are. (8.3.1.2/1)
>
> Paul. One has to die. ... You've got to die, let's do it a nice way, that doesn't hurt. (8.3.1.2/2)

The previous cited arguments regarding the inevitability of death work to construe it, to some extent, as a consequence of the patient's disease or a medical failure to cure. This sees it as out of the ordinary, as a product of error, and thus, though unavoidable, as wrong. By contrast, this construal of death as inherent in the condition of being human ("all of us [die]," "you've got to die"), has many similarities to the 'natural death.' It works to normalise death, rendering it less an external force to be feared, resisted, or explained. Death is perceived as no less inevitable whether it is a corollary of cancer, medical failure, or the human condition, but may be more difficult to accept when ascribed to failure.

8.3.1.4 ... therefore resuscitation is pointless

One of the recurring phrases in this section was that there was 'no point' to resuscitation. Here it is not the life itself that is deemed pointless, but any intervention to prolong it. This was asserted on several grounds, all based on a recognition of the patient's imminent and inevitable death. Resuscitation could not make things better, might make things worse, and ultimately, could not deny death for long.

> Opal. Knowing that there is no cure for the cancer, then I can see no point in resuscitation or anything, if your heart stops it stops and it's over and done with. (8.3.1.4/1)
>
> Vera. I couldn't see the point [to resuscitation]. I mean it's terminal .... (8.3.1.4/2)
>
> Xavier. If the person's choice is to not resuscitate, in other words they don't want it prolonged, what's the point of it? (8.3.1.4/3)

Such language (se also 8.3.1/1, 8.3.1.2/2, 4) works to construe refraining from resuscitation as, not only the preferred, but the normative option for dying persons. Thus the onus is placed upon those who might consider resuscitation for such persons to provide compelling reason for it, to provide justification. Additionally, those who actually perform CPR on the dying can be held to account, whereas those who do not are likely to be perceived as having acted appropriately. Concomitantly, those who make decisions in advance regarding these actions may be similarly positioned: Again, DNR orders are constructed as reasonable and preferred.

This construal has obvious similarities to the medical construct of futility, as the lack of justification for the option of initiating CPR here lies in terms of its failure to provide benefit. This contrasts with the argument that featured when patients spoke of the social aspects of their decisions. In that case, the lack of justification for CPR lay in inappropriately depriving others of valued resources. In a more philosophical frame, what

was at issue was not relative entitlement to beds, or interpersonal obligations, but the probability of achieving a successful outcome from the procedure. This set of reasons for refraining from CPR, appears to proceed from a far less morally loaded position, and would seem less likely to engender negative outcomes for patient and family.

8.3.2 The significance of cardiac arrest

For several patients, the cessation of a heartbeat signalled the appropriate moment of death, either because the (patient's) body was deemed to have reached some limit, or because this was God's notification that it was the appropriate moment to die.

8.3.2.1 When my heart stops, I'm dead

In effect, this argument—that when the heart stopped you were dead—defined death for many participants, and provided a point to cease intervention, a point when the patient might (and should) be left untouched. In so defining death, any intervention following cardiac arrest may be deemed to be effected upon a dead body; Nolan[16] has used similar language in referring to "reviving corpses" (p. 191). Thus CPR may be construed, not only as unwanted, but as an inappropriate violation of the dead, a state which has moral, religious, and legal sanctions potentially applicable.[554, 555]

> Paul. If my heart stops, I would be dead. Leave it that way. … See I've said "If my heart stops, I reckon I'm dead." I don't wanna be resuscitated, to come back to no life literally. (8.3.2.1/1)

> Opal. If my heart stops, they're gonna bury me (laughs), it's as simple as that (laughs). … I'd simply tell [the doctor] to let it stop. (8.3.2.1/2)

Until the mid-twentieth century, the cessation of heartbeat was equated with death, both in lay and medical parlance.[347, 385] Within medical discourse, the signifier of death has now shifted to cessation of cerebral activity,[385] but these excerpts support the contention that the significance of the heart endures for the lay person.[5]

Some patients (particularly Otis below, but also Yves and Una in 8.1.1.1) appeared to accord signification to asystole beyond its equivalence with death, namely, that the body had reached its limit, had "had enough." Here, the heart is endowed with agency and ultimate authority over the individual patient themselves—paradoxically, as it becomes silent, it articulates its message that now is the time to die. The heart was depicted as the last bastion of resistance to the disease from the body, that would only stop when "it's time" to die.

> Otis. I've had a strong heart and that's what's pulled me through a lot of it, but I mostly think if it got to that stage in my heart, if my heart don't want to do it, … it's had enough. … Yeah, it's saying "it's enough Slim [Otis' nickname], … you couldn't do it, and you gave it your best shot and that's the way it's got to be." … Whatever the heart is, that's the thing that does it all, when that's had enough, they go on about the old brain, well, mine's still in plastic (laughter). … [The heart] has been there for me all the time, and to me it's a message to say that it's the end. … When the heart don't want to do it, then it's time. (8.3.2.1/3)

Construing the heart as the ultimate authority in determining the appropriate time for death requires that the patient (and others) comply with it, and specifically denies others this authority over death. To fail to comply with this determination, to attempt to restore life, is thus constituted as an inappropriate (and futile) usurpation of this authority. Corresponding, DNR orders, in forestalling such attempts, are constituted as appropriate. In addition, however, as the patient is positioned as simply responding appropriately to a higher authority, this construal works to de-emphasise the significance of DNR orders, and, to some extent, to reduce individual responsibility for the decision.

8.3.2.2 It's God's call

The heart was not the only construct accorded authority over time of death. Sometimes it was God.

> Oliver. I don't think it's the doctor's right to say whether or not to terminate somebody's life. … It's up to our maker, to God. … God says, and that's it. And He does it to me, well that's it, there's nothing much [more to say]. (8.3.2.2/1)

> Sally. While [God] still wants me to live, I will try to live to the ability that I can and satisfy his wishes for me. But I would definitely like to go when his first call comes, I would not like my life prolonged in any way at all. … And if God calls then it is my duty to go. And to not be pushed into living another week, or another fortnight, or another month, or whatever it may be. (8.3.2.2/2)

Cardiac arrest is here positively construed as God's call, and allowing death to occur unimpeded represented as compliance with God's will. This works to identify death as a religious, rather than medical issue, as medical authority over or even significance in the process is denied. These participants unequivocally stated their wishes to comply with (rather than resist) God's call, thereby also establishing the decision as personal. Yet simultaneously, the role of the individual patient is limited to acquiescence with God's decision, thus minimising both the actual significance of the DNR decision, and patient responsibility for it. To attempt resuscitation is depicted as an act of defiance and impiety. Thus in this construal, the institution of DNR orders is favourably construed as working to ensure that God's will is effected, with patient autonomy realised through their willing

submission to God's will. Although uncommon, this construal was available as an option, and in those social groups that have a strong religious tradition, may be more prevalent, or dominant.

8.4 The DNR category

Most participants in this study favoured the institution of DNR decision in their circumstances: Because the institution of DNR orders is equivalent to rejection of resuscitation as an option, the implication is that CPR was deemed inappropriate. As I have demonstrated above, there were several arguments available and utilised in order to justify this position. To summarise, the institution of DNR orders was variously justified as minimising or preventing suffering (of patients and others), avoiding undesirable sequelae of resuscitation, reflecting the patient's wishes, preventing squandering of resources (both at a interpersonal, and social level), complying with the will of a higher authority (God or the heart), and as the reasonable option because the cancer was terminal, patients were "at that stage," "quality of life" was absent or diminished, and, as it could not forestall death for long anyway, resuscitation was "pointless." Several explicitly used the phrase "I want," (or some variation thereof) thereby establishing patients' desires as critical and pre-eminent (e.g., see 8.1.1/2 & 5, 8.1.1.1/1, 8.1.2/3 & 5, 8.1.3/1 & 3, 8.1.3.1/1 & 2, 8.1.4/2 just within 8.1). Collectively, these arguments work to construct a category of persons for whom DNR orders might be deemed appropriately instantiated and CPR foregone (hereafter referred to as the "DNR category").

8.5 Justifying not establishing DNR orders: Deviant case analysis

There were, nonetheless, 'deviant cases,' that is, instances of talk where (1) institution of DNR orders was not construed as appropriate, which carried the consequence that CPR, as the default practice, was; or (2) provision of CPR was presented as appropriate, and by implication, DNR orders were not. It may be illuminating to explore how patients justified these options, given the overwhelming number of arguments available and used by participants to support considering resuscitation for this population as contra-indicated. This is particularly salient given discrepancies between some patients' actual DNR status as noted on their file, and their expressed views as derived from the interviews (see Table 6).

8.5.1 I'm not in the DNR category

When patients repudiated institution of DNR orders, they typically drew upon previously discussed justifications or markers for the appropriateness of DNR orders in order to

exclude themselves from the DNR category. I earlier examined how Sean and Oliver justified not having considered the DNR decision (see 7.6.2). Although neither specifically stated a desire to be resuscitated, their construal of the decision as appropriately deferred to another time carried with it the implication that CPR would be deemed appropriate at the time of interview. During the interview six other patients (Pete, Tina, Una, Wayne, Xavier, and Zack) specifically expressed a preference that CPR be initiated following cardiac arrest. Pete, Una, and Zack were unequivocal about this, Tina, Wayne, and Xavier expressing different views at different times throughout the interview. Pete did not have a current DNR order on his file, but Una and Zack did (see Table 9).

Table 9. *DNR status of patients who (during interview) indicated a preference for CPR (Study 2 only)*

		Was a DNR order on file?	
		Yes	**No**
Did the patient want CPR attempted?	**Definitely Yes**	Una Zack	Pete
	Yes & No	Tina Wayne Xavier	-

Both Pete and Una justified their preference for resuscitation by establishing their status outside the DNR category. For Una, this rested on distinguishing between those (others) who have a heart attack because they are "advanced," or a "hospice type person" with "heart problems," and those (like her) who are not "at that stage yet" and for whom the heart stopping reflects a temporary and reversible error. Thus, the appropriateness of these categories was uncontested, and what was at issue was their applicability to her. She did not identify herself as someone who might, in fact, die in the foreseeable future.

> Una. When I got brought into emergency, one of the doctors down there asked me, and I thought "What do you mean if my heart's going to stop?" I'd never have thought about it, because I came in for pain, and I thought "What's my heart got to do with pain?" No, I've haven't [thought about it] until then. And I haven't thought about it since. But I suppose you've got to be a bit more advanced to be ill for your heart to stop, so I don't think that I'm at that stage yet. ... I think those people are further down the track they'd be, probably a hospice type person that needs to answer that question. ... It was just a five-second question, I was sort of a bit shocked when I got asked because I wasn't expecting it. All I wanted them to do was to fix my pain up, I wanted to go home. So I haven't really given it much thought after either, but, the right time. I think you know. ... I think your body tells

> you. I think that there is something there in your body … . If I go back to my room and something happens, should I be resuscitated? Probably right at this moment now, I'd say yes, because I'm not aware that I have heart problems. So for my heart to stop, it's got to be something, something's gone, [maybe from] anxiety. Something's gone wrong, so, yeah. Probably, if you're talking about this direct moment, like if I was a lot sicker, well then obviously there's wear and tear all over the body, and, and that would be another decision again. … [When the doctor asked me] I was in pain, and (laughs) I said "What?" I think from memory what I said was "Well, I wouldn't want to live on a machine" … . But I wasn't really thinking that day there and then, I was thinking when I get sicker. (8.5.1/1)

Drought and Koenig have observed that terminally patients often do not associate cardiac arrest and CPR with their own disease.[121] For Una, DNR orders precluding CPR were appropriate for persons who were "a lot sicker," and notwithstanding her assertion that the "body tells you" when to deal with these issues, her own severe pain (requiring hospitalisation) in the context of terminal illness did not signify that death might be imminent. Neither apparently would a cardiac arrest, which she attributed as likely to occur due to, not physical, but psychological failure. Given that psychological failure implies no inherent biological defect to impede successful resuscitation, her decision in favour of resuscitation is justifiable. She died twenty-five days later, five days after her admission to a hospice.

There are several conclusions I want to draw from Una's speech. First, patients do not always recognise the probable progression of their disease, nor agree with medical assessments of where they are within that progression. As evinced by her introduction of the question, Una's doctor apparently considered that Una's physical symptoms indicated both the appropriateness of instantiating DNR orders, and that Una herself would be aware of this. In this instance patient and physician understanding of the significance of specific physical symptoms were not congruent. Nonetheless, in part, Una's position is dependent upon her categorisation of symptoms of pain, and a potential heart attack, as discrete entities and, moreover, devoid of significance in terms of her overall condition. Thus, although Una's assessment of her position appears to contradict the medical assessment, her argument mirrors the medical compartmentalisation of the body, such that the body and the diseases to which it is prone are delineated out and treated by different specialists.[298] It also draws upon a metaphorical representation of the body prevalent within medical discourse—the body as a machine,[31] with parts to "fix up" so the patient can "go home." Particularly with regard to DNR decision-making, this may hinder patients' abilities to apprehend probable causes for and outcomes following cardiac arrest.[556]

Second, Una's statement that "your body tells you" when it's "the right time" supports arguments that the patient's experience of their body is crucial in determining their preferences regarding establishing DNR orders,[198, 202, 204] but gives considerable latitude to what particular form this notification from the body might take. Positing a voice from the body to be acknowledged by the patient (see similar issues in Otis' speech at 8.3.2.1/3) presupposes a mind/body divide, with the body possessing and conveying information to be correctly received by the mind, this latter construed as synonymous with patient identity or agency. Potentially, either the body (saying the message) or the mind (receiving and conveying the message) might be deemed paramount, but ultimately, as both may be said to constitute the patient, only the patient can be privy to this information. This construal thus works to deny medical authority to determine the appropriate time to consider (and establish) DNR orders, thereby establishing the primacy of patient autonomy.

Third, the juxtaposition of the primacy of patient autonomy with the availability and acceptability of the journey metaphor of disease enables patients to assert that they are not "at that stage," and thus that DNR orders are not appropriate. For example, Una was "thinking" about these issues for when she was "a lot sicker," "a bit more advanced," and "further down the track" of her illness. Again, the implication is that although the patient's interpretation of their own physical state may not reflect the medical one, it can be fundamental in determining their position on DNR orders.

Fourth, the assertion that one "wouldn't want to live on a machine" does not equate to a request for a DNR order, although in Una's case, it was apparently so understood, with a DNR order written subsequent to her "five-second" consultation. For Una, not wanting to live on a machine pertained to a future time of increased sickness, but this statement was apparently interpreted by the doctor as having relevance "there and then." The doctor evidently proceeded on the basis that Una *was* sick enough, *was* "at that stage." This again points to the potential for miscommunication between doctor and patient based upon the different signification accorded particular physical criteria. Finally, and relatedly, patient autonomy is by no means assured, even when the doctor (somewhat perfunctorily in Una's description) seeks the patient's views.

Pete, on the other hand, implicated several features of the DNR category, including his diagnosis, dependency, physical impairment, being a burden, and preservation of dignity. However, he established a contrast between "if" he was the way he was now, and "if" these other conditions were operative, thus identifying them as not immediately relevant. This then supported his rejection of DNR orders based upon his current state ("the way I feel

today … I would want to be resuscitated because I've got tomorrow to look forward to"). As did Una, Pete affirmed the significance of criteria comprising the DNR category, but established himself as outside it (as indeed did the majority of participants in the first study).

> Pete. If I'm the way that I am now, the way I feel today, then I think that I would want to be resuscitated, because I've got tomorrow to look forward to. But if I'm in bed, and unable to look after myself, if I haven't got control of my functions, bodily, that sort of thing, then I think I'm a burden to people, and that's where I think I should be allowed to die with dignity, to just pass, without resuscitation. (8.5.1/2)

Pete's emphasis on how he felt now and his list of anticipated bodily deterioration suggests that, as was the case with Una, his subjective experience of his physical state was central in his decision-making, a theme noted in previous research.[557] His assertion that he didn't feel sick enough (yet) enabled him to locate himself outside the DNR category. However, Pete also drew upon some concept of quality of life ("the way I feel today … I've got tomorrow to look forward to") to justify a current preference for resuscitation, thereby placing his assessment of his life as the pivotal issue to be considered in determining resuscitation.

Invocation of these factors works to re-affirm the primacy of patient autonomy in these decisions, as well as prioritising subjective judgements about the value of life—having something to live for justifies resuscitation. This is a logical converse of the position that no resuscitation signals that the patient's life is no longer worth living (see 8.1.2). Concealed within the latter position, however, is the judgement that nothing in the patient's life holds value, that nothing is worth living for. Thus, the mere assertion that some aspect of the patient's life holds worth will suffice to stymie moves to establish DNR orders. Consequently, participants could, and some did—see Xavier at 8.1.2/4, and Wayne at 8.5.3/4—assert that resuscitation might be indicated or justifiable in circumstances where the patient had something to live for.

Resuscitation is thus construed as more than just a medical procedure, but as part of a moral code, part of social behaviour, with the potential for different attributions being made to various participants in the procedure (as similarly noted in Sean's speech at 7.7/1). The construal of the DNR decision as a choice to live for something or not implies a judgement about the perceived value of both the specific thing, and all other aspects of the patient's life, including their social relationships. However, notwithstanding the social import of the decision, what was critical was what the patient wanted, thereby affirming the dominance of patient autonomy.

8.5.2 I want them to try to keep me alive

The construal of resuscitation as holding significance beyond the medical also appears operative within Zack's speech asserting his preference (indeed demand) that resuscitation be attempted. Zack, in contrast with Pete and Una, did not deny potential membership of the DNR category. His preference for resuscitation appeared to rest upon construing it as a symbolic resistance to death: Resuscitation indicated that death had been fought to the very end. Zack repeatedly stated his desire for resuscitation to be attempted, increasing the strength of his assertion from "I want them to try as much as they can" to "I want them to … try damn hard to keep me alive." He corrected my précis of his wishes several times, usually ending each turn of speech with the injunction to continue trying, where, by contrast, I finished with the permission to stop. Furthermore, when I used language that might minimise or trivialise the attempt at resuscitation ("have a go"), he corrected this to "try as hard as they can," only ratifying my paraphrase of his speech when I used the phrase "keep trying." This suggests that for Zack, what was important was not the stopping, but the keeping trying "damn hard" "up to the point of no return."

> Zack. If it came down to it, I'd still want to be resuscitated if I can. If I can't after a certain time, and if it's not going to work, and the doctors realise that they can't do anymore, well there's no use in like giving me all this treatment for nothing, so I want them to try as much as they can, but if they can't within a certain time what they think is that time of no return, I think they should stop. But that, up to say the point of no return.
> Interviewer. So just to clear that up for me, and make sure that I'm understanding you right, would you want them to have a go, and then if it wasn't working for them to stop, or would you want them to, well now would be okay, but then if you get really sick or something, perhaps not to have a go, or, I'm not quite sure.
> Zack. No, no, no, what I'm saying is, if I have those, if I have the chest pains and everything else, I want the doctors to keep me alive. But at some stage if they can't do anything for me, with my heart and everything else, you know like with the things on me and ECG and all that other stuff on me, if they can't revive me after a certain time, there's no use continuing. But I want them to try as hard as they can for me to stay alive. Do you know what I mean now?
> Interviewer. Yeah I think so, so you're saying that whatever, you want them to have a go, and if it works, great, and if it just isn't working then they can stop there, they can stop trying to restart your heart. Is that correct?
> Zack. No.
> Interviewer. No I'm still not getting it right (laughs).
> Zack. No I think you're not getting it right.
> Interviewer. I'm not. OK.
> Zack. I want them to try as hard as they can and for as long as they can to try and resuscitate me, but if they find that after a certain time they can't, they might as well stop. OK.
> Interviewer. Yep, yep.
> Zack. You got it now?

Interviewer. I think so. If they keep trying and it just doesn't work, then they can stop.
Zack. Yep, but I want them to =
Interviewer. To try as much =
Zack. try damn hard to keep me alive.
Interviewer. Yep yep I understand.
Zack. Okay, so that's that's what I want and, so next question.

Zack's speech supports the contention that CPR has symbolic significance, indicating to participants and observers that death could not be averted: Death here is only an acceptable outcome when it has been fought to the finish.[5, 558] This works to counter claims that determining the provision of CPR is a medical matter, based upon medical criteria,[31] and that CPR should only be performed in instances likely to provide medical benefit—that is, the restoration of life of an acceptable standard to the patient.[29]

In contrast to earlier discussed depictions of CPR as a violent impersonal violation of person (see 7.2), Zack's description sees CPR as embodying the desires of patient and doctor to keep the patient alive, and thus as within the accepted parameters of medical practice. This positive construal of CPR therefore acts to legitimise Zack's demand for resuscitation to be attempted. In addition, it works to value the life of the patient under question: They are worth considerable effort (trying "as long" and "as much" as can be done) on the part of the doctors.[558]

This valuing of the patient may be discerned within Zack's subsequent assertion that "everybody else wants me to stay alive," put forward as justification for CPR. This represents his decision as inherently social, but also highlights the moral implications attendant on this construal of CPR. If everyone wants you to stay alive, then the provision of CPR is socially demanded, is morally required. Concomitantly, failure to provide CPR may impute a lack of perceived value of the patient by others.

Zack. Plus with all the prayers of everybody else that I get, and that's how I make my decisions, you know, it's not only me that wants to stay alive, there's everybody else wants me to stay alive too, so, yep.

Although denied the authority to determine whether or not to initiate CPR, according to Zack, the doctor was accorded authority to determine when to discontinue it—when "the point of no return" was reached. The authority of the doctor in this situation is not contested: What is at issue is the point at which it becomes operative. For some, the doctor determined the criteria for appropriateness of initiating CPR but had no authority over the decision to commence resuscitation (e.g., Oliver at 7.6.2/2); for others, doctors determined that the patient did not fit those criteria, and also that they should not be resuscitated (e.g.,

Rex at 7.6.1/1); for Zack, doctors might only determine the point at which CPR should be terminated. Thus although the DNR decision, as the decision to initiate CPR, was construed by Zack as non-medical, the decision to discontinue CPR was re-established as medical—but critically, here with the consent of the patient.

It must be noted that requiring that patients make a decision about the provision of CPR in the first place may be taken to imply that CPR is something to which patients should be entitled should they wish it, thus re-affirming the primacy of patient autonomy over whatever medical determinations may be operative. The issue is thus ineluctably constructed as personal first, then medical, with moral and social implications variously available. Zack's frequent use of phrases like "I want," "that's what I want," and "that's how I made my decision," indicates his assumption that patients' wishes are primary in the matter, that he can in fact demand CPR. For him, as for most, patient autonomy was unquestioned, and represents a challenge to claims that patients cannot demand CPR.[47]

One final point regarding Zack's speech: He presumed that his wishes were known to his doctors, that this determined his DNR status, and at no time appeared aware that there was an operative DNR order recorded on his file. This, despite documentation to the effect that he had discussed this with his doctor.

> Zack. I think [the doctors] know my feelings all about that. Yep. Yeah, … [They] all know the way I feel, and that, so even Dr Chen and that, they all know my whole decision about that and I'm not gonna change that am I, so at least they know my decision what I've told you, so that's that, and they were happy with that.

As was the case with Una, even when efforts are made to ensure patients' wishes are determined, it appears that patient autonomy cannot be guaranteed.

8.5.3 I do, and I don't want resuscitation

Tina, Wayne, and Xavier, who expressed desires for and against resuscitation in their interviews, all had a DNR order recorded in their case-notes at that time. As noted earlier (in 8.1.2), Xavier strongly favoured the establishment of DNR orders, but put forward his current "quality of life," and desire to pursue compensation claims (something to live for) as potential justification for attempting resuscitation. Thus he at least potentially laid claim to status outside the DNR category, and critically legitimised this claim with the assertion of patient autonomy as determinant.

Tina too wanted to have resuscitation attempted—but saw limits in this, perhaps affirming Winzelberg et al.'s[236] suggestion that patients may want a time-limited trial of intervention,

rather than outright repudiation. You should "put those clamp things on," but stop "if they didn't work." Even more than Una (at 8.5.1/1), Tina employed a mechanical metaphor in describing the process, with the human heart akin to a failed car engine that needs to be started up again, revealing the extent to which this metaphorisation of the person has taken hold. Despite this, rather than representing an impersonal mechanistic violation of person (discussed at 7.2), attempted resuscitation was positively construed as indicating that really nothing could prevent death (see also Zack at 8.5.2).

> Tina. Well as I say, just the sort of things they put in those, if the heart went, I think my breathing'd go before my heart'd go, but, to put those clamp things on, and if they didn't work, then just let me go.
> Interviewer. What you mean by clamp things?
> Tina. The shock, they give you =
> Son Nigel. = to start you up again. ...
> Tina. But I definitely don't want to be a vegetable. ... Yeah, I don't wanna be put on one of those life-support or anything. (8.5.3/1)

Failed resuscitation here seems to serve almost as a reassurance that this moment was the time to die. Again, this highlights the symbolic significance that may be accorded to CPR. What may be problematic in Tina's speech, however, is determining the point at which CPR "didn't work." Notwithstanding her endorsement of attempted CPR, she stated her desire neither to be a vegetable (i.e., brain-dead), nor put on life-support, both potential outcomes of attempted CPR in this population.[559] This may support the contention that the primary function of CPR in this instance is symbolic, but also points to the difficulty in precisely determining a patient's wishes when potentially conflicting desires are voiced. In part, Tina's position reflects the dilemma created by the medical ability to restore heartbeat even though its temporary absence may have led to loss of cerebral function.[29] Absence of cerebral function is not coterminous with absence of heartbeat, yet both may be invoked as indicators of death.[29, 385] Thus conclusions premised upon a medical ability to restore heart-beat may conflict with those that focus upon restoration of cognitive function.

This aside, the very terminology of CPR, in referencing heartbeat, not brain function, works to conceal the importance of the latter in both lay and medical discourse. Furthermore, because the DNR order centres around the provision of CPR (with focus on cardiopulmonary function), the situation is engendered whereby patients can voice desires that may be deemed contradictory, that may be differentially interpreted. This may go some way to explaining the finding that physicians do incorrectly assess patients' desires for or against resuscitation.[191] Although Tina expressed a desire not to be on life-support, this did not equate to a desire to forgo attempts to restore heartbeat (see also Una at 8.5.1).

Indeed the talk immediately following Tina's above speech suggests that Tina's family recognised potential discrepancies in Tina's speech, and collectively worked to define more precisely what she wanted.

> Son Nigel. What would happen in the event that they restarted your heart and you turned into a vegetable?
> Tina. Well they'd just cut the =
> Nigel. If they get your heart going again but you've gone brain dead, they just keep you going? Has anyone explained that?
> Daughter-in-law Alicia. At the moment, I think you're actually put in for non-resuscitation, at all.
> Son John. Yeah.
> Tina. I think it'd be for the best. (8.5.3/2)

Nigel twice oriented to the brain/heart distinction. His insistence that Tina consider the possibility of brain death, and that this needed explaining to her, suggests that for him at least, restarting the heart was not the only salient issue, and indeed might be deemed secondary to the possibility of brain death. Alicia observed that there was indeed a current DNR order operative, with confirmation by son John, followed by endorsement of this by Tina. Thus, Tina effectively retracted her earlier expressed desire for resuscitation to be attempted. Arguably, this decision was very much a family decision, and, the DNR decision documented in her file recorded that her family were both present and active at the meeting at which Tina's DNR status had been determined. I will comment further upon patients' talk regarding family involvement in the decision at 9.3.

Despite the achievement of family consensus regarding Tina's DNR order, Alicia's follow-on speech reveals some of the dilemmas and difficulties this posed for them.

> Alicia. I think the hardest thing is, she might be resuscitated, and as you say, (...) resuscitate starts breathing again, that would be fine. But she might be resuscitated but then have something wrong with her, like being a vegetable. So it's hard to say "Yeah, do nothing," because I'd like to still have another two days, three days or weeks or months. But without knowing that by doing that you're going to become a vegetable, or be on life-support, you don't know. You can't. You can't turn around and say "Well look, if I resuscitate her quickly is she going to be OK?" That tough a decision. Yes, you die, everybody'd like to be resuscitated, but knowing before you start to do it, that yes, I'm not going to be (...)
> Interviewer. So the sorts of things that you need to know to think about that decision are?
> Nigel. [Something about a lottery] that you're going to win (laughter).
> Alicia. Yeah, exactly. Well that's it, it's exactly right. You want to know that the ticket you buy has got the numbers. You know, "Am I going to waste my money buying the ticket because I know I'm not going to win anyway?" (8.5.3/3)

In part, the dilemma herein articulated is attendant on the family awareness of the possibility of restoration of heartbeat but loss of cerebral functioning (being a vegetable), but also upon the construal of the decision as both social and moral. Refusal to sanction CPR might be construed as denying Tina the opportunity to be with her family, but not to refuse might result in her having "something wrong with her." To the extent that the family are positioned as at least influential if not decisive in the decision, they are confronted with two unacceptable alternatives and required to choose between them.[57]

There is, however, an escape clause available in this situation, which is alluded to through use of the metaphor of 'buying a ticket in the lottery.' Knowing "before they start" that resuscitation will not provide a successful outcome, patients and families can choose not to buy a ticket—not to take the chance that all might be well. Effectively, this may allow for the redefinition of the decision from a choice as to whether the patient lives or dies, to one of recognising that the patient will die anyway. The decision is rendered less of a moral decision, and more of a pragmatic, even objective one (by virtue of being premised upon a statistical 'reality'). This suggests that if medical practice dictates that patients (and families) must be faced with the decision, this might be made less "tough a decision" if they can justify refusal of CPR through citing the (very low) probability of achieving a successful outcome. Some medical writers recommend such a practice,[559] with some research demonstrating that knowledge of these probabilities can work to change (some) patients' opinions about instituting resuscitation.[206, 525]

Finally, Wayne expressed a number of opinions regarding DNR orders and resuscitation, drawing on different construals of these to justify different assertions. He stated his desire and reasons to continue living—namely, that he had his family to live for—implying a current preference for resuscitation. However, Wayne also envisaged a time when these might not feature (because he was unconscious), and thus when resuscitation might be inappropriate. This, in addition to his assertion that he had not "got around to it" (considering DNR orders) suggests that he deemed them relevant for a future time when he was sicker (unconscious or dying). Thus Wayne drew upon the previously delineated list of justifications for DNR orders, in order to identify himself as currently outside the DNR category, and thereby account for his assertion that he had not yet made a decision.

> Wayne. I've got a lovely wife and a family that [love?] me, and, and just you know, [I want to] fit in with them for a few more hours, be happy with them. It's almost all I can say really. But I just want to live on, I don't want to die tomorrow, you know … [Do DNR orders mean] if I'm dying, don't, just let me die? Well I don't, yeah, yeah, I, if I was unconscious and I didn't know no-one, and I

> knew that my family had said, you know, "That's it," I wouldn't wanna lay here. Like I am now, Jeez, don't kill me now for Christ sake (laughs). No, when it's my time I think yeah. … We [Wayne and his family] can decide between us, I haven't even got around to it, because I didn't think I was gonna actually die yet. (8.5.3/4)

Wayne's speech includes an assumption that DNR orders are only relevant in cases where the patient is dying, which effectively works to construe raising them as signifying the patient's imminent death. As I have noted in 5.1.1, given the understanding that this will be distressing to the patient, this may justify the indefinite deferral of the DNR discussion. He also identified the decision as of social import, implicating his family in it, both through their function as something to live for, but more critically through his assertions that if his family had said "That's it," he "wouldn't wanna lay here," and that "we (himself and his family) could decide between us." Identifying the family as integral to the DNR decision undermines those versions of it that are premised upon an individualistic concept of patient autonomy, and indeed reveals the improbability that patients will be immune from family considerations.

Wayne's continued speech claiming a certain disinterest in the probable consequences of making a DNR decision further strengthened the attribution of the decision to his family, through identifying them as the ones most likely to be affected by the decision. This worked to justify his refusal to make a decision, and to construe family as legitimately having a stake in it (see also 8.2.1 and 8.2.2). This notwithstanding, he then stated that he had agreed with the doctor that he did not want them (doctors) jumping on his chest—which, according to his current DNR order on file, was understood as indicating his refusal of CPR.

> Interviewer. I'm not asking you to make those decisions =
> Wayne. No. No, no, I, I'm not going to say yes or no, because, until that time comes, because they [Wayne's family] might say, like I won't, I'll be laying here, I won't know anything, so, it won't make any difference to me, so I think that'd be all practically, you'd have to ask, you'd have to ask them, that'd be the bottom line.
> Interviewer. Have you spoken about it with anyone else?
> Wayne. Yeah, … Dr Johnson said something about it, what was it, "You don't want us jumping on your chest and doing all this," and I said "No." So, that's about it.
> Interviewer. So in a way, you have sort of made a decision about that?
> Wayne. What about them not putting me down, not, not letting me die? Yeah, well I actually, it all depends see. If I was that bad, that the doctor said that he's not going to live, I don't want to live. It's no good keeping me going … . (8.5.3/5)

Representing his position as merely agreeing with the doctor's recommendation works to minimise Wayne's own role in the decision-making process, and thus responsibility for it. Indeed, when I surmised that Wayne had in fact made a decision, he modified my

suggestion by stressing his reliance upon the doctor's judgement about his medical condition. In so doing, Wayne and others (see Rex and Vern at 7.6.1) appeared to endorse and enact a paternalistic version of autonomy:[84] The patient assents to the doctor's recommendations about what is best for the patient. Although within medical discourse, this is traditionally decried as inappropriate, these participants did not so identify it. There are, moreover, alternative explanations for Wayne's actions available within medical discourse: Wayne, eschewing a detailed technical description of process, legitimately exercised his autonomy through acceding decisional authority to the doctor;[560] or, guided by the concern for patient welfare, his doctor took Wayne's consent to that course of action as implied, rather than requiring it to be formally signed and sealed.[46] Ultimately, Wayne's speech effectively minimised the degree of his own involvement in the decision, through identifying (aspects of) it as social and medical.

8.6 Conclusion

I have here shown that participants construed the DNR decision as appropriate in a number of circumstances—about which there was consensus. Most patients applied these circumstances to themselves, thereby personalising the discussion and decision. However, specifying these circumstances enabled some patients to identify particular circumstances as not currently applicable to them—thus accounting for their preference for resuscitation, or the fact that they had not currently made a DNR order (as also noted in Chapter 7).

The dominant construal of the decision was that it was a matter of individual (patient) autonomy, but this was often tempered by the invocation of medical, and social (moral) concerns. Medical considerations were most often cited as determining the biological condition of the patient with a few framing the decision as medical. However, the majority cited the patient's biological condition as operating to limit medical authority: At that point medicine had nothing more to offer, and so should butt out. For a few, the decision also had religious connotations which also operated to restrict medical authority. The symbolic significance accorded to the heart, and to attempts to restart it similarly functioned to undermine construal of the decision as predominantly medical.

Participants implicitly held patients to account regarding their entitlement to utilise resources—patients should not become a 'burden,' either in terms of others' time and effort (interpersonal), or their access to scarce resources (societal). Patients were constructed as responsible for the welfare of others, while these others (whose resources are depleted due to a patient's continuing existence) might be deemed to have a stake in

decisions made. The 'burden' argument inevitably works against a notion of individualistic, independent decision-making characteristic of traditional decision-making models, rather identifying the decider and decision as inherently social. It also works to place a moral obligation upon the patient to make the decision. This may act to coerce the patient to make the DNR decision, even when they would rather not.

Notwithstanding that the construal of the decision as personal works to confer responsibility for it upon the patient, the presence and operation of other construals can work to problematise this. For example, the construal of the decision as medical inherently implicates the doctor, and as social, the (proximal) family and (distal) community are depicted as factors that the patient is obliged to consider. In the next chapter I shall further explore how participants spoke about issues of responsibility for the decision, also considering the consequences of the ways they justified or accounted for including, excluding, or excusing particular parties from the decision.

Chapter 9. Study 2. Patients, others, and decision-making

In designing this study, the lack of consensus within the medical literature regarding who is ultimately responsible for legitimating DNR orders, in conjunction with the value accorded patient autonomy, formed the rationale for the following research questions: To whom do patients attribute responsibility for the decision? How do they justify or account for their views? In previous chapters I demonstrated that participants' construal of DNR orders was not homogenous, being represented as personal, medical, social (thus moral), legal, economic, and religious (in approximate order of most commonly presented construal). These had associated implications regarding who might be held responsible for, or authorised to make the DNR decision. This chapter more specifically addresses this: I analyse participants' responses to prompt questions including "Who should make a decision to apply DNR orders?," "Who should be involved?," and "Should patients ever not make the decision?" I demonstrate that participants routinely assigned the DNR decision to the patient, thus construing the decision as predominantly personal, but that the invocation of alternative construals worked to challenge this assignation. I also examine how participants drew upon commonly available constructions of doctors and family juxtaposed with particular construals of the DNR decision in order to establish them as both appropriate and inappropriate surrogate decision-makers. Throughout, I comment upon the implications for medical practice that may be drawn from this analysis.

9.1 The patient should make the decision

When asked about who should make the DNR decision, the vast majority of participants nominated the patient, thus construing the decision as predominantly personal. This was both the most common initial response, and the 'home-base' to which participants returned after considering other options. As I noted in the first study, this reflects the dominance of the autonomy discourse in this setting, and is congruent with the current common understanding, accepted in medical, legal, and lay parlance, that individuals should determine what happens to them—even to the point of their death.[3, 119]

> June. Oh the patient [decides]. Yeah, I mean, ultimately nobody else is involved as far as that goes … . I think it just comes down to the patient. (9.1/1)

> Lois. I think that that should be the patient. … Yeah, I don't think you can just roar in … and say "No, we're terminating" if the patient said no. (9.1/2)

> Scott. I think it's up to the patient for themselves to make that decision. And the family should discuss it, but it's up to them isn't it? If they want to go through all that worry that they do go on life-support and one thing and another, that's up to

them, if they want to put themselves through it I think that's their decision, but I've told my family, they're to stick by what I want. And that's it. They're not to change it. (9.1/3)

Interviewer. That decision not to attempt resus belongs to?
Wendy. The patient. Yeah. ... Well, if the patient wants them to have a go, well, sure, if that's their wishes, let them sort of have a go, and try and resuscitate if they can. (9.1/4)

Both requiring or refusing CPR were deemed equivalent in terms of operative force, which further works to construe the DNR decision as essentially personal: What the patient decides is what is done. Participants' presumption that the patient's (their) desires were paramount, merely requiring expression to become operative, appeared to be a default position, particularly when they were explicitly asked about responsibility for the decision (as it was in Study 1, see 5.1). One of the benefits of this is that determining what course of action should prevail is relatively uncomplicated: Just ask the patient. This acts to legitimise those practices aimed at doing precisely that, for example, use of advance directives.

However, there are several features of participants' further speech that suggest that establishing the DNR decision was rarely as simple as 'Just ask the patient.' Participants regularly implicated other individuals or social processes, even when the decision was attributed to the patient. For example, for some, the decision was depicted as a matter of freedom, as their (legal) right. This draws on highly prized liberal ideological constructs, thereby strengthening allocation of the decision to the individual patient. Nonetheless, the use of such language also works to construct the decision as more than an individual personal matter. It has legal implications and, by definition, presupposes a social community that establishes, accepts, and maintains legal guidelines that circumscribe patient choice.

Sean. I think it should be a freedom of choice. I mean, if you put the hard and fast rule and say "No, don't do that," you're ordering somebody to do something. Why, why shouldn't they have the freedom? (9.1/5)

Yves. I think it's the patient's ultimate decision. ... [E]veryone's got their rights, and I believe those rights should be adhered to in those sorts of situations, particularly if the person's like meself, (laughing) I think I'm in sound mind .... (9.1/6)

Xavier. Absolutely I believe it is [my decision], absolutely. Because there's no reason why legally intervention has to be taken, and therefore my wish is paramount I believe, not anybody else's. ... [My] wife has a medical power of attorney, and we've all discussed clearly what our wishes are .... (9.1/7)

Eight patients (including Xavier above) spoke of the various avenues they had pursued in legally documenting their preferences. For most this involved the nomination of some other person as Medical Power of Attorney, who would best convey the patient's preferred options when the patient was no longer capable of so doing. I will not explore this aspect of the DNR decision extensively, but will briefly note some functions and consequences of this practice, particularly those that may be problematic (see also 7.5 on DNR orders and documentation). All eight took it for granted that such legal documentation would guarantee that others would ensure that their (the patient's) wishes about medical treatment would prevail. Therefore, in these accounts, the DNR decision was simultaneously construed as legal, social, medical, but primarily personal.

> Nina's husband Ray. We each have a Medical Power of Attorney over the other … . Nina's made that decision, and she's told the doctor of that decision, and that's in the medical records. I believe that she doesn't want to change her mind over that. (9.1/8)

> Uri's wife Violet. We've actually spoken about that, … we've actually made our powers of attorney and stuff, so that if Uri … were incapable of making that decision, we've gone through all that … .
> Interviewer. So Uri, in those circumstances, you've given the responsibility for that decision to your wife? =
> Uri. Yep. (9.1/9)

> Vera. We got the papers and signed and everything … . It's called Medical Power of Attorney, and my daughter and two of my sons had that. And … the hospital's got one, and the doctor's have got one, and all that sort of thing, so that decision has been made. (9.1/10)

The assumption, however, that patient autonomy is guaranteed through patients' completion of these legal practices is questionable. As previously noted (see 7.5 and Table 5), four of these eight patients had no current DNR order on file, nor any record of their having established legal documentation of their wishes.

There is, moreover, a certain onus placed upon those endowed with Medical Power of Attorney to be able to produce evidence of this, and to ensure that appropriate authorities know and consider the patient's wishes. Therefore, actualisation of patient autonomy presumed through legalistic documentation of patient wishes may be dependent upon others, while the existence of forms presumed by the patient (and family) to have operative force may work to promote a false sense of security that the patient's will will be done. Thus, conditions presumed to actualise patients' autonomy may work to compromise it.

Finally, patients' completion of documents, or participation in conversations regarding their wishes does not ensure their apprehension of (and therefore informed consent to) whatever is duly recorded—though this is a fundamental presumption in medical discourse. According to their case-notes, both Una and Ross were asked their preferences, and their documented DNR orders were allegedly based upon their responses. Although Una's DNR status definitely contradicted her present wishes (see 8.5.1), Ross' probably did not. Nonetheless, during his interview Ross indicated that neither he nor his wife had clear recollection of precisely to what he had agreed, and signed.

> Ross' wife Margie. Dr Abbott just come and asked us what we had thought about (...), he just asked us if we wanted to sign that. Some papers to say, authorisation papers ... .
> Ross. You talk about it, and then you're given a form to sign. And I was saying that even though I've read it, I can't visualise it now, or record that now, or bring it back to memory. I wouldn't even know where to start, what was on there. (9.1/13)

Pragmatically, Ross (or his wife) could access that signed document to determine the agreed-upon treatment plan, but his speech at interview does not reflect assumptions of models of decision-making that require informed consent as a necessary precursor of patient autonomy. Rather, it supports Dodd's[35] contention that the mere state of being a patient precludes the enactment of autonomy because of the inevitable presence of factors (e.g., fatigue, emotional turmoil, lack of necessary expertise) deemed to interfere with the process of informed consent. Yet despite Ross' assertion that he was unsure of what he had decided, he maintained that doctors need to elicit and comply with patients' wishes, that without the patient's authorisation to refrain from CPR, resuscitation would be attempted.

> Ross. I think that it's important that [the doctors] know [what patients want] yeah. Because they are on the spot. ... Because if it comes to them making the decision, don't they need to know that, otherwise no decision? (9.1/14)

This common misconception rests upon the construal of the decision as predominantly personal and the presumption of CPR as default for all patients. In practice and in direct contradiction to these participants' presumption, the physician may construe the decision as predominantly medical, citing medical futility as grounds for refraining from CPR, and need neither elicit nor comply with patients' wishes (although failure to comply with an explicitly stated preference might prove difficult to justify, given the priority accorded autonomy). This poses a continuing ethical dilemma for the medical profession.

9.1.1 Challenges to patient decision-making

There are, however, additional problems inherent within the construal of the DNR decision as personal and consequent allocation of responsibility for it to the patient. For example, it is presumed that patients will be able to articulate their desires, and be consistent in so doing. Others have queried this,[37, 234] and within this study, several patients expressed potentially contradictory views (see 8.5.3), indicating that this presumption is untenable.

In addition, participants' assignation of the decision to the patient was presented as an imperative, as revealed by the use of the imperative 'should,' and phrases like "it just comes down to the patient" (see 9.1/1) and "it's up to the patient" (see 9.1/3). This works to structure the issue as an obligation laid upon the patient—they must know and express their wishes, regardless of their own desires to do so. However, some patients appeared discomforted by discussion of the issue (see 7.6.1/1 and 7.6.1/4-5), and some specifically rejected personal responsibility for the decision (see 7.6.1). As also noted in Study 1, the valorisation of autonomy, thought to advantage the patient, may achieve the converse.

Furthermore, the presumption of patient autonomy also works to marginalise other construals of the decision (as medical, or social). This may obscure the extent to which invocation of other construals may neutralise the operative force of patients' decisions. If participants presume that patients' wishes are determinant, they may not recognise the possibility that other construals of the decision may be invoked to counter this.

Finally (as previously noted, see 5.1.2.3) , nomination of the patient as ultimately responsible for the decision epitomises an atomistic, individualistic, isolated construction of the individual making decisions completely independent of social influences.[123, 129] It dismisses as irrelevant the interest and wishes of individuals other than the patient in the DNR decision. This works to undermine the possibilities that decisions may be socially negotiated, and minimises the significance of any social consequences of individuals' decisions. Certainly, even when participants assigned the rights and responsibility for the DNR decision to the patient, this assignation was not unconditional nor the decision unassailable. As will be discussed below, participants regularly held that patients and their ultimate decision had to meet certain criteria. Many also noted that some patients would not make the decision, while some might change their mind.

9.1.1.1 Excluding the patient

In this study, as in the first, even when the DNR decision was allocated to the patient, it was designated as appropriately made by those who were cognitively intact. Participants excluded those who were not, applying what I have earlier called the Sanity Test. Most envisaged some time in the future when they would fail this test, and would be excluded from both participation in, and responsibility for, the DNR decision. As patient participation in the decision was taken as desirable, this provides some impetus to making the decision earlier in the disease process than later.

> Lois. If I was like I am now, where I feel I'm still pretty lucid, and pretty much in control of my faculties … (laughs), then I think that that should be the patient. But if you go into a coma or you can't, you're totally delirious, or you're obviously not with it, then hopefully you'll have discussed that with your family member before. (9.1.1.1/1)

> Interviewer. Do you think there's ever a time when a patient shouldn't or can't make that decision?
> Uri. Well that depends on how far they are drugged I suppose, and how far they are out of their [mind], not in their all-together … .
> Wife Violet. Because when he's got cancer, you don't always know where it's going to go and so =
> Uri. Yeah it can go up into your head, and then you're not capable of making those decisions, and things. (9.1.1.1/2)

Participants here use terms that denote what is often referred to as 'competency' within medical discourse and (as by these participants) is considered essential for the exercise of autonomy.[124, 127] However, participants' default assumption of patient autonomy in part masks the facts that decision-making is limited to those who fit this criterion of competency, with the medical profession alone authorised to assess this (although it may only be formally determined through legal process).[415] Although competency is presumed as a default state,[155, 415] any decision of the patient is potentially always revocable through a medical denial of competency. Thus, even as the issue is construed as personal, and the decision attributed to the patient, it is simultaneously identified as medical, with the latter ultimately empowered to override the former. Furthermore, the presumption that some (incompetent) patients may not determine their DNR status, works to strengthen the assumption that all other (competent) patients may do so. This is neither the case in theory, nor in practice, as doctors may and do establish DNR orders without patient knowledge or consent.[30, 61, 62, 187] As a final point, the taken-for-granted exclusion, by these participants, of those who are deemed to be incompetent, overstates the ease with which those kinds of judgments are made. Small alterations in thinking can be difficult to detect clinically, but may represent grounds for challenging any decision made.[169]

9.1.1.2 Patients deciding not to decide

As noted above, the allocation of the DNR decision to the patient presumes that the patient will actually decide and state their preferences regarding CPR. How did participants account for situations wherein patients did not state this? For some, patient silence was taken to indicate their desire to leave the decision to the doctor (see 7.6.1), with the implication that non-resuscitation was an acceptable option. But for others, it indicated that they were not ready to die, and therefore would have to be resuscitated (see 9.1/14, and 9.1.1.2/1-2). Again, although deduced from an absence of expression, the operative force of the patient's wishes is uncontested—even if this wish, this decision, represents their refusal to make a decision.

> Wendy. If [patients] don't want to make that decision, then we [nurses] ask them if there is somebody that they would like to talk to help them with their decision.
> Husband Dennis. … And then, on the other side of it, those who don't want to make a decision, well, you have to resuscitate them every time. If they don't want to make the decision, they're saying "No, I don't want to die," regardless of their quality of life. And religious beliefs and things like that uphold those decisions, so you have to, you have to follow it really. (9.1.1.2/1)

> Interviewer. What if the patient is mentally alert, but doesn't want to make a decision?
> Una. Tough one yeah. Well I think then you have to respect the wish of the patient because obviously they don't want to let go. … So I think while they're mentally alert, you have to respect that. Because whether it's family reasons or you know "I'm too young" or "It's not fair, why me?" I think you have to respect that in a patient. (9.1.1.2/2)

To not make a decision is here construed as refusing to say 'don't resuscitate me,' and is presented as both acceptable and authoritative: "you have to follow it," "you have to respect that." This equation of silence with an expectation of (indeed insistence upon) resuscitation is based upon the understanding that resuscitation is a default option within a medical institution. As previously noted (see 5.1), if the possibility exists that patients will assume that they will always be resuscitated (in the absence of their expressed wish to the contrary), to not resuscitate them, specifically without informing them that this is the current plan, can be construed as a breach of trust.[46] Practically, one solution for the clinician to the potential ambiguity implied in silence might be to explain that should a patient not make a decision, the default option of resuscitation will apply, or that the doctor may make a decision on medical grounds. Better informed, some patients may change their decision to not make a decision, but others may not. In such cases, respecting patient autonomy may require respecting an informed choice to not make the decision, at least at that time.

Although presented as acceptable options, patient refusal and patient acceptance of the decision were not, however, construed as totally equivalent. Consistent with the prioritisation of patient autonomy, pressure to make the decision might be applied to the patient (see 9.1.1.1). Nonetheless, assertions that you "have to follow [the patient's wishes] really," or "obviously" carry with them the implication that this is true even when a patient's wishes (not to decide) are judged as wrong. This notwithstanding, although the ultimate right of a patient to make a decision not to decide was accepted, it appeared to be accorded lower status, as such patients were negatively construed as emotionally unable to come to terms with their condition. They were unable to let go, to recognise that they will die, which in a society which demands that patients recognise and plan for their death[561, 562] is negatively valued.[329, 347] Nonetheless, this was not taken to disqualify any decision they made (even the decision not to decide), demonstrating the ultimate authority accorded to any decision of the patient, and further strengthening the construal of the decision as predominantly personal. Whether the patient makes a 'good' decision, a 'bad' decision, or no decision, the best decision that can be made, is deemed to be that made by the patient.

For the most part, participants tended to assert their own ability and desire to make the decision, attributing an avoidance of, or inability to make the decision to others (see also Study 1). As people usually locate themselves outside of a dispreferred category (cf. [315]) this further established the relative desirability of making the decision, and moral superiority of those who are not the 'others' who cannot.[451] The DNR decision is thus construed as a moral issue, and the making of it by the patient as a moral obligation, which, though difficult, should be faced—as explicitly asserted by some participants (see 8.1.4).

This notwithstanding, other interpretations of the significance of making the decision were sometimes invoked in order to positively construe *not* making the decision. This strategy was particularly evident within the speech of those participants who had not done so—not surprisingly, as it enabled these patients to avoid the negative connotations that might otherwise be attributed to their actions, and to represent themselves positively. For example, Wayne juxtaposed the equivalence of the DNR decision and an acceptance of death with the discourse of will that sees the patient as instrumental in overcoming their disease to imply that making a decision would be detrimental to his health.

> Wayne. I don't wanna make any decisions, really. You'd be Jonahing yourself. (9.1.1.2/3)

"Jonahing" here refers to the biblical character of Jonah, and is colloquially taken to indicate the bringing of bad luck,[563] here upon oneself. Under this interpretation, Wayne

choosing to make a decision would signal his giving up and thereby increasing the probability of the bad outcome of death (see also Chapter 10 on hope.) Although this construal assigns the patient responsibility for outcome, the culturally accepted understanding that patients resist (and thus avoid culpability in) their death works to legitimise Wayne's decision to not make the DNR decision.

In accounting for his decision not to make a DNR decision, Sean presented a similar argument (as discussed at 7.6.2), but also drew upon the notion of freedom of choice (essential to patient autonomy) in arguing that a patient's current decision might not be the patient's final decision.

> Sean. [Whatever is recorded] can be made as the point that, P.S., should you at sometime rethink your decision on this particular question, please contact us, and we can offer that. People don't like to be tied. They like to have breathing place. They don't like to be told what to do, and when to do it.
> Interviewer. So you would always want to be able to say, I've changed my mind =
> Sean. That's right. That's right. Freedom of movement, yeah. And once you feel that you're locked into something, people don't like to feel locked in. They like to feel free of mind. (9.1.1.2/4)

Once recorded and actualised, the DNR decision inevitably becomes independent of the patient, and might not ultimately reflect their wishes at the moment when invoked.[43] Sean presented the making of a decision as 'locking' or 'tying' the patient to a course of action, and restricting their (current) freedom. Given the high value accorded to freedom, this works to negatively construe the making of a decision, even by the patient, as impinging upon an individual's freedom, and therefore as undesirable. Consequently, it represents a push to defer any decision.

This account takes as given the possibility that a patient's views might change over time, thus weakening both the confidence that can be placed in the determination that this (recorded) decision really reflects the patient's wishes, and the operative force of that decision. What if they change their mind? Arguably, the high value placed upon an outcome desired and directed by the patient can work to challenge the desirability of the patient actually making the decision right now—again legitimising deferral of making the DNR decision. Although such deferral has been labelled procrastination,[525] it may be justified by and follow from patients' desire to ensure an earlier stated wish does not commit them to a course of action they may not later endorse.

Sean's speech also highlights another paradox inherent in the construct of autonomy—that, where a decision refers to the future (as many decisions do), the patient's right to decide

the outcome can undermine any actual decision made. This provides some validation for those who question the desirability of promoting advance directives, based upon the problems attendant on predicting what one might wish for a future self.[43, 115, 165, 166, 564] Certainly, Opal's reference to the difficulties of making a decision in advance supports the contention that only the patient in the specific moment that might prompt a DNR decision is experienced enough to make that decision—even an earlier self deemed unqualified to do so.

> Opal. It is [a difficult situation], yeah, and I suppose unless you actually go through it yourself, you've got no idea of judging how you're going to react do you? … It just depends on how it turns out in the long run. (9.1.1.2/5)

The assertion that "unless you actually go through it yourself, you've got no idea" reflects and reinforces the importance placed upon contextual experiential information to decision-making,[137] but this also works to provide some sort of escape clause for patients otherwise subjected to pressures to make the DNR decision, with the implication being that they should make it now. Thus, although Opal had earlier spoken against resuscitation (see 7.4), her claim that "it just depends how it turns out" acts to justify a (potential) change of opinion. Although the onus placed upon obtaining the patient's decision can serve to validate any decision that they do make, the stipulation that this be based upon relevant contextual information means that all decisions are deemed to be context-dependent and potentially subject to change by the patient. This can be a two-edged sword, however, as doubt regarding the true status of any specific decision can be always be cast—does it really reflect the patient's current wishes incorporating all relevant contextual information?

Another aspect of Opal's speech works to challenge the assumption that a patient's current decision will reflect their future choice. What she mentioned as salient in determining choices was how the patient might "react." This refers to the patient's emotional response to circumstance and, outside the domain of the rational, is beyond rational prediction, certainly by others, but also by self. As noted in Chapter 5, patients' emotional responses were construed, at least by some, as a legitimate factor in decision-making, even when they subverted rational decision-making.

> June. When it gets a little bit closer to the time, I daresay you'd think more about it, when you've kind of done the logical thinking beforehand, and then I guess you do a bit more of the emotional thinking and, different things. (9.1.1.2/6)

Here, the pairing of emotion and logic as equivalent components of thinking works to establish emotion as a legitimate factor in decision-making. Furthermore, "emotional

thinking" was construed as not only capable of disrupting choices based upon "logical thinking," but as legitimately superceding such choices. It appears that if the most recent choice of the patient represents emotional thinking, or an emotional reaction, this does not invalidate that choice. This functions to strengthen the value accorded to the patient-based decision (and to reinforce the dominance of the personal construal of the decision), but also the value accorded to emotion.

9.1.1.3 Patients making the wrong decision

Although most participants held that the patient should direct the course of events, a patient-made decision did not *ipso facto* constitute a 'good' decision—some spoke of patients making a 'wrong' decision. This implies that there is, in fact, a 'right' decision, which might be determined by an observer, which in turn relies upon an assumption that decisions may be critically assessed against some predictable, that is, rational model of decision-making (see Stacey,[565] Chapt. 7).

> Interviewer. Do you think there's a time when [the DNR decision] shouldn't be left up to the patient?
> Kate. Possibly. If they've got the wrong reasons for wanting to do it … . (9.1.1.3/1)

> Ruth. I know a lot of individuals who would say "No, I have to live at all costs" when that's perhaps not the most appropriate decision that they could make. … I'm not saying that attitude [is] right or wrong but there comes a point where you have to say "No, enough is enough." (9.1.1.3/2)

Any decision made, even if justifiable according to the autonomy principle, when assessed against standards of rationality, may be deemed not to be the best decision, and thus may be disapproved—though both Kate and Ruth avoided direct condemnation of a patient's decision. This probably reflects the high status accorded to the patient's decision, but nonetheless demonstrates that patients' decisions are available for evaluation, with judgments made as to the moral status of the person themselves. Thus, patients are held accountable to others for the decisions they make, with negative consequences ensuing if a decision is deemed to be not the most "appropriate decision that they could make," or is made for the "wrong reasons." This works to locate the individual within a network of moral and social obligations, thus challenging the notion that a patient might freely make any decision, and (potentially) undermining the operative force of the patient's decision.

To summarise thus far, participants' exclusion of the non-competent patient from the DNR decision works to strengthen the assumption that competent patients should make the decision, as well as the construal of the decision as essentially personal. However, although

the dominant underlying assumption of these participants was that the (competent) patient should decide what they want to do about the DNR decision, other assumptions and other construals of the decision might be invoked in order to modify this. Consequently, participants could endorse a number of positions that were not necessarily congruent. For example, patients might legitimately choose to make the decision now, or defer indefinitely, thusly: Although the prerequisite of competency in decision-making functions as a pressure to make the decision now, because changes in experiences are deemed relevant, the need to ensure the decision reflected their current position works to counter this. Additionally, though a patient might rationally make a decision, this might be subsequently subverted by the invocation of emotional factors. Indeed, the presence of emotion was taken as effectively excusing patients from decision-making, or rather, accounting for their implicit decision not to make a decision. Nonetheless, those who chose this option were positioned as 'other' and morally inferior to those who actively determined their DNR status. The construal of the decision as personal therefore appears to be overly simplistic, as patients variously implicated medical and social (with attendant legal and moral) aspects that impacted the decision. Even so, whatever the patient wants emerged as the dominant justification for any decision made.

9.1.1.4 Decisions at the moment of crisis preclude patient participation

Some participants observed that at the point of cardiac arrest, the patient would be unable to participate in determining what action was effected. Again, when patient autonomy is deemed essential in order to achieve the best or most appropriate outcome, this calls for earlier rather than later elicitation of the patient's desires.

> Oliver. Well, it's not the patient who's making the decision is it? I assume that that's out of the patient's hands because he's not knowing what's happening. (9.1.1.4/1)

> Ross. Well, I guess the most qualified person has got to make the decision. Well, it certainly wouldn't be me. Because if I was in that situation I wouldn't know. (9.1.1.4/2)

The patient's inability to direct affairs requires that, for their views to be effected, someone be responsible for relaying their wishes, acting as the patient's surrogate. It must be acknowledged that the physical circumstances of the event itself may determine who participates in the decision: Put bluntly, decisions regarding CPR require an immediate medical response, which by definition involves the doctor, and may preclude consultation with others. Nonetheless, the overriding preference given to the patient-based decision works to sanction surrogacy as an essential component of patient autonomy (see also 9.1).

Who is "the most qualified" to act as that surrogate (thereby enabling decisions to most closely approximate the patient-preferred decision) may then be debated. Given that participants alternatively construed the decision as medical and social, the two primary contenders for the role are the patient's doctor, and the patient's family, and I will now examine some of the ways these featured in participants' speech about the DNR decision.

9.2 Doctors and the DNR decision

In the context of decision-making, the relationships between patient and doctor can take various forms: The most common modes of interaction are deemed to entail patient control, physician control, and shared control of the process of decision-making.[84] Arguing for the latter as a "partnership," Deber and Baumann[566] have defined decision-making as comprised of several different aspects: Problem-solving, in which the expert (the doctor) identifies options based on diagnostic and prognostic criteria; and, decision-making *per se* which may be made unilaterally by doctor, or patient, but optimally might represent some form of shared decision-making, with the doctor responsible for conveying information to the patient.[38] But, shared decision-making is unproblematic only when all parties are agreed. When differences of opinion about treatment options at the end of life arise, someone's decision must prevail, leading to what Marshall[567] has termed a "struggle for authority over the patient's body and the patient's wishes" (p. S10). Although both doctor and patient are consistently cited as relevant in DNR decision-making by clinicians, patients, and families,[38, 44, 48, 568] who is pre-eminent? As previously noted, this is contested within the medical literature, but rests predominantly upon how the decision is construed: if fundamentally personal or moral, the patient;[46, 83] if medical, the doctor.[30] These construals also feature in arguments regarding surrogate decision-making. If the decision is medical, then the doctor is the obvious and only choice, with no case to be made for involving family. If it is personal, then family are the obvious, but not the only choice, with the doctor potentially qualifying.

Within this study, where the decision was construed as fundamentally medical, the doctor was positioned as responsible both for making and carrying out the decision (see 7.6.1). By contrast, the construal of the decision as fundamentally personal (see 9.1) sees the patient as responsible for making the decision, and the doctor consequently positioned relatively passively as carrying out the wishes of the patient. These would appear to represent the extremes of the paternalistic (physician-controlled), and informative (patient-controlled) models of autonomy.[84] However, although the majority of patients construed the decision as personal, most identified the patient's diagnosis at the time of arrest and probable

prognosis after arrest as relevant, with medical expertise critical in establishing these. The saliency of medical knowledge thus establishes the doctor as a logical participant in the process, bearing some responsibility for outcome, though the precise nature of that responsibility varied. In addition, some participants stressed, not just the medical knowledge possessed by the doctor, but personal knowledge of the patient gained through interpersonal interaction with them.

9.2.1 DNR orders as medical: Doctors know the medical facts

The construal of the decision as medical was invariably associated with nomination of the doctor as an appropriate person to make the decision. However, where Rex and Vern drew upon this construal to argue that patients should not, or need not be consulted (see 7.6.1), others suggested that the patient might proactively delegate responsibility for the decision at the moment of crisis to the doctor as they (the expert) were in the best position to determine the immediate medical facts, and the likely outcome of (not) undertaking resuscitation.

> Nina. [My doctor and I] spoke very frankly about different things, and as I said, at that time, if he'd thought there might be a slender chance, he's to do what he thinks best, but if he thinks there's not a hope in hell, no. (9.2.1/1)

> Zack. If it came down to it, I'd still want to be resuscitated if I can. If I can't after a certain time, and if it's not going to work, and the doctors realise that they can't do anymore, well there's no use in like giving me all this treatment for nothing. … I think the patient first [decides what to do if their heart stops], and then the doctor decides as he's going along with the treatment. (9.2.1/2)

Here, although doctors are charged with actually making decisions required when the patient was arresting, the patient is primary in that these decisions are deemed to reflect the patient's wishes for themselves in such circumstances. Even though doctors draw upon their medical expertise in deciding whether to continue with resuscitation, their authority to do so is construed as dependent upon patients granting this. Nonetheless, the focus on medical expertise required to correctly interpret the patient's circumstances (particularly given that the patient is unlikely to actively direct affairs at that moment) works to support the nomination of the doctor as patient surrogate.

Others similarly focused on the doctor's ability to interpret the patient's circumstances, but in the context of consultation between them prior to arrest: The doctor was charged with provision of medical information to 'help' the patient make the decision, and then bound by the patient's ultimate decision.

> Maud. Yes, the patient and the doctor make that decision. He knows what you're going through, what's the cause of it and everything. … You should be free to talk to your doctor about it, your doctor should be free to talk to you about it. And ask you what would you like done, and you can answer him, or you can go to him, and say, "Well doctor, I'd like so and so done, I don't want so and so." (9.2.1/3)

> Ruth. I feel that it should be the patient's own [decision]. Yeah, but I also feel that people should be free enough and comfortable enough to be able to ask [their doctor] for options, in order to help them make that decision. Not be told what to do, but to ask for information about choices. (9.2.1/4)

These accounts represent the consumer, or 'informative' model of patient autonomy currently dominant in bioethical, medical, and legal discourse.[84] The DNR decision was construed as predominantly personal, with the doctor relegated to the roles of detector and transmitter of information—the problem-solving expert,[566] and executor of the patient's wishes. Although this follows from the current emphasis on patient-directed decision-making, there are a number of questionable assumptions inherent within it.

First, there is the presumption that patients who lack medical training and are, by definition, ill (and in these instances, terminally), can comprehend and interpret complex technical information. Several researchers have refuted this assumption,[35, 85, 197, 198] and some patients here made similar assertions (e.g., see 7.6.1, and 9.1/13). In addition, the ethical principle of non-maleficence would mandate that patients do not suffer harm by such discussions. Some have observed that this is not guaranteed[197, 199, 569] (see also 7.6.1/4-5). Furthermore, and particularly where the doctor is assigned the responsibility for the immediate decision following patient arrest, the presumption is that the doctor will be the epitome of the medical scientist—that their actions will be determined solely by rational consideration of medical fact. Again, research suggests that doctor's decisions do not always follow this precept[4, 72, 570] (see also 9.2.2 below). Finally, it casts the doctor as relatively disengaged from the entire process, as neutrally conveying information with no interest in outcome. In contrast, studies into doctor/patient interactions have concluded that physicians' presentations of options to patients are not neutral, but organised in order to elicit a desired response from the patient.[72, 171] The understanding that patients should make their own decision may work to conceal the extent to which doctors influence outcome. Perhaps illustrating this, Sally corrected her speech saying that doctors "make certain decisions," to their making "suggestions" from which the patient would "come up with" a decision.

> Sally. Once you're in the doctor's hands, you rely on them to look after you, to take care of you, to make certain decisions, or suggestions perhaps I should say. And leave it up to me then what decision I come up with. (9.2.1/5)

Although this suggests that patient-, rather than doctor-directed decisions are the more desirable of the two options, it also indicates that patient reliance on doctor's recommendations can be construed as normal within the doctor/patient relationship, with such guidance comprising part of appropriate medical care.

When asked "What if the patient doesn't want to make that decision?" Sally, as did Vera, also nominated the doctor as responsible for the decision.

> Sally. Well I don't know if I can answer that. That's something to think about I think too. … If they [patients] haven't notified beforehand, and it's not their decision, I think then it would be in the doctor's hands at that point. Because that is what they have promised to do, isn't it? To make life as possible as can be, while they are treating the patient. But if that patient cannot say what they want … then it would be the doctor's decision I think. (9.2.1/6)

> Vera. A person in their right frame of mind, and fully within their faculties, yes, I think they have a right, but somebody who's not, it's a very difficult decision for somebody to have to make for them, isn't it? … I don't know, I truly don't know who should make the decision [if the patient can't]. I mean there are so many factors in it, I mean, depending on the person's, whether what is wrong is terminal, whether they're in a lot of pain, you know. There are heaps and heaps and heaps of things that are involved in that, and then I guess it's up to the medicos. But I don't know, I can't answer that, sorry (laughs). (9.2.1/7)

Their statements that in such circumstances "it would be in the doctor's hands … because that is what they've promised to do," and, "then I guess it's up to the medicos" depict the doctor as decision-maker as being part of normative care—what patients might reasonably expect from doctors. This nomination was further strengthened by the focus on the medical aspects of the situation, manifested in references to the "treating" of the patient, the "whether what is wrong is terminal" or to the patient as "in a lot of pain."

However, when nominating someone other than the patient, determining the appropriate decision-maker seemed troublesome, as participants appeared to equivocate somewhat and to debate alternatives (here the doctor, but see also family at 9.3.3/1). The undesirability of a situation wherein the patient has not made a decision may be further surmised by contrasting these responses with the definitive and relatively short answers given when the patient was unproblematically assigned responsibility for the decision. Such speech characteristics again identify the patient-directed decision as the preferred option, all other responses being correspondingly dispreferred, and requiring explanation or qualification (Kitzinger,[571] p. 174 and Potter,[294] pp. 58-60 have provided similar examples). However, here, the focus on the medical aspects of the situation worked to justify allocation of the DNR decision to the doctor.

9.2.2 DNR orders as personal: Doctors know the patient

According to many participants, knowledge of the patient's medical circumstances was crucial in the DNR decision. This permits an argument that the best decision is the one that reflects a comprehensive and accurate appraisal of the consequences of attempted CPR. The involvement of doctors is thus cast as integral to the process of decision-making, whether as transmitter of that information (using their medical expertise) to the patient, or as surrogate decision-maker entrusted to make the best decision on behalf of the patient.

There was, however, an alternative construal of the best decision, which worked to undercut the importance of the medical circumstances, though not necessarily the appropriateness of the doctor as surrogate. Namely, that the best decision is that desired by the patient, regardless of medical consequence (see also 9.1.1.2). If the patient cannot voice their wish, then others may claim knowledge of this, supporting such claims in one of two ways. First, the patient may have told them directly; alternatively, they may claim familiarity with the patient's wishes on the basis of sustained (usually positive) interpersonal interaction with them, effectively establishing a personal relationship. Though family are the obvious candidates for this role, because patients, particularly those dying from cancer, spend increasing amounts of their time within a medical setting,[210] doctors (and other health professionals) may have established such a relationship, and thus qualify as appropriate surrogate decision-makers.

This was the argument used by Otis to support his nomination of his doctor, Dr Glen, as appropriate surrogate decision-maker. Although this doctor (presumably) possessed medical expertise, the language used by Otis reflects interpersonal constructs, linking Otis and his doctor in a positive relationship over time (e.g., "that person that's been here with me all this time and knows me … . Because he knows me, I've got trust in him, … he's always been there.") This works to prioritise interpersonal interaction in legitimising surrogate decision-makers

> Interviewer. Who should make that decision [not to restart the heart]?
> Otis. Whoever's there, whoever's been looking after you and knows you, and whoever's that person. And whoever that person is, if that person [can say] "Slim [Otis' nickname] wouldn't like this." … But see like, sometimes I've been here with a whole lot of different nurses and doctors and all of a sudden, that person that's been here with me all of this time and knows me, goes, and they mightn't be here at that time. That's the sad part about it, and then you get some person who really doesn't know me, or never really met me and all of a sudden he is the one to say. … Since I've been in this place here I've come and I've got a lot of respect for [Dr] Glen. Right? Whatever he said and decided would be the thing to do it, would be "Yeah." I've got complete faith with my whole life in him. … Because he

> knows me, I've got trust in him, I've got faith in him, … he's never bullshitted to me, he's always been there, and yeah. (9.2.2/1)

Otis depicted what Schneider[37] has called "the traditional ideal" of the doctor-patient relationship, one established over time, and "governed, mediated, and protected by the principle of trust" (p. 202). This "trust" or "faith" may be demanded as a consequence of the patient's relative lack of expertise,[572] but the development of a personal relationship is also deemed to place moral obligations upon the doctor that operate to ensure that the patient's welfare is placed first.[37] Trust, in Otis' account, rested not solely upon medical expertise, but upon the establishment of an interpersonal relationship: Doctor Glen 'knew' Otis. By contrast, Otis identified as "sad," thus undesirable, the situation wherein hypothetical other carers, who presumably were possessed of appropriate medical expertise, but who did not "really know" him, might make the decision. The best decision required patient knowledge.

The nomination of the doctor on the basis of interpersonal, rather than medical knowledge, works to strengthen the construal of the decision as personal, rather than medical. However, other health professionals might legitimately be presumed equally likely to possess such knowledge. Thus, for example, in responding to the question of "Who should make the decision if the patient cannot or will not?" Ruth named the "wider circle" of persons for whom the common relationship with the patient could only be non-medical. Even palliative care, provided by medical practitioners, was valued not for the provision of (medical) care, but for the social support they might provide, again implying knowledge of a patient's social and personal circumstance. Similarly, her friend Tania's recommendation of the doctor who sees the patient as "more than just a body of symptoms" works to minimise the significance of medical knowledge, and prioritise knowledge of the patient themselves.

> Ruth. Then I think that you have to look at the wider circle around them. Which would include family and friends, medical and nursing staff, perhaps palliative intervention, the palliative care team, again, not necessarily in order of priority.
> Friend Tania. … Or what you do is you have your doctor who tracks one patient, who is sensitive … [and knows that] people are more than just a body of symptoms.
> Ruth. And I think palliative care can help there. We had palliative care in very early in the piece, not because I needed palliative care as such, but I was looking at it from the point of view of the support that they could offer with CanTeen and so forth for my children. (9.2.2/2)

Lois also mentioned non-medical staff, namely, a psychologist, as able to help her with decision-making. In 'running' through it all with the patient, the psychologist

simultaneously acquires knowledge of what the patient has decided, thus can "remind me [the patient] of what I'd said before."

> Lois. I might want to run it all through a psychologist first, and then I'd like to talk to the doctor, maybe with the psychologist present, because I tend to say one thing sometimes to some people and another thing to other people....So I think I'd need someone there to remind me of what I'd said before. Just so we got the true picture, or as close to the true picture as possible. ... I know two [psychologists] that I feel comfortable with, and I don't know any friends or family that are experienced enough in that sort of thing, and I don't know anyone else who knows me well enough. (9.2.2/3)

Although knowledge of the patient's wishes, and therefore, the patient's wishes, were thus construed as determinant by Lois, one problem with this may be deduced from her observation that she says different things to different persons. This suggests first, that patients may neither possess nor articulate consistent desires, and moreover, that it may be problematic (and certainly open to debate) which of several different contenders knows her "well enough" to justify claiming the position as surrogate decision-maker. For example, if knowledge of the patient is asserted as legitimate grounds upon which to make a DNR decision, then nurses, who have the highest amount of interpersonal contact with the dying patient, can potentially claim that authority to themselves.

> Interviewer. What if a patient doesn't want to [make a decision]?
> Wendy. Well, I'm not sure. Probably based on the quality of life, I know the nurses will take that responsibility on, sort of how fast they'll bring the crash cart, and stuff like that. But we usually get a verbal from clients, ...[where the patient] says "if I get that bad, don't bring me back." ... Because it's a small country hospital, you generally know the people, you've talked to them, or at least one staff member will have talked to them. (9.2.2/4)

Here, Wendy (herself a nurse) justified nurses' practices of go-slow manoeuvers as being "usually" based upon a "verbal" from the patient, implying their knowledge of the patient's wishes. Such practices are decried in medical discourse, and leave nurses vulnerable to legal recriminations.[6] But they derive in part from, and thus can be justified through appeal to the preference given (and insistence upon attaining) the patient-based decision. Indeed, in situations wherein the nurse is aware that current established medical directives regarding a patient contravene that patient's preferences, the nurse may be deemed to have no other morally acceptable alternative, but to comply with the patient's request (as described by Mappes,[573] pp. 558-9). Regardless, the insistence on determining the patient's wishes inevitably works to strengthen the construal of the DNR decision as inherently personal. Predominantly, these participants drew upon a discourse of autonomy, wherein the 'best knower' of the patient makes decisions based on what they would have wished—

but professional caregivers, rather than the family, were identified in this role. However, because there are persons in various professional and personal relationships to a patient who might be represented as best able to determine patient wishes, the issue of surrogacy premised upon that claim becomes complicated. The issue is far less complicated when the decision is deemed to be primarily medical when the doctor emerges as *the* appropriate decision-maker.

Doctors were further construed as appropriate surrogate decision-makers through invocation of the Stability test. As previously discussed, this stipulates that decisions should reflect a process of reasoned deliberation, rather than being emotionally derived. Una, for example, invoked the Sanity Test to exclude the mentally compromised patient, applying the Stability test to reject family as appropriate surrogate decision-makers, on the grounds that they would be too emotional and involved. This implies that the alternative candidate, the "head medical person," would not, and that this emotional distance is a desirable quality to possess in making the decision. Being neither mentally compromised, nor emotionally involved the doctor is thus depicted as sane and stable—as both (capable of) observing rational principles and immune from emotional influence.

> Una. If the patient is not of mental capacity to make that decision, I think it's up to a medical doctor. Not the family because they get, there's too much emotional and other involvement. … If the patient is not mentally alert, I think it's up to the head medical person looking after them. … I make sure that Dr Baker [her senior consultant] will see me on a daily basis in case something crops up or I have doubts, or, even the simplest of questions, she'll have an answer to it. (9.2.2/5)

The discourse of rationality can be used to support nomination of the doctor as surrogate decision-maker in two ways: Doctors know the medical facts, and can deliberate upon these without emotional distraction. However, Una did not nominate any doctor, but the "head medical person looking after [the patient]," again placing emphasis on an interpersonal relationship. "Looking after" implies the provision of care over time resulting in increased knowledge of the patient, and Una had actually worked to establish such a relationship with her own "head medical person," Dr Baker. Nonetheless, Una presumed that the establishment of this relationship, enabling Una's wishes to be known and effected, would not preclude her doctor from making the appropriate rational decision. This presumption may not hold in practice, as the development of a personal relationship over time has been associated with increased error in medical judgement.[174]

9.2.3 Challenges to doctor decision-making

To summarise to this point, doctors were identified as appropriate decision-makers through various strategies: If the decision was deemed medical, then the doctor qualified as medical expert. Similarly, if rationality was a prerequisite for decision-making, then the doctor qualified as the rational scientist, presumed unaffected by emotional involvement. If, on the other hand, the decision was deemed personal, then the doctor was held responsible for conveying information to the patient, who might then entrust the expert doctor with making the appropriate response at the time of arrest. Alternatively, the doctor might qualify as decision-maker on the basis of personal knowledge of the patient gained through interpersonal interaction, with the assumption that this would not prejudice their ability to make a rational (non-emotional) decision.

In representing these as normative and appropriate characteristics of the doctor, participants delineated what constituted a good (and by implication, a bad) doctor. The good doctor herein depicted embodies the ideal of the compassionate, knowledgeable physician, for whom scientific authority and interpersonal commitment to the patient are fundamental and indisputable.[37, 567, 574] This is both what is emphasised in the training of doctors,[452] and what patients expect from doctors, according to Barber,[575] forming the basis for the trust and responsibilities accorded doctors (pp. 131-62). Both these aspects then—knowledge of medical facts, and of the patient—are deemed to constitute the doctor's 'job description,' to actuate appropriate and normative behaviour, thus ensuring that their decisions are 'good.' In effect, the very constituents of the doctor's job—what it is to be a (good) doctor—constitute grounds for allocation of the decision to them. Conversely, the bad doctor would lack or fail to utilise either or both of these (medical or patient knowledge), and would make 'bad' decisions, this constituting grounds for precluding them from decision-making. Three patients spoke of instances wherein doctors might make 'bad' decisions.

> Kate. [A patient might] just want to be released from the pain they've got and they don't want to be dragged back to life to face that pain again if they specifically asked not to be. Really, I mean it's all very well for the doctors to have their record, and you know "No-one's died on me today" sort of thing, but they're not the ones that're involved. The patient is the one that should have that call, not medical staff. It's probably egos .... (9.2.3/1)

> Paul. I would hate to get a young doctor who's had a very bad night, and wants to take it out on somebody, and (...) this old sod. No, leave it. I think I've been reasonably sensible so far. I have [made a decision], but I don't want to sort of advertise the fact that, at your first opportunity, get rid [of] this one on social security or something. (9.2.3/2)

> Scott. It should be up to the individual, the person that is the patient, and the family. Because in some cases you don't know what the doctor's up to which happens. But most, I would say 99.9% of the doctors are good, but you get the bad one or two that's a bit on the devious side, but no. I would say the patient and the family … . (9.2.3/3)

In these excerpts, the identification of the doctor as a 'bad' decision-maker was used to bolster the argument that the patient should make the decision themselves. However, this negative construal of the doctor was somewhat differently effected in each case. Kate's opening phrase, "dragging the patient back to life to face that pain," negatively positioned those who might do so—here the doctor—as failing to act in the patient's best interests and lacking compassion. She then spoke of such doctors being driven by their "egos," such that they might go against what the patient had "specifically asked." This depicts doctors as failing to apply medical or patient-based knowledge, thus: Their actions are motivated by an egoistic (emotional) desire to achieve some sort of quota, rather than by rational consideration of medical fact. Additionally, in making decisions on the basis of achieving personal gratification, they override the patient's wishes, thereby demonstrating neither compassion nor respect for patient autonomy.

Paul spoke of the "young doctor who's had a very bad night and wants to take it out on someone" and "get rid [of]" the "social security" patient. Here, defining the doctor as young implies a relative lack of experience in medical practice, with a possibility that the doctor might not adequately consider medical fact. This possibility is further established as the doctor's actions are depicted as an inappropriate emotional response ("taking it out on") to circumstance "("a very bad night"). Paul's phrase "getting rid" implies the disposal of something that is not valued, suggesting a lack of care for or knowledge about the individual patient. This implicit devaluing of the patient attributed to the doctor is further strengthened by (1) the identification (attributed to the doctor) of the patient (Paul himself) as "this old sod"; (2) the impersonal pronoun referencing the patient used to describe the doctor's plan to "get rid [of] this one;" and, (3) specific reference to patients on "social security." This refers to patients who, lacking independent income, might be deemed to represent a 'burden' upon the medical system. The posited young and callous doctor was thereby construed as making decisions on the basis of an emotional reaction to circumstance, or a prioritisation of economic factors—further establishing a lack of care about, or for, the patient.

Finally, Scott's statement that "you don't know what doctor's up to," carries with it the implication that they are up to no good, and therefore that the patient cannot be sure that

doctors will make appropriate decisions. His conclusion that "99.9% [of doctors] are good but … the bad one or two … [are] a bit on the devious side" works to reinforce the accepted and acceptable version of the knowledgeable compassionate doctor, but also to challenge it. Not all doctors can be so described; not all doctors can be trusted. The quality that Sean cited as identifying the doctor as an inappropriate decision-maker (deviousness) is typically taken as indicative of a negative personality characteristic and, I suggest, ascribes to them a negative emotional quality precipitating behaviour that defies rational prediction and renders them untrustworthy. In this sense, then, the devious doctor fails the Stability test. As a possibility (however unlikely it is deemed to be), this supports the attribution of responsibility for the DNR decision to the patient (and family)—because ultimately you cannot trust doctors not to be a bit on the devious side.

What these excerpts share in common is that doctors' suitability as decision-makers is taken to rest upon their exemplary enactment of the rational, knowledgeable, and compassionate expert which legitimises their position as worthy of trust. Where this is called into question, they become inappropriate decision-makers. Effectively, doctors may be disqualified from decision-making in one of two (related) ways: (1) They fail the Stability test, behaving in ways that cannot be understood according to rational criteria. (2) They either do not have or do not apply knowledge of the patient which would entail putting the patient's needs first. Indeed, the above accounts all imply the absence of an interpersonal relationship between the patient and doctor making the DNR decision, such that doctors decide on the basis of their own needs, or pressures endemic within system within which they work.

To the extent that these negative construals are inherent in the definition of the 'good' doctor, so doctors may always be negatively defined, and not be trusted to make the appropriate decision. Although these 'deviant' doctors may function as exceptions that ratify the rule, the concerns raised by these participants mirror those voiced in the academic and medical fields. Other writers have identified several shifts in the medical profession that have worked to erode the traditional interpersonal relationship that engendered 'trust' between patient and doctor. These include the tendency for modern hospitals to be progressively more bureaucratic, impersonal, and subject to economic rationalisation; the increasing, and increasingly technical knowledge-base that widens the distance between expert doctor and bewildered patient; the increasing improbability that a patient will remain in the care of one particular doctor; and, the move towards a consumer-client model with attendant commercialisation of the doctor/patient relationship, such that

responsibilities become construed in terms of commercial contract rather than moral obligation.[37, 136, 567, 572, 576] Schneider[37] has argued that these changes have been instrumental in the shift towards "mandatory autonomy," to wit: Lacking the guarantee afforded by an interpersonal relationship, patients can no longer trust their doctors, and thus must make their own decisions (pp. 195-206). This inevitably works to challenge medical authority in decision-making, and to construe all (even medical) decisions about the patient as fundamentally personal.

The logical corollary of all this (that the best decision is one that the patient would prefer, that the existence of an interpersonal relationship that engenders moral obligation between doctor and patient can no longer be taken-for-granted, and that this constitutes appropriate ground for denying doctors authority to make the DNR decision) is that the nomination of the family as (better) surrogate decision-makers is accorded more weight. Family are typically presumed to be characterised by the presence of interpersonal relationships entailing knowledge of and obligation to the patient, and thus may represent themselves or be represented as best able to stand in for the patient, as best ensuring that the right (personal) decision was made.[116, 427, 577] Although I do not intend to do an exhaustive examination of the ways in which family was depicted throughout the interviews, I shall briefly discuss the ways that family was construed as either appropriate or inappropriate participants in the decision-making process, and the implications of these upon assumptions underpinning particular medical practices, specifically surrogacy.

9.3 Family and the DNR decision

I have described previously some of the ways in participants implicated family in the DNR decision. For example, I discussed how some participants nominated the effects of their actions (making or not making) upon their family as legitimate factors to consider in the DNR decision (see 8.2.1 and 8.2.2). Patients might make the decision themselves to save their family from making the decision or to prevent family suffering due to their prolonged existence (see 8.1.4). Others held that family might have some kind of stake in the outcome and sometimes this constituted grounds for family directing the decision (see 7.7 and 8.5.3). Eight participants had established Medical Power of Attorney, naming some family member (usually spouse) in that role (see 9.1). Others cited the family as constituting a reason to live, drawing on this to rebut any assertions that CPR might not be appropriate for them, or that DNR orders should be instantiated (see 8.5.3). Alternatively, Una argued that family's emotional attachment to the patient should disqualify them from any direct involvement in the decision (see 9.2.2/5), and the construal of the decision as medical

renders family involvement in the process somewhat superfluous. However, the most prevalent representations of family saw them as supporting the patient in their decision (foregrounding the construal of the decision as personal), or as having some legitimate interest in the outcome that mandated their more direct involvement (foregrounding the construal of the decision as social, or moral).

9.3.1 DNR orders as personal: Family as support

Participants' accounts of their own decision-making unquestionably lend support to models of decision-making that presume autonomy to have a relational component.[35, 131, 132] Although the majority of participants held that the DNR decision was theirs to make, some family involvement appeared to be taken-for-granted. However, what particular aspects of patient-family interaction were established as significant, and the relative agency attributed to the family, varied.

Most participants said that they had, at some point, discussed the issue with various family members, suggesting that family were cognisant of the patient's wishes. Many participants spoke of family as supporting or agreeing with their decision, thereby identifying this as desirable. Some participants referred to specific family members (most commonly, a spouse), while others spoke more generally of 'family.'

> Xavier. We've discussed these issues in principle and in detail, many many times. So they know my personal wishes, and as a family we have a consensus, on the sort of process. So, we're a tight family, a good family, we're close and we share. (9.3.1/1)

> Ross' wife Margie. I can understand the illness, and we've [she and Ross] already talked about it, and so the decision could be [up to] me. …
> Ross. I've made the decision on the path that I'd like them to follow. (9.3.1/2)

> Uri. I've made my decision and my wife and I have talked about it, and we've just made the decision that if it comes to that point, that I've instructed her not to go ahead with it, and, so that's how we've made that thing go. … And that's my decision, that's how I feel anyhow. I feel that the other one is quite capable of making a decision for you if you're not in your right mind at the time. (9.3.1/3)

These participants re-presented the conventional version of the family as literally and figuratively 'there' for the patient, and thus as best qualified to know and convey the patient's wishes.[116] They, as do many medical writers, appeared to take some level of family involvement in the decision-making process as normal and appropriate.[58, 83, 111] In fact, the role of providing support, in the guise of participation in discussions about

decisions affecting the patient, has been described as the predominant mode of involvement for the family in medical decision-making.[95, 113]

The language used in these excerpts nonetheless constitute the patient as primary. Patients make the decision, speak to their family, who then "follow," "know," or are "instructed" accordingly. In the process, family are both informed of the patient's wishes, and placed under some obligation to abide with them, to stand in for the patient should they be unable to do so themselves. There is, moreover, a reciprocal implied obligation that the patient should actually make the decision, most clearly articulated by Vera and her husband Ben.

> Vera. But basically I guess I decided all myself. Didn't I, because you wanted me to do =
> Husband Ben. Well it was your decision =
> Vera. what I wanted to do.
> Ben. That was my thinking on it. … That you had to make that decision, and then I'd support you and go along with it. But I think that that had to come from you … . I think the whole family sort of thought like that. (9.3.1/4)

Thus, although the family might support Vera, she "had to make the decision … . [It] had to come from [her]." This assignation of decider and support roles is relatively uncomplicated in the majority of cases wherein the patient accepts responsibility for making the decision, but is problematic if they do not (see 9.3.2).

Nonetheless, the majority of participants re-presented the independent individual (patient) as making the decision that will determine outcome, with the traditional corollary surrogate role as normally accorded to families. However, familial discussion might also fulfil functions other than establishing patient decision with family support.

> Uri. To a point, you must discuss it first because, you know [your family] have got to have some point of intake too that you, that they can point out things that you might have overlooked on the way … . (9.3.1/5)

> Maud. I think you should have a talk to your children and tell them how you feel, and see how they feel … . It's not that you want to involve your children in something, other people could have hurt them afterwards (…) (crying) I'd hate that.
> Interviewer. So you wouldn't want them to be blamed or anything, is that what you mean?
> Maud. No. I (…) (crying) so they'd really have to be involved. (9.3.1/6)

These participants construed the relationship between patient and family as one of mutual obligation. Uri saw family input as useful in aiding the patient to consider all relevant information, identified as a further aspect of the support role by Reust and Mattingly.[95] However, he also implied that the family's "point of intake" constituted relevant

information for the patient in the process of considering their decision. Similarly, Maud spoke of a mutual exchange of feeling, implying that awareness of her family's emotional state was important to her—supporting my earlier contention regarding the saliency of emotions in decision-making. Her concern regarding her family was evident as she became distraught (and unintelligible) when discussing the possibility that her family might incur some blame following whatever actions were taken. This further attests to the moral implications of the DNR decision.

Both Uri and Maud, as did Scott and Tom below, depicted a conversation with the family as mandatory, using imperatives such as "must discuss it," "you should have a talk," and "it's vital." This language serves to establish the inclusion of the family in the process as an obligation placed upon the patient, again highlighting the moral aspect.

> Scott. I discussed it with … me whole family … . If you don't [discuss with them], my opinion is if you don't … they'll tend to think "Well he never discussed it with us, and he's left us out in the lurch" or whatever. And I think it's vital that the family, that they do talk it over with the family. Because … then it's up to you, the final decision is up to you what you do. But the family will then have a good idea what you're doing. … Yeah, keep them in the know, yeah. (9.3.1/7)

> Tom. I can't see why anyone wouldn't wanna discuss it [with their family], I mean, if they didn't wanna discuss this, I think they'd be a pretty cold attitude of looking at the situation. … I think the more open it is, about the situation, the better. But when the time comes it's still a blow, but perhaps lightened, lightened the way by sort of talking … . (9.3.1/8)

Here, patients who might refrain from discussing the DNR decision with their family were negatively construed as leaving family "out in the lurch," and as displaying a "pretty cold attitude." Conversely, keeping family "in the know" and being "open … about the situation" was positively presented as benefiting the family. This works to define such discussions as doing more than either conveying the patient's views to the family in order that they can know and relay the patient's wishes, or as ensuring that patients have adequately considered relevant factors. Although others have noted that patients consider the consequences of their decision upon family,[95, 116] this analysis demonstrates that participants also considered the consequences of including (or not) the family in the decision-making process. What were featured as important were the consequences upon the family's emotional and moral status, either at that time, or in the future. Discussing the issue with family is thus further rendered a moral necessity for the patient, as part of appropriate behaviour for the patient in the familial relationships. It also, however, establishes the family's participation in the process and interest in the outcome as normative. I shall discuss this further at 9.3.2.

Notwithstanding family's entitlement to inclusion or consideration in decision-making, many asserted that ultimately the patient's "opinion," "what [they] want to happen" should hold sway, even in the face of potential disapproval or disagreement from family. The language used by Yves and Opal, moreover, suggests that there may be some obligation laid upon family to work to effect the patient's wishes ("I'd appreciate those things being observed," "They'd [family] go along with what I wanted").

> Yves. I said to [my wife] before, "It's probably me being selfish in my views, but they're my views and that's what I want to happen." (laughter). … I said, "It may be selfish to you, but it's not to me, it's my opinion, it's what I want … so I'd appreciate those things … being observed." (9.3.1/9)

> Opal. I suppose if I'd made the decision not to go along with [resuscitation] … that should apply. But I suppose the family also should have a right to say whether you can or not, I guess it'd be up to them as well. I don't know. No, the only thing I would feel is that if I told them definitely that I didn't want to be put on life-support then they wouldn't do it you know. They'd go along with what I wanted. (9.3.1/10)

Family is here construed as appropriate surrogate decision-makers on the grounds that they would represent the patient's wishes, that they enact patient autonomy,[95] regardless of their own position on the matter. Although Hardwig[118, 135] might consider that the exercise of patient autonomy should not include a right to assert their values over those of their family, this particular representation by participants corresponds with that of those medical writers who suggest that patients' consideration of family dissent or disapproval constitutes one more factor that patients might legitimately take on board in the process of arriving at their own decision.[111, 578]

9.3.2 DNR orders as social: Family with a stake in the outcome

Concurring with the observations of many writers examining patients' preferences for surrogate decision-makers,[112, 222, 238] participants most often nominated family (or a specific family member) as surrogate decision-makers when considering a situation where a patient's decision was not available at the point when a decision might be needed—at the moment of crisis, for example. Moreno[168] noted the common-law assumption that family have the right to be consulted in such circumstances, with appropriate explanation and justification required if they are not. This appears evident in the language used by Wendy's husband Dennis—"the son would be asked," "they'd ask the next-of-kin surely."

> Wendy's husband Dennis. But doesn't it often then, it comes back to the next family member? … If you ask "Well do you want to resuscitate?", isn't it the mother, the son would be asked I know that if she's too far gone to make a

> decision, they'd ask the next-of-kin surely, to make that decision for them, is what they'd do. (9.3.2/1)
>
> Yves. I mean it's different if a person is in a kind of comatose or vegetive [sic] state. It revolves [sic] to the next-of-kin then I should say. ... If they won't make the decision, I think it's best off for the next-of-kin to make the decision that's best off for them. (9.3.2/2)

It is worth noting that use of the terms 'family,' and 'next-of-kin,' may be problematic. As generic categories, their use obscures the fact that the entity to which they refer is composed of individual members in different relationships to the patient (who is also part of that family), and probably with different sets of values, experiences, and needs. In nominating family as the surrogate decision-makers, participants reproduce the construction of the family as a homogenous 'superpersonality' which thinks and acts as one:[239] This despite much evidence to the contrary,[235, 239, 275, 286, 438, 553, 579] including within this research (see 5.2/8-11, 9.3.3/4, and 10.2/15). Furthermore, despite the use of 'next-of-kin' in medical and lay parlance, the term has no formal legal status within South Australia.[580] Nonetheless, one might conclude that these participants attest to the dominance of what Rhoden[116] called "a presumptive right" of the family to make decisions on behalf of the patient who is unable to do so.

I suggest that the relative positioning of patient and family with respect to the DNR decision (including process and outcome) can be usefully characterised along a continuum. At one extreme, and through emphasising the personal aspect of the decision, patients may justifiably assert their views over that of the family. Even so, the invocation of the social and moral aspects of the decision, attendant upon the individual patient's location within a set of interpersonal (familial) relationships, may render such patients likely to incur some opprobrium for displaying inappropriate disregard for the well-being of others.

This latter point presumes family to have an interest in the outcome. This might enable them to claim (or be assigned) greater involvement in or responsibility for the decision. Within this study, discussions with patients and families were not depicted as just a one-way street wherein patients considered family's views and then informed the family of their decision (e.g., see Tina and Wayne at 8.5.3). Sally, for instance, reported herself as having formulated her opinion on at least one decision after obtaining family views, basing her decision upon their expectations of her.

> Sally. [My family and I] all got together, as many as possible one day, and I said "This is it, it's up to us now what to do." And they all gave their opinions, I said I wasn't going to give my opinion at first. And they all gave their opinions on it. And

> they were all heartily agreeable that I should fight on. Do, take the necessary precautions, the treatment that was being offered to me, and that. That they were behind me. And they spoke so nicely about it that I didn't answer them straight away, but I thought about it, and I thought "I cannot refuse them that, try, try it." (9.3.2/3)

What is interesting about this excerpt is the way Sally established and balanced her obligations to (1) take responsibility for the decision that is ultimately about her treatment, and (2) consider others. She began her account by identifying the decision, not as hers, but as her family's ("it's up to us"). Nevertheless, her family's acquiescence with the terms she set for this encounter—that she not voice her views initially—suggests some tacit acceptance of her authority to control the decision-making process. In addition, (again, by her account) the family construed the issue and potential future actions under review as hers (she "should fight on" etc.), with themselves in a supportive role ("they were behind me"). This further confirms her in the primary role, albeit including family "opinion" in her decision-making process. However, although this might be taken simply to enact a process of rational decision-making, I suggest that Sally's explanation that "they spoke so nicely about it that … I thought 'I cannot refuse them'" attests to the complexity of this situation and decision for Sally: It was not any information conveyed by the family that she identified as the relevant factor in accounting for her decision, but the "nice" way that they presented it. "Nice" carries an evaluative and emotional connotation, which works to stress the emotional as an important element in this process. Furthermore, Sally's presentation of herself as obliged to responding positively to a family request ("I cannot refuse them") works to construe the decision as having social and moral import.

Nonetheless, Sally's authority to make the decision is implicit in her statement that she "didn't answer them straight away, but I thought about it." This represents her as weighing up her family's requests, with an implied ultimate right to accept or decline their preferences. Thus, and despite the invocation and force of other construals, decisions about an individual are established as fundamentally personal. In this account, Sally, as the individual patient making decisions, articulates the dilemma of liberal ideology (see also 4.2.2): The exercise of autonomy includes the obligation to consider the welfare and interests of others, yet to assume the decision as one's own.[398, 399]

At the other extreme on the continuum of involvement of family in decisions about the patient, some participants cited family's interest in the decision as entitling (and sometimes implying an obligation for) family to make the decision. I have already discussed examples of speech by Wayne (at 8.5.2) and Sean (at 7.7), that supported their nomination of family

as the appropriate decision-makers. Yet at other times during their interviews this position appeared problematic. For example, an interchange between Sean and his wife Vicky shows some disparity and contestation regarding whose point of view should prevail. It followed on Sean's justification of his deference to his family, and specifically, his positioning of Vicky as integral to any decision-making involving him.

> Sean. [I've] never even thought about anything like that [the DNR decision]. But I think, yeah, I think my answer would have to be, well, ... I'd be happy that the family, whoever were around at the time, would do just what they wanted to do. ... I want to be so independent. And I don't want [Vicky] cracking herself up because of me. ... I'm tossing over so many things, and ... it is a lot to take in. Especially because we've [Sean and Vicky] worked so much together, that I don't like to work independently. (9.3.2/4)

Here, Sean reiterated his earlier discussed position that he had not previously considered the DNR decision, and willingness to leave it to the family to do what they wanted. Nonetheless, he also expressed a desire to be independent, associated with an expression of concern for his wife Vicky. Typically during interviews, the importance of 'independence' was associated with the patient assuming responsibility for the decision in order to relieve others of the decision (e.g., see 8.1.4 and 8.2.2). This actually values independence because of the effects manifested within an interpersonal relationship. Independence does not therefore imply separation from others, but attachment to them: Independence connotes interdependence. Viewed thus, Sean's asserted desire for independence neither contradicts his demurral regarding the decision, nor his later statement that he does not "like to work independently" from Vicky. Sean also presented this interdependence as the habitual mode he and his wife used in dealing with information potentially requiring decisions, providing further support for his deference to her (as a specific member of family). Drawing upon the construal of the individual patient as appropriately enmeshed in, and considerate of familial relationships, as well as the construal of the DNR decision as social, Sean was thus able to justify his position of non-acceptance of responsibility for it.

His wife Vicky, on the other hand, invoked the primacy of a patient-based decision to justify her insistence that he decide, and that she function merely to carry out his expressed wishes.

> Vicky. I don't want to get involved. I want to get his opinion, not mine. I just want him to say what he wants. ... Well, I think my decision really, should rest with the patient, so that his wishes are strictly carried out, and that is my opinion. That is strictly my opinion. Whether it is his opinion is totally different ... . I won't say too much, because I don't want to sway him, but I really want him to have his say in what he feels, and what he wants.

> Sean. Well, I feel I want you to say. I have said what I wanted to say. And I haven't asked you many questions. I haven't asked you for many questions.
> Vicky. No, but I came in here to listen =
> Sean. Yeah, I know. …
> Vicky. You can see that different people do have different views which is why I've kept quiet, I just wanted to get his. (9.3.2/5)

Critically, although Vicky was ostensibly prioritising Sean's "wants," his wants were repeatedly framed in the context of what she wanted ("I want to get his opinion, not mine. … I just want him to say what he wants. … I really want him to have his say … ."), thus asserting the weight of her own wants. In doing so, Vicky (1) effectively invalidated Sean's position of wanting not to actively articulate (or make) the decision, and of wanting to know her position; (2) countered Sean's wants with her wants; and (3) placed some moral obligation upon Sean to respond positively to her desire to know his wants. Indeed, the conversation emerged as the clash of "wants." Both, however, can justify their own silence on the matter (and deferral to the other) through invocation of particular aspects of autonomy, with associated representations of the DNR decision: Sean, through appeal to autonomy as encompassing the views of others, and construal of the DNR decision as social; and Vicky, through appeal to autonomy as holding the individual responsible for decisions, and construal of the DNR decision as essentially personal.

Nonetheless, (and perhaps unfortunately for Sean), both accounts function to identify patient's avoidance of the decision as problematic, thus: Although Sean might continue to maintain his silence, to do so would be to risk disappointing Vicky, demonstrating a dismissal of her views—which he has already identified as important to him. Conversely, Vicky's repeated preference that Sean *does* decide works to undermine the validity of what might arguably represent autonomous decision on Sean's part *not* to decide regarding the DNR issue. In addition, to the extent that Sean's equivocation can be construed as failing to meet his obligations to her or as failing to enact the autonomous adult making decisions about his own healthcare, Sean would be likely subject to some moral censure. Thus, in contrast to normative assumptions regarding autonomy, both versions might work to oblige individuals to disregard their own preferences.

9.3.3 Challenges to family decision-making

To summarise to this point, the nomination of family as appropriate DNR decision-makers was primarily justified through invocation of characteristics that normatively constitute 'family.' These include the construal of the patient and family as subject to a reciprocal set of obligations, as well as the mutual exchange (and co-creation) of personal history and

preferences. Accordingly (and acknowledging an oversimplification of argument) family might be deemed to extend patient autonomy (manifested in family's advocacy of the patient's needs and preferences), or to be integral to the expression and formation of it (manifested in the patient's prioritisation of family's needs and preferences). These two alternatives parallel the two construals of the decision as personal or social, and sanction a range of possibilities regarding who might ultimately claim (or be assigned) responsibility for the decision. For example, with emphasis on family's obligations to patient and construing the decision as personal, the argument might go thus: Family know the patient's preferences, and are enjoined to effect them—even if this contradicts their own. Conversely, emphasis on the patient's obligations to family and construal of the decision as social might suggest that family's needs and preferences can contend with, even override the patient's. Finally, either option might justify the patient's allocation of the decision to the family, construed either as family enacting the patient's preferences, or as the patient deferring to the needs of the family.

Nonetheless there were instances within the interviews wherein participants drew upon specific construals of the decision, or of the family, in order to challenge the appropriateness of family in the surrogate role. This was particular pertinent when participants considered the situation where family were not aware of the patient's wishes. However, as previously commented upon at 9.2.1, determining who then might be appropriately assigned this decision appeared problematic for many. Lois, for example, repeatedly displayed uncertainty in her talk about this possibility ("I don't know … . I guess … . I'm not sure … ."), characteristics also shown by Sally and Vera at 9.2.1/6-7.

> Lois. I don't know if you [the patient] haven't discussed it who makes it, but I guess maybe you could ask [your family members] to confer. … I'm not sure about the ethics of doing that to someone else. I think it'd be all right if you had discussed it with them, and told them that that's what you want. … [Otherwise] that the decision's a bit too hard for everyone else. … Well maybe with discussion with doctors and with themselves, and if the medical people are suggesting that … eventually the outcome is going to be death, then maybe they might agree. But if they don't well, I don't know that you could do anything. Because the decision is too hard for them. (9.3.3/1)

All three speakers (Sally, Vera, and Lois) also qualified their eventual nomination of the doctors as appropriately involved, using "maybe," "I guess," or "I think." Collectively, these linguistic features work to construe their responses as provisional,[581] indicating that the issue was not clear-cut for them. This equivocation also points to the difficulty of nominating an alternative decision-maker, which in turn serves to demonstrate that the decision itself is difficult (see also 8.1.4).

The construal of the decision as difficult also alludes to the moral implications of leaving it others. Indeed, Lois specifically identified the issue as ethical (i.e., moral), construing the allocation of the decision to another as "doing that to someone else," with the "someone else" apparently the family. This phrase positions the patient who has not stipulated their own views on the matter as displaying an inappropriate disregard for their family, further implied in her description of the decision as "too hard for them." The construal of the decision as having moral connotations works to challenge the suitability of appealing to family to make the DNR decision.

Another version of the DNR decision—as choosing between life and death (see7.2 and 7.5)—may also be implicated in Lois' speech, operating to reinforce the negative moral status of leaving the DNR decision to the family. Given the normative bonds presumed operative between patient and family, the requirement that family make the decision as to whether the patient should live or die can be deemed to impose an undue burden upon them.[113, 438] Lois specified two sets of circumstances as liable to alleviate this: The patient may have "told them [family] what they want." This option, which was presented as superior ("I think it'd be all right if …"), depicts family as passively conveying the patient's views, and thus not to be held responsible for decision or outcome. Alternatively, doctors may suggest that there is no real choice to be made ("eventually the outcome is going to be death"), similarly absolving family of responsibility. The explicit construal of the situation as not requiring a choice between life and death works to minimise the moral connotations of the decision, rendering it (as indeed Drought and Koenig[121] have claimed) more as one of pragmatic acceptance of the inevitability of death (see also 8.5.3/3 and discussion). It is here implied as likely to reduce the difficulty of the decision for the family, allowing that this might lead them to arrive at a decision. This is, however, presented as not guaranteed ("maybe they might agree"), suggesting that family are unlikely to be unconflicted by their involvement in the decision.

These construals of the DNR decision (as difficult, as patient-directed, as not one of life and death) all function to support the removal of responsibility for the decision from the family, thus to promote the suitability of doing so, and consequently, to undermine appropriateness of assigning family the surrogate role. They can be discerned in Nina's discussion with her husband regarding their endowing "Bridget and David" (their most closely-related family members) with Medical Power of Attorney in the context of making the DNR decision.

Nina. Putting it bluntly, we dumped this onto Bridget and David. And I think that it was a bit of an imposition, dumping it on to them, when they needn't have had that responsibility.
Husband Ray. Medical Power of Attorney, is that what you're talking about? =
Nina. Yes. Oh yes, Bridget, they were happy to take the responsibility, but I don't know as if we had the right =
Ray. To ask them. … [But] Bridget didn't hesitate to accept it, did she?
Nina. Yes, when she said "What happens if there's no alternative?" and I said "You pull the plug." …
Ray. Oh I see. The decision of life didn't rest with her, in other words. … And when you told her that she didn't have to make the decision "Well what would I do? Will I keep her alive or let her die?" Is that right?
Nina. Yeah.
Ray. Yeah.
Interviewer. Yeah. And she was OK with that then?
Ray. Yeah. (9.3.3/2)

Nina's initial description of her allocation of Medical Power of Attorney (effectively authorising her relative Bridget in the surrogate role) achieved several (related) things. For example, it was construed as a "bit of an imposition." This description negatively positions Nina and Ray as contravening some norm, as requiring more than one uncontroversially might assume as unexceptional within this familial relationship. This representation was further strengthened throughout Nina's account ("we dumped this … . I don't know as if we had the right.") The phrase "we dumped this" also works to depict the extent to which Bridget might refuse acceptance of the "responsibility" as somewhat limited. The conferral of responsibility was not, for example, described as negotiated between parties. Finally, Nina's negative assessment of assigning responsibility for the decision further bolsters the construal of the decision as difficult, all of which work to establish the moral dubiousness of assigning it to another.

This notwithstanding, the description of Bridget, as "happy to take the responsibility" and not hesitating to "accept it," works to establish a counter-position that sees family acceptance of this "imposition" as a positive option, and one that follows from the aforementioned normative assumptions of (moral) obligations that characterise family. Yet the obligation that family put themselves out for other family members (namely, the patient) is balanced by the obligation of the patient to limit the burden placed upon family. Ray's question, however, attributed to Bridget, ("Will I keep her alive or let her die?") assigned maximum responsibility (maximum 'burden') for outcome to whoever is held accountable for making the decision. Ray, Nina, and Bridget (by report) all appeared to take as given the construal of the decision as one of life and death, identifying as undesirable that this should "rest" with Bridget. Correspondingly, Bridget's acceptance of the surrogate role was only ratified by all parties once it was established that "she didn't

have to make the decision [of life]." This was achieved through Nina's articulation of what she wanted, as specifically requested by Bridget, as well as Nina's construal of the situation as not requiring a choice between life and death ("if there's no alternative … pull the plug"). Ultimately, assigning family responsibility for the decision was rendered problematic, with minimisation of the responsibility deemed preferable. This works both to reinforce the dominance of the personal construal of the decision and highlight the moral aspects.

Also drawing upon normative notions of family, Una spoke of family's "emotional and other involvement" in the situation, taking this as grounds for allocating the decision to the, presumably non-involved, doctor (see 9.2.2/5). However, this emotional closeness can be deemed to justify family's nomination as surrogate (see 5.2 and 9.3.1). As in the first study, accounts that appeared to challenge family's suitability in the surrogate role most often appeared in descriptions of families' experiences at this time (near the end of life). For example, Pete and Opal implied that "accepting" that the patient's death was imminent and inevitable was difficult for some family members (as it was also for some patients, e.g., see Sean at 7.6.2/1, Una at 8.5.1/1, and Wayne at 8.5.3/4). "Acceptance" implies the potential for denial, and both Pete and Opal cited examples that can be taken to demonstrate some form of denial by family.

> Pete. I guess it [responsibility for DNR decision] depends where there's acceptance of where they're going, you know, (…) the family stuff. I know with my neighbour, she stood by her husband's bed day and night saying all the time "Don't you dare leave me, don't you dare leave me." And (…) how could he die? … she never wanted to talk about it. (9.3.3/3)

> Opal. Although he [Opal's husband] knows it's inevitable, he's a bit of an ostrich too, he doesn't sort of want to think about it yet … . I said to Beckie [Opal's oldest daughter] "Further down the road you've got to see to this, see to that," and she seems to be accepting of it all, she's not quite, buries her head like her dad … . (9.3.3/4)

Here, the spouse, who (according to most hierarchies of surrogacy) would likely be called upon in the surrogate role, was characterised as avoiding thinking about or discussing "it," that is, the patient's imminent death. Why this should be so is suggested by the emotive connotations of the descriptions. Burying your head like an ostrich usually connotes a fear-based denial of something inescapable; while the language ascribed to Pete's neighbour is typically associated with an angry fear of abandonment. In both cases, the behaviour of the spouse fails to meet standards required for rational decision-making, and can be readily understood as emotionally-derived. And for both, this was taken as potentially justifying

exempting (or excusing) the spouse from the responsibility of the decision (Pete saying "it depends," and Opal shifting the responsibility to her daughter, Beckie): These family members failed the Stability test.

There is, moreover, another aspect of family avoidance of the issue that can work to challenge them as appropriate surrogates: If family and patients can justifiably avoid these discussions as liable to have a negative effect on their (emotional) well-being—because the issue is difficult, because the decision is construed as one of life and death, because the emotional attachment between all parties renders them unwillingly to upset the other—then there can be no guarantee that family will actually know what the patient wants. Indeed, studies suggest that family and patient discussions regarding the imminence and inevitability of death are often limited.[286, 438] What is critical here is that family (including the patient) members' performance of good familial relationships may work to compromise the extent to which they can know and represent the patient's wishes. Thus what constitutes a 'good' family can be invoked to render them both appropriate and inappropriate decision-makers. This is in contrast to the situation described with relation to the doctor and the DNR decision (at 9.2.3), wherein a 'good' doctor was always represented as eminently qualified to make the decision.

As a final point: These participants assumed that a patient's nomination of family or doctor as preferred or appropriate decision-maker on that patient's behalf would so unequivocally assign decisional authority to those parties. They did not appear to consider any legal stipulations that might be brought into effect to challenge this (see Appendix B and Chapter 5, p. 77), which may engender confusion and distress if disputes arise and relevant legislative processes are invoked.

9.4 Conclusion

In this chapter I have demonstrated that participants presented the DNR decision as predominantly personal, which worked to assign responsibility for the decision to the patient. The presentation of this as preferable and normative was achieved in several (mutually reinforcing) ways. For example, most participants reported having made their own DNR decisions with the presumption that their preferences would have operative force. In addition, where their nomination of the patient as decision-maker was relatively straightforward, nominating another appeared difficult. Furthermore, because patients were construed as obliged to consider the effect of their actions on others, those who were perceived as not doing this, by, for example, refusing to make the DNR decision (by

default leaving a difficult task to others), were negatively construed and subject to moral censure. Although this identifies the decision as having moral and social import, it strengthens the construal of the decision as personal, obliging the patient to make it.

This notwithstanding, participants were able to draw upon alternative construals of the decision in order to justify other conclusions. For example, not only did some participants assert the right of the patient not to decide, but some positively construed this choice, identifying it as actively resisting the disease, waiting until the appropriate moment to make the decision, appropriately deferring to medical expertise, or as motivated by a desire to consider family's wishes. Similarly, participants' assertion that decisions should be made while the patient was competent, which might function to oblige the patient to make the decision relatively earlier, coexisted with the implication that later might be better, perhaps because this would ensure adequate consideration of contemporaneous experiential information, or would enable the patient to continue their fight against death.

In analysing talk regarding nomination of appropriate alternative (surrogate) decision-makers I identified two potentially competing notions of what constitutes the best decision, namely (1) one derived from rational consideration of medical fact; and (2) whatever the patient wanted. These, I argued, saw knowledge of (1) medical fact and (2) the patient, as critical and corresponded to the construal of the decision as respectively medical, or personal. Participants selectively drew upon these to justify differential assignation of responsibility to doctors or family. However, although enactment of the 'good doctor' role (exhibiting caring and competence) qualified the doctor on both counts, the potential that individual doctors might deviate from this worked to recommend that patients make their own decision. With regard to family, participants drew upon normative characteristics constituting family to identify them as appropriate decision-makers (e.g., by virtue of a presumed knowledge of, and care about the patient) but also as inappropriate decision-makers (e.g., by virtue of a presumed emotional attachment to patient taken to preclude rational consideration, and relatedly, as liable to suffer harm through being asked to determine whether the patient lives or dies). I further suggested that the construal of the decision as predominantly personal worked to oblige family to comply with the patient's preferences (even when they disagreed), but that the construal of the decision as both social and moral might work to moderate this, obliging patients to attend to families' preferences (even when they disagreed).

To summarise, participants variously held that patients should, but need not make the DNR decision; recommended making the decision earlier and later; represented patients, family,

and doctors as appropriate and inappropriate decision-makers; concluded that best decision reflected knowledge of medical fact, and of the patient's preferences (respectively construing the decision as medical, or personal); and obliged the patient to consider the effects of their decision upon the family whilst maintaining their right to dismiss same. The diversity of potentially justifiable views available to (and here accessed by) patients suggests that devising a single policy to address DNR decision-making may be challenging.

Chapter 10. Study 2. The discursive properties of hope in talk by dying patients

In my analysis of hope presented in Chapter 6, I concluded that *hope*, as used by patients with cancer, represented a multi-faceted construct, that incorporates, but is not limited to, those versions represented in medical literature. There were, moreover, consistent differences in functions and consequences associated with patients' use of hope as noun or verb. In this chapter I similarly examine the use of *hope*, as spontaneously used in interviews with patients dying of cancer, replicating the procedure followed in Study 1 (see 6.2). My aims are to explore how hope was constructed and shaped discursively for this population of dying patients, to demonstrate how particular uses of hope were associated with different consequences for patients and, in keeping with the rest of this dissertation, in so doing to highlight how patients might flexibly draw upon different construals of (in this instance) hope to justify a variety of views and positions taken.

During the interview, in absence of direct prompting, twenty-six persons used the word hope or a derivative thereof, with a total of twenty-five interviews featuring hope in some unprompted guise. As the interviewer, I also unpremeditatedly used hope a total of twelve times within ten interviews. To summarise numerically, within this category of spontaneous manifestations of hope

- seventeen persons (including myself) employed the noun or adjective version (HN) thirty times in total within fifteen interviews;
- twenty-three persons (including myself) used the verb or adverb version (HV) fifty times in total within twenty-two interviews.

As in the first study, the use of each was associated with markedly different implications for the patient.

10.1 Hope-as-a-noun

As noted at 6.2.1 hope-as-a-noun (HN) intrinsically depicts hope as an thing, which is or is not there. In this study, as in the first, when employing HN, participants most commonly appeared to reference the probability that medicine could successfully intervene in the course of a patient's disease, averting or delaying death.

10.1.1 Objective characteristic of the situation

Consistent with my earlier analysis, when this version of hope was featured, it was most typically phrased in the negative, as 'there is no hope.' Particularly in the context of discussions about the DNR decision, the absence of hope constituted justification for the doctor to not attempt resuscitation, for refraining from medical intervention aimed at preventing or delaying the patient's death.

> Tina. Well if there's no, not much hope sort of thing, just let me go. … Let me go to sleep. (10.1.1/1)

> Nina. I said [to my doctor] if he'd thought there might be a slender chance, he's to do what he thinks best, but if he thinks there's not a hope in hell, no, [don't commence resuscitation]. (10.1.1/2)

> Wayne. [DNR orders apply] if a doctor knows there's no hope for you, and that when you go, … that there's no chance … to get [you] going. (10.1.1/3)

What is omitted here (cf. Chapter 6) is any form of explanation as to what 'no hope' means. The object of hope was typically left unstated by these participants, suggesting that the meaning of hope is here taken-for-granted, constituting a shared cultural assumption.[582] I have suggested that this HN represents "the existence of treatment/s that would ensure that they [the patient] would not die (constituting cure) or, at the very least, ensure long-term reasonable health" (see 6.2.1.1, p. 112). Determining this is deemed to be the prerogative of the medical profession, who then report upon this empirical fact. Hope is thus overwhelmingly associated with the physical prognosis for the patient, and linked to their survival—referencing treatments to cure or remit the disease.[434] Correspondingly, 'no hope' means no such treatments are available, with the associated inevitable imminence and irreversibility of death. As medical science discovers and offers those treatments, so medical science as an institution may be deemed to provide the hope, further strengthening their authority in this construal. Indeed, one of the most common manifestations of hope within the medical literature references the potential that new treatments might have to cure or successfully treat disease,[470] thereby justifying both the necessity and funding of various research endeavours (e.g., see Good et al.[425] on oncology; and Mulkay[494] on genetics). Thus, to a certain extent, treatments need not be here-and-now in order to provide hope—hope may reside in the potential just-around-the corner efficacious treatment that may become available (just-in-time for the patient). Indeed, Gordon and Daugherty[176] observed that American oncologists in discussions with their patients specifically cited the potential of new therapies emerging, with the avowed intent of increasing patients' hope, while Hagerty et al.[273] reported that the doctors' provision of the

most up-to-date treatment was frequently endorsed by cancer patients as engendering hope—more so than any other behaviour that the doctor might display. Paradoxically, however, although medical science may be held responsible for creating hope (in the sense of discovering new treatments), the medical practitioner who actually interacts with the patient is absolved of any such responsibility, as they merely report upon or provide available treatments.

It is this version of hope (denoting possible cure/remission) that appears operative here. Although these patients (10.1.1/1-3) were actively stating their own wishes as to appropriate courses of actions in the absence of hope, the existence of hope (or indeed the determination that it does or does not exist) was depicted as beyond their direct control. Thus, in this version of HN, the agency of the patient is limited: Hope exists independent of the patient, and its presence or absence is determined by others, with attendant consequences for medical decision-making.

According to these participants, the condition of 'no hope' (the absence of effective treatments) constituted justification to refrain from medical intervention, and the ultimate and acceptable consequence of this course of action was that the patient's death occurred unhindered. Sometimes the 'no hope' argument was also called upon as justification for initiating medical intervention aimed at actually achieving the patient's death, that is, to justify the practice of euthanasia (see also 6.2.1.1/5).

> Oliver. Well, I suppose that if there's absolutely no hope and the person can sense themselves, then, [euthanasia is] fair enough. (10.1.1/4)

> Opal. I'm all in favour of [euthanasia] if it's done the right way. … I think in a case where there is absolutely no hope at the end of the road, then I can't see the point of it just going on and on, it's so stupidity to me. (10.1.1/5)

Accepting 'no hope' as justification for actions that will result in the patient's death works to construe HN as having life or death implications for the individual. Hope is thus established as fundamentally important to the individual patient: Presence of hope means life, absence of hope means death. Yet hope itself is located outside of the individual, is inherent in the situation, objectively ascertained by the clinician as expert. This reified version of hope may serve several functions. As previously noted, it may work to minimise the extent of the clinician's responsibility in actions predicated upon the presence or absence of hope—they merely report upon and respond to an objective circumstance. It also, however, works to minimise the significance of any quality of the individual patient other than the medically-determined status of their disease. Patients are construed solely in

terms of biological features (how sick they are) that in turn inexorably equates to a presence or absence of (an objective) hope. Thus, the significance of other specific individual characteristics of each patient that may inhere in alternative construals of persons (e.g., those that foreground emotional, psychological, or interpersonal constructs) is diminished. This strategy works to render a potentially complex and contentious issue (here euthanasia) rather more simple and unproblematic, as a particular outcome is seen to inhere in the characteristics of the situation itself (see Potter,[294] pp. 183-7).

This aspect of HN (focusing on a biological to the exclusion of any other construal of individuals) appears evident in Xavier's speech endorsing the practice of euthanising humans, wherein the human individual without hope is compared to a dog or a cat. What is significant in terms of justifying the outcome is established as independent of whatever characteristics may be deemed to distinguish humans from animals.

> Xavier. What if your cat or your dog was in this position, would you keep prolonging it, or would you want it to go quickly and quietly when it had no hope, and it was in pain? And the answer would be that it would have to go, really. (10.1.1/6)

Here, the response of euthanasia is presented as a reasonable and routine (even trivial) response to the circumstances of no hope, with no culpability attributed to those responsible for it. Equating animals and humans also works to minimise the significance of any agency that might reside within the individual (patient) under consideration, as it is presented as acceptable that others make the assessment as to what course of action is appropriate.

There were other consequences of the life and death implications of this version of HN. First, because conveying that there is no hope may be taken as equivalent to delivering a death sentence, it could reasonably be expected to be negatively received by patients. Thus, although the patient's doctor may not be held responsible for the presence or absence of the hope itself, they might be held responsible for relaying (or even implying) a lack of hope to the patient. Second, the assertion of the smallest amount of hope (again construing it as objectively assessable) may serve to rebut the conclusion that death is inevitable, an argument called upon by Ruth.

> Ruth. I saw an oncologist whose attitude unfortunately all the way along was very much, "you're terminal and there's nothing we can do." ... There was never any hope offered. Of any kind, and I mean, let's face it, if you have a one-percent chance, then there's hope, and while I wouldn't want it to be overblown or

> overdone, neither can you say that there's none. … [He] was very fond of using words like "terminal" at a stage when I was not ready to use them. (10.1.1/7)

Ruth explicitly established a link between hope and the probability of successful treatment ("'nothing we can do'"), and her oncologist's failure to "offer" hope, however small, was negatively construed as inappropriate and insensitive to her needs. Such terminology serves to re-present the active role of the medical profession in this hope—Ruth is merely the potential recipient of this 'gift,' with limited capacity to affect the outcome. Nonetheless, within a culture where fear of death is the norm, the implication that it is inevitable and imminent is likely to be negatively perceived.[347, 429] Drawing upon the equivalence of 'no hope' and death, Ruth argued that even a "one-percent chance" of hope means "there's hope" and therefore death cannot be presumed to be inevitably imminent. Moreover, as even small 'amounts' have vital import in relation to life or death, Ruth's argument works to further endorse the value of hope. This understanding then formed the basis for her criticism of her oncologist ("using words like terminal"), with the inference that the clinician conveying judgements about the inevitability of death should be responsive to a patient's readiness to receive them. It has been noted that this contributes towards a dilemma for clinicians who, although endorsing the need for patients to be informed of their prognosis, may yet be hesitant to assert unequivocally that there is no chance that the patient may be well, that there is 'no hope,' and unambiguously to predict the patient's death.[174, 176, 179, 583] However, the no hope equals death construal of HN may function as something of an escape clause inherent in the above-cited pro-euthanasia statements: Determining that there is "no hope"—indeed, that there is "absolutely no hope" (see 10.1.1/4-5)—may be open to contestation.

In Study 1, some participants drew upon the value accorded HN in arguments regarding the timing of discussions about DNR orders. It was, for example, argued that such discussions should not proceed until there was 'no hope' (see 5.1.1 and 6.2.1.2). One potential consequence of this is that DNR discussion itself may be taken to connote the lack of hope. This seems evident in this study, as Vern used this phrase when responding to a question about whether DNR discussions should occur between doctors and patients. His rejection of this option appeared to rest upon the notion that the DNR discussion would remove from the patient the possibility that all will be well, and confirm that there is "no hope."

> Interviewer. Do you think that the doctor should discuss [the DNR decision] with the patient?
> Vern. No. … Maybe it's just somebody with a bad heart. They think maybe, maybe, maybe [I'll be OK]. But then he knows there's no hope. (10.1.1/8)

Although Vern did not define the nature of this absented hope, the context suggests that he was drawing upon the version of hope discussed above: That there is no hope means that there are no treatments available that might successfully intervene in the patient's disease and that death is inevitable. Regardless, that there is 'no hope' is imbued with negative connotations, and the doctor held responsible for acting to convey this to the patient.

As a summary, this version of HN is construed as an objectively present probability that something, usually medical treatment provided by the clinician, will successfully intervene in a patient's disease. In terms of the relative agency accorded the patient and the clinician, in this context, HN minimises that of the former, increasing that of the latter (acknowledging that the clinician too can be deemed to be somewhat passive, in that they are construed as just conveying that there is or is not hope, rather than being held responsible for discovering the critical treatments). The patient is located as merely subject to the situation, and actions or outcomes deemed appropriate according to various biological parameters, as determined by the expert clinician. Additionally, conferring upon medical science the ability and prerogative to determine the existence and legitimacy of hope in the guise of discovering new evermore potent treatments, this constitutes the most common representation of hope within the medical literature.[470] It is a powerful rhetorical tool in establishing the status and legitimacy of medical scientific endeavour, one that sees hope as fundamentally intertwined with the aspirational values of science.[493]

10.1.2 Subjective possession of the patient

As well as this construction of HN as objectively present in the situation, participants also presented a version in which the patient did feature rather more prominently—wherein hope was deemed to be a possession of the patient. In Chapter 6 I argued that this hope was construed as some thing subjectively held by the patient (something patients have), as varying in amount, and as having implications for the patient's well-being. It was nonetheless depicted as susceptible to medically determined factors, in that it was deemed dependent upon patients' interpretation of doctors' actions, including the provision of treatment (see 6.2.1.2). A similar construal may be seen in Lois' speech, wherein the cessation of treatment was established as causing a sudden and extreme reduction in hope, with consequent negative implications on her well-being.

> Lois. I'm really sad about this, them saying there's no more treatment now, because I think that that hope at the end, that really plummeted and I know it shouldn't but, maybe I'll feel better after a while, but I feel really sad … . (10.1.2/1)

In this context (discussing end-of-life decisions), HN appeared overwhelmingly medically oriented, even when construed as the subjective possession as a patient. Much of the talk about the patient's hope appeared to rest upon the assumption that this (subjective) hope is influenced by the medical (objective) hope (with implications regarding the probability of imminent death), and that a reduction of hope has negative implications for the patient (see Figures 8 & 9, and associated discussion at 6.3.1). Thus, for example, as did Vern (see 10.1.1/8), many patients considered that (1) the introduction of the DNR discussion would negatively affect the patient's hope, and (2) this constituted justification for avoiding the DNR discussion itself. The following excerpts were part of a discussion about appropriate timing for discussing DNR orders.

> Oliver. I don't believe my life is finished because I've got so much [going] for me. … And therefore I want to hang on to this, and I don't want anybody to take the last vestige of hope that I've got away from me. That's the last thing I want, … and at least then if I lose that fight then I've lost it, I haven't given up on it. (10.1.2/2)

> Tom. I might live for another 12 years, and to live that way, knowing that I've just talked about a lot of end-of-the-road things, you know, it wouldn't go over well for me, because that way I believe that I've given up a bit of hope, and fight and that, you know. (10.1.2/3)

Both Oliver and Tom depicted hope positively as a vital resource in their "fight" (see also 6.2.1.2). This draws upon a dominant theme in Western culture: Patients with cancer are typically depicted as engaged in a fight against their disease, and ultimately against death, with hope regularly implicated in this.[174, 347, 506, 584] Their reference to a small quantity of hope ("a vestige," "a bit") works to establish both that hope may vary in amount (thus reinforcing its status as a 'thing'), and to endow hope with considerable potency: Thus even small amounts of hope (whether construed as objective, as in Ruth's speech at 10.1.1/7, or subjective, á la Oliver and Tom) are deemed to play a significant role in the patient's fight against their disease.

There is some difference between how Oliver and Tom depicted hope, pertaining to the patient's complicity in the process by which their hope might disappear. Oliver implied that discussion of the DNR decision would have the consequence that his "last vestige of hope" was taken away (i.e., by others, he being involuntarily deprived of his hope). This facilitated the positive construal of his avoidance of the discussion as actively protecting

his hope and as enabling him to continue the fight. For Tom, discussing the DNR decision meant his actively giving up "a bit of hope" (i.e., voluntarily relinquishing some hope). This assertion enabled him to justify not talking about "end-of-the-road things," and to positively construe avoidance of the DNR discussion as continuing the fight. For both Oliver and Tom, however, any discussion of the DNR decision was taken to result in a reduction of hope, and was negatively construed as associated with giving up the fight. Because patients can be held responsible for giving up the fight, and for reduced levels of hope,[493, 565] they can thus justify refusal to participate in such discussions. Indeed, both Tom and Oliver construed the discussion as having personally undesirable consequences ("the last thing I want," "it wouldn't go over well for me"). Practically, insisting that patients participate in discussions about "end-of-the-road things" (e.g., the DNR decision) may be problematic: It may be interpreted as requiring them to acknowledge the inevitability of their own demise, thereby giving up hope—contradicting the cultural injunction that they actively resist death, and that hope is vital to maintain this resistance.

Wendy also established a causal relationship between the introduction of the DNR decision and a negative effect on the patient's hope. She held that the DNR discussion might "take away some of that hope" and depicted hope as enabling patients to "get through" treatment, a phrase that connotes the endurance of a difficult experience. This (again) works to establish hope as a vital resource for patients. Indeed, according to Wendy, and further strengthening the value assigned to hope, on diagnosis, hope is the only thing that patients have.

> Wendy. You wouldn't ask them [about the DNR decision] straight after diagnosis. … [At that time] you need some hope to help you get through just the treatment, and if you've discussed [the DNR decision] … it might take away some of that hope. And I don't think they need that. They've nothing else, for a while. (10.1.2/4)

This works to attribute fundamental importance to the patient's hope, but also to establish that the medical profession should consider this in their interactions with patients—which in turn construes it as vulnerable to medical practice. Wendy twice refers to "some" hope, qualifying the amount of hope under consideration. This again reflects and reinforces the ideas that hope can vary in quantity (thereby attesting to its status as a thing), and that relatively small amounts of hope are significant (in that she did not speak, for example, of 'lots of,' or 'all' hope). This version of HN is valuable, yet vulnerable.

It follows that where HN is construed as vital in the fight against specifically cancer, so might there be an obligation for people to maintain hope. Hope may be a moral imperative

to be maintained in the face of death,[470, 585] with individuals held accountable for possessing hope.[493] As illustrated by Dennis below, to 'have hope' in this instance parallels 'being positive,' an idiom commonly drawn upon in talk about cancer, and one that also typically appears in the imperative.[444]

> Wendy's husband Dennis. The patient must have hope … . If they don't have hope, and they're not positive, they're not going to get very far at all. But they don't need other people trying to load that on to them, I think they get that more often than anything else, yeah. (10.1.2/5)

Although Dennis himself, using the imperative "must have," construes hope as mandatory, this is later balanced against the negative depiction of others who might suggest a similar sentiment to the patient. The need to "have hope" is here potentially negatively construed as a burden that "other people [try] to load" onto the patient—as something unwelcome, or an imposition. It is somewhat ironic that such a negative construal of hope is made possible by the value placed upon it, intersecting a number of dominant cultural discourses regarding body and mind, life and death: If hope was not deemed primary in the maintenance of life (with increased saliency for cancer patients), then the perceived urgency in maintaining hope would not exist; if hope was not held to be a possession of the patient with the implied ownership and responsibility for it, then patients could not be held responsible for having or maintaining it; and without this, others could not exhort them to maintain hope. As it is, the moral imperative to have hope (and particularly in the medical arena) is inherent in the cultural construction of hope.

At the same time, the necessity of hope referenced in the depiction of it as a vital resource may be juxtaposed against other versions of HN to construe the DNR discussion as fundamentally incompatible with the aims of treatment: Patients need hope (subjectively held) to get through treatment; because of its association with imminent death—in turn implying that there is no (objective) hope, the DNR discussion takes patients' hope away; therefore the DNR discussion is not appropriate for patients undergoing treatment (see also 5.1.1). This relationship may play somewhat differently, but to similar effect: The DNR discussion may be taken to signify that treatment is no longer appropriate, and that patients need not have hope because there is none. Thus in this construal, hope and the DNR discussion are locked in a mutually exclusive relationship which mandates against the routine introduction of the latter. Patients are unlikely to separate the DNR discussion from any implications regarding the success or availability of treatment. Indeed, in Wendy's further speech about the DNR discussion, hope appeared to constitute not just a resource, but also some form of motivator for continuing treatment: If you have hope, then you

undertake treatment. Although oncologists might deem hope to be something they offer through treatment,[176] hope may also be a reason for treatment.

> Wendy. [I]f you haven't got any hope, there's not much point in even going there for the treatment. … That's because you need that hope to keep you coming back. If you had no hope then you wouldn't come for your treatment, you'd virtually give up. (10.1.2/6)

As the justification for (and thus reason for undertaking) most treatment following diagnosis of cancer rests in some probability that it will successfully intervene in the disease, the patient's hope (or this version of it) is again established as dependent upon their reception of medical information. Without hope that treatment will be successful, patients can have no reason to undertake it—they would "give up." With that hope, treatment is acceptable. As previously noted (see 6.3.1), this aspect of hope, functioning to encourage patient participation in or compliance with a medical regimen, constitutes a major reason for the medical interest in hope.[425, 493, 508]

There is some indication too, that the relationship between hope and treatment can be construed as reciprocal, thus: In addition to functioning as a reason to undertake treatment (if you have hope, then you would commence treatment), hope may be construed a reward for treatment undertaken (if you commence treatment, then you would have hope). This reciprocity works to enhance the value of both treatment and hope.

> Una. Chemo's … a disgusting treatment, it makes you ill, vomit, lethargic, all sorts of stuff. It's poison going into your body. And just why, just to have that extra hope. (10.1.2/7)

Here, the merits of hope, though unstated, are contrasted with, and thus construed as having equivalent, if opposing value to, the "disgusting" effects of treatment. Notwithstanding the litany of negative physical consequences for the patient, to have chemotherapy is to have extra hope. This works to further reinforce the (dominant) construal of HN as medically oriented.

It is worth emphasising, however, that neither treatments, nor discussion of treatment options, nor the DNR decision, just happen: They are typically instigated by doctors, and as noted above, it is they who may be held responsible for any effects upon the patient's hope. Thus doctors may be deemed able to "give" or "offer" hope to the patient (as indeed assumed by many oncologists),[176] but also held accountable for this—see, for example, Ruth's speech above criticising her oncologist for failing to "offer" hope. It cannot be concluded, however, that to be "given" hope is ipso facto good.

> Ruth. [My surgeon] was very human, I felt he was on my side, and he did a lot for me, both in terms of explaining and reassuring, but without ever giving me false hope. He was always saying that "no, this is a tumour that we're taking out for symptomatic reasons only, it has already spread, we are taking it out because it's so damn big. And for no other reason." (10.1.2/8)

Ruth here speaks of "false hope." Within the medical literature (as discussed at 6.2.1.3), this most often appears to reflect a discrepancy between the medical opinion regarding a negative prognosis for the patient, and the patient's own hope (or desire) to get better (the latter being the "false hope"). By contrast, however, although also construing it negatively, Ruth identifies false hope as consequential upon a communication, from doctor to patient, that might be taken to imply a consequence of, or reason for, a treatment decision other than that expected by the doctor. Therefore, given the described tendency of patients with advanced cancer to believe that offered treatment options are intended to cure them,[248] if one of the reasons for a treatment might be to successfully intervene in the course of the disease (as surgery may), then if this is not case, it behoves the surgeon to ensure that the patient knows that. To do otherwise is to risk giving "giving … false hope," here presented as undesirable. Klenow[480] has similarly defined false hope within the patient, identifying it as generated through deception on the part of the medical profession. Parenthetically, it seems likely that, by definition—and in implicit contrast to a 'true' hope—'false hope' will consistently be negatively perceived, but that what constitutes false hope may vary.

At this point it seems apposite to examine more precisely the nature of the patient's hope. As was the case with the 'objective' hope, the object of this 'subjective' hope remains unstated, again suggesting the existence of a shared cultural assumption about it. I suggest that it refers to the patient's belief that something, or some action, or somebody will be successful in preventing or significantly delaying their death. And for the most part, what intervenes to provide this represents some form of medical authority. Overstating it somewhat, in this version of HN, the patient's hope represents their belief in a cure, not surprisingly given the overwhelming focus on cure within medical discourse.[446, 462, 476, 497] The construal of this subjectively-held hope is so similar to the earlier definition given regarding the objective hope (see 6.2.1.1, p. 112) that I suggest that these two versions of HN are two sides of the same coin—a supposition that would account for the interdependence of these two version earlier noted (see Figures 8 & 9, and associated discussion at 6.3.1). Both centre upon cure, and in doing so, both identify the medical profession as primarily responsible for, and capable of providing this; thus both locate agency outside of the patient themselves—a point argued theoretically by Beste.[446] This does not negate the observation made at 6.2.1.2 that patients' hope, though influenced by

the medical profession, is not entirely amenable to professional control. For example, patients may draw conclusions from particular medical decisions (such as to provide treatment, or to introduce a discussion on DNR orders) that do not necessarily concur with those held by their doctors—particularly where these may have potential implications regarding cure or long-term reasonable health.

Thus, for example, Lois' plummeting hope followed on the cessation of efficacious treatment (see 10.1.2/1); Oliver and Tom's rejection of the DNR discussion followed upon its association with imminent death (and thus the inability of the medical profession to prevent it) (see 10.1.2/2-3); Wendy (10.1.2/4, 6), Una (10.1.2/7), and Ruth (10.1.2/8) all spoke of hope with reference to treatment, normatively undertaken to some positive effect upon the disease; and Ruth (10.1.2/8) alluded to the possibility that patients might derive a 'false hope' from the actions of their surgeon—that is, might incorrectly assume that surgery would 'cure' their disease.

Whether hope is deemed objectively present, or subjectively held, the agency of the patient is minimal. It is also implicit that patients deemed without hope by the medical profession are going to die. Usually. Unless something else intervenes. Although it is normally not alluded to, this aspect of hope rests upon the realisation of a future outcome that, though predicted, may not come to pass. Oliver spoke of such a situation.

> Oliver. [There are cases where patients] have been given up as hopeless by the medical profession and yet miraculously, they have healed, self-healed. … One had lung cancer, and was given up as hopeless, with negative time to live, he's still alive ten years after it. … And (another cancer patient) self-cured, by meditation. (10.1.2/9)

Oliver did not contest that these patients were indeed without hope—hopeless—suggesting that the prerogative of the medical profession to determine hope was unchallenged. It was not that the medical assessment was wrong, but that some other 'higher power' in the form of 'miraculous' self-healing, intervened. Although Oliver here identified the patient's self-healing as attendant upon a process of meditation, thus positioning the patient as instrumental in the outcome, his reference to the miraculous suggests the involvement of other forces. Indeed, in his later speech regarding meditation and miracles, he identified God and Jesus as fundamental to his own self-healing.

> Oliver. You meditate more and more … and then miraculous things start to happen. … If I can get over this, then I can self-cure. … When I meditate I try to make them [God and Jesus] come into me. "Please come into my body and cleanse me," it's really the same. (10.1.2/10)

Typically taken as manifesting a supernatural authority, a miraculous event is one that is beyond rational prediction.[413] Thus, this understanding that miracle cures may exist simultaneously challenges medical authority (the predicted outcome did not occur) and reinstates it (the appeal went to a higher court, as it were). What remain unchanged are (1) the object of hope—briefly, that the patient might be cured; and (2), the relative lack of agency attributed to the patient. Either doctors or God are identified as primary in determining outcome—both typically construed as possessing significant knowledge and power in excess of that possessed by the patient.

One further patient referred to a possibility that persons or processes other than the medical might bear upon a patient's hope. Opal spoke of hope in the context of considering the use of various so-called alternative therapies.

> Opal. I think I'm too realistic for these naturopaths, and all the rest [alternative therapists]. … You hear of these others who get robbed left right and centre too, because they're that gullible that they'll do anything, but, no, it's just whatever makes that particular person happy I suppose, if it gives them a certain amount of pleasure or hope or whatever then go for it, but it's not my thing. (10.1.2/11)

There are several features of hope that may be discerned within Opal's speech. For example, HN is presumed to be tangible and quantifiable, something that can be 'given,' and given in 'amounts.' Furthermore, this hope is intrinsically valuable: Although she characterised those who consult with naturopaths as unrealistic and gullible, Opal ultimately positively endorsed the actions of such patients ("go for it"). Specifically, she took as given that the provision (or promise) of hope accounts for the otherwise negatively construed actions of these patients. However, hope not only accounts for (in the renders-understandable sense), but also validates these actions as acceptable. Her categorisation of hope alongside pleasure further works to normalise actions taken to attain hope, and indeed, Opal's use of hope here is similar to that of Una above: Hope functions as a reward for actions undertaken. At the same time, Opal established that patients may get hope from sources outside of the dominant medical enterprise, whilst implying that this hope is of questionable legitimacy: She's "too realistic," she would not "go for it." As the available alternative to alternative therapies is allopathic medicine—an activity culturally affirmed and prized as the epitome of rational endeavour—this implicitly reinstates the latter as more legitimately conferring hope.

To summarise, in the context of discussions about the end of life, participants most commonly depicted hope-as-a-noun as a thing, with all associated properties, and one that had immense significance for the patient. Although the reification of hope glosses over the

necessity of an object for hope, here, that object invariably referenced the possibility that someone or something might intervene in the disease process to avert or delay death. Critically, patients do not determine the hope, but are subject to it, whether it comes from God, alternative therapies, or most commonly, medical science. Thus, the presence or absence of hope is associated with life or death for patients, but even when construed as a subjectively held possession of the patient, hope largely depends upon circumstances beyond their control. Whether objective and located within the situation ('there is no hope') or subjective and within the patient ('you have to have hope'), HN works to establish hope as fundamentally important, but to confer upon the patient a relative lack of agency, and relative powerlessness to affect their circumstances.

10.2 Hope-as-a-verb

As noted at 6.2.2, the primary consequence of using hope-as-a-verb (HV) is the introduction of the subject—the someone who hopes. The presence of the subject inherent in HV has many consequences: Hope becomes personalised, determined by the patient, and independent of medical prognostication or control. As a verb, hope implies a 'doing,' an active occupation of the patient, which works to establish and confirm their agency, rather than their passivity. Rather than construing individuals (patients) as being *subject to* the vagaries of an implacable reality of impending death (implied in the 'no hope' version of HN), HV functions to enable participants to represent themselves as *the subject*, and I contend, to affirm their presence and participation in life's activities.

However, while the presence of the subject is important, the object of HV—the thing for which they hope—may also have ramifications regarding the construct of hope itself, and equally, regarding the subject—the one who hopes (hereafter referred to as 'the hoper'). I now examine both these (and other) aspects of participants' spontaneous speech using HV.

One of the most common ways that participants used HV was in the context of a future identified as desirable (in the sense of being desired). This was often, but not always, established through contrast. Some patients spoke of a negative potential future outcome and hoped to avoid it (see 10.2/3, 5, 10) or of a present unwanted circumstance that they hoped would change for the better (see 10.2/1-2, 4). Hope-as-a-verb appears to allow for acknowledgement that both the positive and the negative are possible in the future, but to orient towards the former. This aspect of hope appears conceptually similar to some features noted by other writers: Morse and Doberneck,[490] for example, included not only "the envisioning of alternatives and the setting of goals," but also "a bracing for negative

outcomes" as two of their seven components of hope, and Parse's[586] theory of hope posits hope as a continuum of "hope-no hope." In these conceptualisations, hope connotes positive and negative possibilities. As I demonstrate through analysis of participants' speech, HV works to identify what is positive, but to acknowledge the potential for the negative. This may perhaps allay the fears of those who consider that hoping for some future outcome that may be deemed unlikely represents a denial of the possibility that it might not occur:[462, 484, 485] Hope references both possibilities.

For some hopers, the object of HV was related to a desired change in their own medical circumstances. However, although involving the medical, the attainment of this object would enable them to engage in life's activities outside the medical domain.

> Una. I get my pains at unfortunately odd hours of the morning, but hopefully we'll find a blend of drugs that I can go home without this little box [morphine syringe driver] that's attached to me. (10.2/1)

> Zack. If I hold off [more treatment] just for a little while longer and concentrate on everything else, hopefully you know, as long as I can stand up and I can walk around on my own two feet, or, 'cos I'm going to organise a wheelchair and a walker … . (10.2/2)

These and other participants used hope in the context of an imagined future with themselves active in it—here, as walking, organising things, or going home. Indeed, a common object of hope for these participants was going or being at home which, by definition, necessitates their departure from the medical environment.

> Wendy. Well, I hope [that I won't return to hospital]. I haven't made any more appointments. I'm just going to do them as need be … . (10.2/3)

> Lois. I hope I'm going home, they haven't told me that … . (10.2/4)

Although referencing medical circumstance, again, the focus was on what was possible, what was preferred, in other areas of their lives. This use of hope thus appears to facilitate the envisaging of a possible future with positive aspects to it, in which patients are construed both as active, and as not completely subjugated to medical circumstance. Nunn[587] has spoken of hope in similar terms, asserting that hope commonly references an envisaging of self, in a future that is good in some (but not necessarily all) respects. Similarly, Stephenson[473] described hope as including anticipation, a positive future orientation, and what is meaningful to the hoper. This aspect of HV appears as a marked contrast to the HN version that works to construe patients as subject to medically

determined circumstances, as relatively passive, and with an overwhelmingly negative future.

Indeed, even when participants referred to their death, hope functioned to identify the positive option and thus what outcomes patients valued for the future—below, a relatively easy (short, natural, comfortable) death. If death is inevitable (as it is for all, but rather more imminently for these individuals), HV may allow patients to express and arguably to anticipate ways in which it might be acceptable.

> Kate. [My death] is not going to be as long and drawn out as hers [another cancer patient on the ward], I hope (laughs). (10.2/5)
>
> Vera. Let nature take its course. … Yeah, and hopefully that's the way it will be. (10.2/6)
>
> Wendy. [Doctors] have already said that there's not much more that they can do. I just hope that they understand what I want, and yeah, just keep me comfortable, and just understand my needs … . (10.2/7)

Implicit in the use of hope here (and indeed within all instances of use of HV) is a recognition that attaining the desired outcome is not a foregone conclusion, and that the capacity of the hoper to achieve it is limited. For example, that doctors may not understand Wendy's needs and wants is established as a possible future outcome, but one which is negatively valued. Hope thus refers to a future which is beyond the speaker's control and unknown. It is one, nonetheless, in which certain outcomes are deemed more or less likely (by virtue of being spoken about or implied by contrast), and more or less preferable (denoted by their positive or negative relationship to hope and thus to the hoper).

It is worth here pointing out that HV is employed in spoken interaction with others, and that what is hoped for may involve others (often in the speech of these participants, the medical profession). Where HV signals what (outcome) is valued and desired by the patient, to the extent that others may be deemed responsible for achieving this, it may function to establish moral obligation and thus reinforce interpersonal ties between individuals. This use of hope may be seen in the following speech excerpt, part of Xavier's account of his interaction with his doctor following his terminal diagnosis.

> Xavier. [I said to the doctor] I hope that you're not going to try and prolong things, when they shouldn't be prolonged … . (10.2/8)

Here, in using HV, Xavier could identify what he wants, and acknowledge that this desired outcome is not completely under his control. In the context where patient autonomy is

theoretically primary, but doctors are the ones who act to realise this, I suggest that hope functions to oblige doctors, as individuals independent of their professional role, to consider Xavier's wishes. Xavier's use of HV was not merely to impart a strict injunction that the doctor (to whom the speech is directed) follow some desired course of action. In conveying "I hope you don't do this" rather than "Don't do this," Xavier introduced two agents ('I' the speaker, and 'you' the listener), locating them in an interpersonal relationship wherein the actions of 'you' will affect 'I,' and where some action is preferred by 'I.' He specifically used a negative case construction: What was not preferred should not be attempted. In so doing, Xavier in effect utilised hope to warn doctors that the described actions will disregard what he wants, thus negatively construing such actions. This works to establish that the issue has personal implications both for Xavier and the doctors: It is not just that things "shouldn't be prolonged," but that Xavier does not want them to be prolonged. Given this, for his doctor to prolong things would be wrong, not only because they would thereby violate some prohibition (evident in the use of the imperative "shouldn't be prolonged"—with "prolonged" signifying exceeding an appropriate limit), but, more compellingly, because they would be knowingly countermanding Xavier's desire. Thus, although the ultimate outcome was undeniably important, it was placed in the context of an interpersonal relationship between two persons, thus establishing it, and hope, as having moral connotations.

Nonetheless, as use of HV enables acknowledgement of a relative lack of power on the part of the speaker to effect the desired outcome, it therefore functioned in Xavier's speech to acknowledge and enact the structural relationship between doctor and patient, simultaneously placing moral obligation upon the doctor to positively respond to the patient. An individual's use of HV in interpersonal exchanges may consequently act to increase the probability that their desired outcome is achieved, and thus to establish and enact their agency. This aspect of HV can be discerned in Zack's speech answering my direct question about what he currently wanted from doctors involved in his case.

> Zack. I know that [doctors] are under stress, but just be a bit more gentle, and that's, I think that's all I want to see around the place. You know. So yeah. That's it. And I hope you can relay that. (10.2/9)

Zack's use of "I hope you" functions very similarly to that of Xavier above. It identifies the preferred outcome, acknowledging Zack's limitations in achieving this. Accordingly, this works to acknowledge and enact the interview structure, reflecting Zack's—the interviewee—relative lack of power within it.[323] At the same time, however, it counteracts this through establishing a moral obligation on the part of the listener (me) to respond

positively to effect the preferred outcome. Hope here works as a request from I to you, and, as Potter[294] noted, the appropriate response to a request is a positive acceptance (p. 61). In operating as a request, HV construes a negative response on the part of the listener as negatively preferred, thereby increasing the probability of attainment of the preferred outcome. Parenthetically, I did subsequently talk with his caregivers relaying his concerns. Given that there is nothing inherent in the interview protocol that might oblige me as an interviewer to mediate between Zack and his caregivers, this suggests that I at least received this hope as akin to a request and as instilling some moral obligation upon me to act positively to effect the desired outcome.

The use of HV can thus establish and reinforce interpersonal ties and moral obligations between individuals, arguably elevating these above those derived from structural or contractual obligations inherent in the context of the encounter. Ultimately, the "I hope you" version of HV positions the speaker as having agency, as valued, and as connected to and affecting others. This aspect of HV operative within speech may be akin to the "relational process" posited to be an attribute of hope by Farran, Herth, and Popovich,[456] to the "interconnectedness" identified as a factor of hope by Herth,[484, 485] and the "affiliative" dimension of hope proposed by Dufault and Martocchio.[463] Beste has argued that a "relational" hope could provide a useful counterpoint to constructions of hope that see it as an individual attribute with emphasis on cure—alternatives that seem to parallel my presentations of HV and HN.

The examples I have presented above (10.2/1-9) have all had some bearing upon the patient's medical circumstances. However, hope sometimes referenced activities outside the medical domain.

> Tom. [My wife and I] are just at the stage of getting the cemetery stuff sort of organised, not organised, but finding out about dollars and all that sort of stuff. I mean, I hope we don't use it, we've decided … to be buried [in the same grave]. (10.2/10)

There are couple of features of hope-as-a-verb that may be surmised from the above excerpt. First, although hope functions to indicate what outcome is preferred by the hoper, that outcome need not be objectively attainable—in contradiction to the 'reality' grounding of hope maintained by some.[483, 490, 499] Tom's hope that he does not utilise funeral arrangements is ultimately unattainable as he and everyone will die, and indeed he goes on to describe what he wants when he does die. Sandwiched between two descriptions of preparation for death, I suggest that hope here functioned to enable Tom to counteract the

potential conclusion that he is resigned to death (normally negatively perceived in cancer patients), simultaneously allowing him to present himself as responsibly taking action needed because he will die. Precisely because hope carries with it the possibility of alternative futures, to use hope is to acknowledge this. Hope thus serves the dual purpose of enabling the positive presentation of self as aware of alternative possibilities, whilst aligning self with the favoured alternative.

However, neither the possibility of alternative futures nor the inability to completely determine the outcome precludes active attempts on the part of the speaker to attain what is hoped for. Indeed, as noted above, where the listener may infer some form of personal obligation for them, the very act of hoping (to others) might represent an active attempt on the part of the hoper (the patient) to increase the probability of attaining the goal. Thus HV can position the hoper as actively engaged in their life—particularly pertinent for patients in the terminal phase of an illness. This agentic aspect of hope has been discussed and delineated by many others. It is fundamental to Snyder's[474, 499, 588] cognitive conceptualisation of it, which stressed agency and goal-directed behaviour. Owen[471] also identified "goal setting" as the first of six subthemes of hope. Jakobsson et al.[486] similarly included agency, in the form of an ability and capacity to influence outcome in life, as one of their three factors of hope. Finally, Nowotny[489] likewise named one of her six subscales of hope as "active involvement," again identifying agency as primary in hope. What this discursive analysis adds is a clarification of how this is performed in situ, showing how hope functions in speech to establish and enact agency.

As an example of enacted agency, Zack used HV in the context of relating his part in his ongoing and developing relationships with significant others.

> Zack. Julie is just another friend. And I've got, well, hopefully, I've asked this friend of mine, Rebecca, … if she would marry me … and she's agreed to. (10.2/11)

Many of the aforementioned aspects of hope may be discerned in Zack's speech: 'Hopefully' functions to signal what is valued, and—given that the future, including Zack's presence within it and Rebecca's future behaviour, remains unrealised—to acknowledge the uncertainty of attainment of this. Notwithstanding the uncertainty, what was depicted, what was valued, was a future that not only featured Zack, but in which he is linked (indeed, married) to another person. To marry is to assert the strength of an interpersonal bond with another, and normatively, to undertake a future together with that person. Thus Zack established himself as connected to a future time, and some other

person. In doing so, he affirmed his own worth, and the worth of any other implicated in that hope. Used thus, the 'reality' of attaining what is hoped for (the object of hope) is irrelevant, as hope functions to value both the desired object, and the one desiring it.

It seems likely, therefore, that in referring to future outcomes, hope enables the patient to envisage themself as present in the future, and as valued in some way. At times, this presence was physical (e.g., see Zack and Tom above), but it was not always so construed. For example, for some patients, the object of hope was some outcome in a future where they were physically absent—after their death.

> Sally. I hope that [how I've dealt with dying] might perhaps reflect back onto my children when I go. When I die, that they will get a lot of comfort from the things that have happened in our life, even to the last. (10.2/12)

> Sean. I want to try and [make sure] … that [my family] all get on well together, and share everything together, like they do now. So, I've got three families that are virtually next-door to one another, and they help each other. … And I love to see it, and I hope it continues it, you know. (10.2/13)

This HV referenced an ongoing effect of the hopers' actions before death—an enduring legacy, as it were. Others have asserted the merits of such a perception, Duggleby and Wright[589] identifying the leaving of a legacy as one of their themes for fostering hope, and Beste[446] including it in a range of hope constructs that both emphasise what is meaningful to the patient, and provide an alternative focus to cure. Here, the future depicted represents Sally and Sean as having value even after their death, affirming that they have had a positive effect upon others. This establishes their agency, their active participation in life. But there are several further consequences of this construal of hope.

First, as what was hoped for entailed a positive future for those others (e.g., with the positive experiences of having comfort, sharing with, and helping others), HV serves to affirm the value of those others. At the same time, in establishing the interest that the speaker has in the future experience of others, HV values and reinforces the interpersonal ties between both parties. Finally, to the extent that the others might be aware of the hoped-for future for themselves, there is some moral obligation upon them to work to achieve it, thereby positioning the patient as having an active presence in life, even if not their own. Again HV functions to identify what is valued for the speaker, and to connect them both with a future and with others.

However, hope did not have to refer to the hoper at all. As occurred in Study 1 (see 6.2.2.1/6-7), although participants often spoke of themselves in relation to hope, sometimes the object of HV (what was hoped for) concerned others.

> Opal. [My daughter] had the first signs of [cancer] too like me, they've removed all hers, she's had no treatment so hopefully there's nothing anywhere else. (10.2/14)
>
> Otis. [My family] felt they knew [my brother] and they didn't … . I was right, but that's the way it is. And it's gone and life went on with that, and I got over [the disagreement], and I hope they did. (10.2/15)
>
> Tom. While there's not a cure for [cancer] yet, hopefully down the track, there may be. (10.2/16)

In these speech excerpts, HV functions to establish (1) what is deemed good and positive by the speaker; (2) their relationship to that good (that they want it); (3) their interest in those others implicated in the hope (thus connecting themselves to those others). On that point, (4) to the extent that what they hope for entails a positive state for the others, this also works to value those others. And finally, (5) it also enables acknowledgement that the attainment of that good is beyond the control of the speaker.

Opal and Otis' speech (10.2/14-15) also point to another feature of hope: Although hope typically references the future (and most conceptualisations of hope stipulate the future as primary, e.g., [471, 473, 484, 487, 489]), it need not. For these participants, the object of HV is that the occurrence of something in the past produced a desired state in the present—Opal wants her daughter cancer-free now; Otis wants his family equilibrium restored now. There is nonetheless an implied passage of time inherent in hope: from the past to the present (see 10.2/14-15), or from the present to the future (see 10.2/16, and most other excerpts). This may be perhaps what was meant by Dufault and Martocchio,[463] who referred to a temporal dimension of hope. Nonetheless, whether hope is present- or future-oriented, the uncertainty of outcome is invariant.

There are yet further consequences that may follow on use of HV. Precisely because hope-as-a-verb construes the outcome (typically, a future outcome) as uncertain, it can enable the speaker to disavow responsibility for whether or not a preferred outcome is realised. Thus the speaker may imply support for an outcome without claiming responsibility for it. For example, Zack's use of "hopefully" (see 10.2/11) indicates the preferred outcome (marrying Rebecca), but establishes that not everything is under his control. Similarly, Otis' use of HV (see 10.2/15) indicates the preferred state (family harmony), but

establishes that he cannot dictate this. Thus, if the stipulated outcome is not realised, the speaker cannot be held responsible.

It is this aspect of hope that I exploited in the next excerpt. This followed closely (two sentences) upon Zack's earlier examined statement "I hope you can relay that" (see 10.2/9).

> Interviewer. Thank you, it's been really lovely talking to you and getting your thoughts, and I hope I can pass these things on. (10.2/17)

The use of HV here enabled me rather adroitly to endorse the value of Zack's request that I pass on his views, whilst establishing that fulfilling it was not a done deal, that it might depend upon factors outside my control. Thus, I established that any failure to attain the preferred outcome was not attributable to me, proactively absolving me of any blame.

In a like manner, the use of HV in the following extracts also enabled the speakers to confirm their previously stated desire for (and thus allegiance to) a future outcome, but in establishing the limits of their control, to temper the extent to which they might be held responsible for achieving this.

> Xavier. I think I will know [when I'm close to death]. I hope I'll know, but there are a lot of people who don't want to know. (10.2/18)

> Sean. I'm going to put myself through a test, and I'm going to try and do better than what I can do now. And if I succeed in that, then I think I'll get over it. I hope. (10.2/19)

This use of "I hope" HV (following on the use of "I think") functions both as an acknowledgement of a level of uncertainty of outcome, and to position the speaker as aware of this. This in turn serves to deflect the potential interpretations of their speech that they are being unrealistic or unreasonable in predicting a future outcome. Hope here works to moderate modality, which Fairclough[590] identified as the degree of commitment of the speaker to the truth or necessity of the utterance (p. 242). In effect, Xavier and Sean 'tone down' the strength of their previous assertions: that they 'think' something will occur becomes that they 'hope' it will occur, signifying a lessened commitment to the actuality (whether or not it will occur) of outcome.

However, HV also carries with it something about the relationship of the speaker to the given outcome. "I hope something will happen" implies an active desiring on the part of the speaker for, and thus commitment (in a difference sense) to the outcome that is not implicit in the "I think" version. Thus HV enables these participants simultaneously to

assert their commitment to the preferred outcome, and acknowledge their own limitations in achieving this. Put another way, HV serves to increase the speaker's commitment to the outcome itself (via an implicit valuing of the object of HV), but to decrease their commitment to the fact that the outcome will occur (via an implicit acknowledgment of uncertainty in HV). Whether through the acknowledgement that the future is uncertain, or through the presentation of the self as aware of this, the use of HV works to reduce the speaker's responsibility for any non-realisation of the preferred outcome.

The final use of HV I wish to consider here incorporates many of the features mentioned above. At the end of the interview it was my practice to thank interviewees for their participation at which point ten (over one-third) responded with "hope," prompting responses from myself that were remarkably similar across interviews.

> Kate. I hope I've helped a little bit.
> Interviewer. I'm sure you have, I'm sure you have. (10.2/20)
>
> Maud. Well, I hope I am some help.
> Interviewer. I'm sure you will be. (10.2/21)
>
> Oliver. I hope it's been a help.
> Interviewer. It certainly has. (10.2/22)
>
> Vera. I hope it's some help to you.
> Interviewer. I'm sure it will be. (10.2/23)

In these couplets, participants positioned themselves as the hoper, and thus as desiring some particular outcome. In each case this desired outcome was that their participation in the interview would have (or had) benefit—in the form of help. As this was a stated aim of the interview at commencement (that their participation would enable us to improve patient care—or, would help), this use of HV enabled them to assert this outcome as a good, and consequently to align themselves with the aim of the research, and by extension, with the researchers. I suggest that this use of HV signals goodwill on the part of the speaker towards the listener, and thus can be employed to denote solidarity between parties. It thereby works to strengthen the interpersonal connection between them. Indeed, the regularity of my response, taking the form of a reassurance that what they desired would occur or had occurred, further attests to utility of hope in facilitating goodwill, solidarity, and interpersonal connection.

In this guise, it appears plausible that HV constitutes part of an adjacency pair (see Potter,[294] pp. 58-61): To hope to another requires that they not only respond, but respond appropriately. This is evident in the sole negative case instance appearing in this context.

Otis. I hope I haven't been too boring.
Interviewer. Not at all. (10.2/24)

This is an instance of potential self-deprecation on the part of the speaker, with a particular response called for on the part of the other:[294] For Otis to allude to himself as boring requires the listener (me) to rebut such a conclusion, as indeed I did. Here, as in the above couplets, hope enabled the hoper to affirm their own value and agency in interaction. Finally, appearing so regularly at the end of the interview, hope may also function as part of a social ritual to satisfactorily end the conversation, signalling a mutual valuing of the encounter and of parties within it, as well as both indicating and enacting a positive interpersonal transaction.

10.3 Conclusion

At this point, I wish to draw attention to some of the clinical implications of my analyses presented both in this chapter and in Chapter 6. I then present a preliminary 'taxonomy' of hope, highlighting the variety of ways that hope was construed by these participants, and comparing this with previous research findings. Following this, I note some specific limitations that pertain to this analysis of hope.

The multiple employment of *hope* demonstrated within these two studies suggests that hope cannot be simply defined as an entity to be operationalised and measured, but can accommodate a plethora of meanings. The versatility of hope influences communication between patients and physicians in several ways. Indeed, the following points may pertain to patients' interactions with all medical staff.

First, doctors (and other healthcare workers) may not be able to ensure an absolute and enduring unanimity of interpretation of the word *hope*, as it may be used in completely different ways. This is particularly the case for patients with cancer, for which the outcome is life-threatening, the social consequences potentially devastating, and the degree of uncertainty for the patient regarding treatment and prognosis extreme.[229, 436, 506] In addition, for both patient and staff, the word *hope* may signify different things at different times during a discussion, or even over the course of an entire relationship, further increasing the probability that some miscommunication may occur.[43]

Second, a patient may take any aspect of the consultation, including the doctor's positive manner or proven expertise to indicate that there is hope (as HN). The patient's perception of hope is thus beyond the control of medical staff, who may be unaware of factors or processes that engender hope within the patient.

Third, regardless of how medical staff perceives treatment and prognosis, patients may take treatment to indicate that there is hope (again, HN). According to Kodish and Post,[177] any treatment carries an implication of hope. If this is so, given the importance placed upon sustaining hope, one might conclude that treatment is always beneficial, and can never be dismissed as "futile" if desired by the patient. This understanding might, however, conflict with issues of resource allocation within the medical system.[508] This uneasy contradiction, which must impact upon clinical practice, contributes to a continuing debate within medical circles.[390, 591, 592]

Fourth, although participants insisted that doctors should take patients' hope into account, should preserve this hope—thus implying its vulnerability—they also perceived hope as enduring and impervious to any attempts to alter or remove it. Such endeavours may therefore be considered futile. This does not diminish the doctor's obligation to provide patients with available relevant medical information, but it might justify placing less insistence on determining appropriate levels of hope for an individual patient, and acting to contrive conformity to this standard.

Fifth, these patients did not distinguish between realistic or unrealistic hope, identifying hope as a probable source of strength and a means to withstand current or anticipated hardships. Attempts to demolish unrealistic hope might therefore conflict with the mandate that the actions of medical staff should maximise patients' well-being.

Finally, it appears that there were consistent features (across and within both studies) associated with patients' use of hope as noun (HN) or verb (HV) (see Table 10). Patients' use of HN, commonly expressed as "no hope," invariably referenced the medical domain, and specifically, a cure. This was considered to be within doctors' jurisdiction to determine; it often implied an unfavourable end for themselves, and, in the guise of the objective facts, left little room for perceiving or anticipating any positive outcome. It was, therefore, employed to justify somewhat extreme courses of action, but typically positioned patients as subject to the authority of others. However, HV functioned to endow the patient with agency, was restricted neither to the medical (indeed, often referenced the personal or interpersonal domain), nor to the present. Rather than appearing as the negative (as "no hope"), HV (as "I hope") appeared to identify the positive representing an active desiring of a positive future (and thus envisaging this). It positioned patients as potentially influcncing outcome, with goals that may be achievable, in contrast to their position as relatively helpless to effect change referenced with HN. The focus upon positive possibilities and their role as agentic may have therapeutic implications for the patient.

Hope-as-a-verb further functions: to acknowledge the possibility of alternative futures, but to identify what outcome or course of action is deemed positive by the speaker; to acknowledge a relative inability to guarantee or attain a preferred outcome, but also to represent the active effort of the hoper to increase the probability of realising the preferred goal, sometimes through establishing a moral obligation upon others to effect this preferred outcome; to value the subject (the hoper), and the object of hope, and the relationship between them; or, to establish solidarity or consensus with others (including, in the above instances, the interviewer). Hope-as-a-verb affirmed the presence and value of the hoper, connecting them to a good, to a future, and to others. In so doing, this hope may encourage independence or separation from their medical regimen with the inevitable end-point of death, connecting them rather to life's meaningful activities—to life.

Table 10. *Summary of different functions and consequences of participants' use of hope as noun or verb*

Hope as noun	**Hope as verb**
Limited to medical domain	Not limited to medical domain
Typically "No hope"	Typically "I hope"
Negative future	Positive future
Absolutes	Possibilities
Construes the patient as *subject to*	Construes the patient as *the subject*
Limits the patient's agency	Endows the patient with agency
Construes the patient in biological terms	Construes the patient in psychological, moral, and interpersonal terms
Focus on death	Focus on life

I have argued for the significance of patients' differential employment of hope, based upon their linguistic and grammatical properties. The two versions of hope analysed—hope-as-a-noun and hope-as-a-verb—have some conceptual similarities to the two discourses of hope delineated by Little and Sayers:[437] respectively, a discourse "of life and death" and "of meaning in life." Beste[446] has made similar distinctions between hope for a cure or remission, and hope that focuses on meaning in life. Where the former sees hope as narrowly defined and overly medicalised, the latter allows for a multi-faceted construal of hope that allows patients to autonomously determine what is meaningful to them.[446] Others have similarly asserted the value to patients of a hope that exceeds that determined by medical professionals, one that endures beyond the biological decline associated with terminal illness.[583, 593] Given that patient autonomy and patient welfare remain primary

concerns for medical staff, these may be better served if, when asked "Is there any hope?", healthcare workers respond "For what are you hoping?" thus enabling the patient to express and engage in what is important to them, to that which gives their lives meaning.

The failure of many researchers of hope to recognise the variety of its versions may explain the difficulties earlier discussed (in 6.1), difficulties both in devising the definitive version of hope and achieving consensus regarding its meaning. Rather than continuing a search for the "true" hope, I here present a preliminary taxonomy of hope, stressing that it is unlikely that hope is limited to the constructs shown in Table 11. This notwithstanding, it may be useful to acknowledge the possibility of combining a range of meanings (rather than focusing on only one) and viewing hope as located within the following sets of dualist constructs.

Table 11. *Selected summary of potential dualistic constructs constituting hope as spontaneously used in speech of patients*

Hope may be deemed	
Objective	Subjective
An evaluation	An expectation
An empirical fact	An individual desire
A warrant for action	An excuse for inaction
Present-oriented	Future-oriented
Focused on the self	Focused on another
A burden	A resource
Vulnerable	Impervious
A feature of the patient	A feature of a caregiver
An attribute of the individual	An attribute of the situation*
Inherent within the individual	Inspired by sources external to the individual
A reason for treatment	A reward for treatment
To establish moral responsibility	To avoid moral responsibility
To warn	To request
To acknowledge uncertainty	To identify what is valued
To acknowledge the limits of agency	To create opportunities for agency
To enable connection to the future	To enable connection to another person

* Some other individual, however, assesses the situation itself.

Although aspects of dualistic constructs can be found in other models, this taxonomy is based solely on unprompted elicitation of hope and, as such, represents hope, as it were, 'in action.' It affirms the multiplicity of hope, commented on by many.[456, 463, 479, 490, 492] I agree with Farran et al.[456] that those measurements of hope that are uni-dimensional, focusing on a singular aspect (e.g., [457, 458]) cannot do justice to the complexity and multiplicity of hope. To a lesser extent, this also applies to scales that tap into multiple aspects of hope, but then combine them in a single score (e.g., [484, 485, 594]).

In addition, measurement *per se* tends to obscure diversity, ignoring subtle yet important variation, and statistics, whilst seductively reassuring in that they give the illusion of objectivity, may encourage the production of "appropriate" norms and endorsement of standardised intervention.[595] In selecting aspects of hope which are amenable to measurement, scale devisers run the risk of distancing hope from its context of use, from everyday parlance, thereby decreasing relevance for patients themselves. Measurement also obscures the dynamic, multiple, and changing nature of hope.[479, 595] Rather than attempting to measure (and therefore limit) hope, further research should perhaps look at its function—recognising that this can vary, and asking to what degree a particular operation is useful, and for whom. Rather than defining (delimiting) hope and then assessing patients against this, based upon this research, I suggest that consideration of the specific meaning of hope for specific patients at specific times and places may have merit (see also [461, 492, 495]). Furthermore, rather than label hope true or false, the medical profession should recognise that individuals may differ in their understanding of hope, and of the relevance or meaning of any specific version in any particular situation.

There are a number of features (in addition to those applying to the study as a whole) that may limit generalisability from, or representativeness of, this analysis. The selection procedure and subsequent sample group may have led to the predominance of particular constructions of hope, as the speech of emotionally stable patients with cancer may differ from that of the emotionally labile or those with another illness. Furthermore, patients were talking about DNR issues, which may have influenced the ways that hope was construed by them. Nonetheless, there were marked similarities between the two different groups studied. In addition, their use of hope here analysed was unprompted, and emerged in the context of a number of different questions. It was, however, relatively infrequent. Although I consider that the spontaneous use of hope was beneficial in analysing the discursive properties of hope, a direct question about hope may enable comparison of considered and spontaneous talk about of hope by patients with cancer. It may also be instructive to

examine these within a population of healthcare workers, including oncologists, physicians, and nurses, in order to further explore potential problems in communication between these and patient populations. I note that Clayton et al.[277] went half way to this: Conducting focus groups and interviews, they directly asked healthcare professionals about hope, but also considered instances wherein "patients and caregivers spontaneously volunteered their perspectives on hope" (p. 1973). However, as their qualitative analysis appears to be primarily thematic, and the sole quote on hope specifically attributed to a patient does not actually feature the word hope (p. 1970), any comparison with the present study is difficult. A similar point may be made with regard to a study by Hagerty and colleagues[273] which aimed to investigate how patients with cancer define hope, and how their hope is affected by the behaviour of oncologists when disclosing prognoses. As part of a larger (predominantly survey and quantitative-based) study, they asked patients to endorse "four exemplar hope definitions, using the words of the patients from a previous study" (p. 1279). However, they did not present any analysis of the discursive or linguistic properties of these, nor of the qualitative data provided by the majority of participants in their study who ignored their exemplars, and "wrote their own definition" (p. 1281). Parenthetically, I observe that the parameters of the set task implicitly constructed hope as a thing to be defined, and moreover, that many patients rejected the offered definitions, preferring to provide and endorse items that were personally meaningful.

It seems likely that part of the importance that medical writers and patients, including these participants, have placed on hope is based on its flexibility and ability to incorporate a range of meanings. Stotland[596] suggested that hope could be regarded as "shorthand term for an expectation about goal attainment" (p. 2). As it emerges from the speech of these participants, hope represents a shorthand term representing a number of different constructs. If genuinely concerned with patient well-being and the effect of hope on this, the role of medical staff should be to determine precisely to what that shorthand term refers—most effectively achieved through genuine communication with patients themselves. It seems probable, however, that the chameleon-like nature of hope in everyday speech ensures that medical staff can neither wisely nor ethically assume a shared or enduring meaning of hope as some patients may hold that "there is no hope" yet conclude that "one can always hope."

Chapter 11. Conclusion: What does it all mean?

The primary aim in this thesis was to enrich the complex and controversial discussion surrounding DNR orders through analysing and reporting upon how patients (some facing a serious illness, some dying) talk about these and associated practices.

So—how did patients (and in some instances, their families) talk about DNR orders? The short answer is that, just as there are a number of competing representations of DNR orders within the medical literature, so too are there within participants' talk. Some of these are congruent with the dominant medical representation of these orders as a matter of patient autonomy, but some lend support to alternative constructions. It was certainly the case that patients assumed that their wishes would be primary with regard to process and outcome of DNR decisions and decision-making—but precisely what form their wishes took, precisely how their autonomy might be realised, varied considerably. Furthermore, although some patient assumptions regarding the process and outcome of DNR decisions and decision-making are compatible with those shaping medical practice, some are not. Finally, the presence and interplay of these competing representations within participants' talk poses particular problems for practitioners and policy makers endeavouring to respect and best care for patients at the end of their lives.

To elucidate: Overall, participants recognised that DNR orders countermand the otherwise routine provision of CPR and that patients with such orders will die. The dominant justification for sanctioning DNR orders was that they reflected the patient's wishes to forego what was often construed as a violent inappropriate medical intervention (i.e., CPR) in a personal and natural process (i.e., dying). Participants drew upon a network of arguments to legitimate this process and outcome, citing patients' unacceptable quality of life (before or after CPR), avoidance of suffering (patient or others), avoidance of burdening others (both proximal or distal), and the inability of medicine to meaningfully prolong life or prevent the inevitability of death. Thus participants effectively constructed a category of persons for whom DNR orders might be justifiably instantiated, and drew upon dominant discourses within Western society to render this appropriate, identifying it as being compassionate, natural, reasonable, and above all, in keeping with patients' wishes. Participants appeared to take it for granted that what the patient wanted (and particularly in the second study, what *they* wanted) was what would determine process and outcome.

However, for every conclusion that might be made from these participants' accounts of DNR orders, there is a qualifying condition that works to problematise it: a series of "This,

but on the other hand … ." To this extent, the DNR decision (with associated practices) might be said to constitute an archetypal dilemma for participants, with competing and often incompatible precepts simultaneously deemed relevant. For example, participants held both that patients should make the DNR decision, but did not have to if they did not want to: They could either choose not to make the decision (i.e., delegate it to another, usually the family, but sometimes the doctor), or be excused from involvement should they or others deem that the discussion would engender emotional distress. Attributions of responsibility for the DNR decision to the patient typically conformed neatly with dominant models of decision-making, drawing upon a 'modernist repertoire' of self and reflecting individualistic notions of autonomy, with the patient independently and responsibly undertaking a rational decision-making process. This operated to characterise the best decision as one made by the patient that reflected rational consideration of medical circumstance. Accordingly, some patients were excluded from this process—those failing a Sanity test, or who were cognitively compromised. As this was deemed an almost inevitable consequence of approaching death, this construction of the DNR decision functioned as an impetus for discussing, determining, and recording patient preference before this happened, that is, relatively early in the disease process.

However, this was potentially countermanded by invocation of an alternative 'romanticist repertoire' of self, one that sees individuals' actions as contingent upon emotional and interrelational factors. Participants held that discussions about DNR orders should not be raised with patients who were emotionally unstable, that is, those who would fail a Stability test. Drawing upon dominant representations of the relationship between reason and emotion, the presence of emotion was deemed to interfere with prescribed rational decision-making processes, and to excuse an affected individual from involvement. This precept held true for all potentially involved parties, including patients, families, and even physicians. Again, under this construal the best decision that could be made represented the most rational decision, one that best considered and reflected the medical facts. Critically however, the very nature of the DNR decision itself, referencing the patient's impending death, meant that DNR discussions might be infinitely deferred, as they were inherently likely to engender negative emotions in the patient.

Closely connected with this perception was the understanding that doctors not only should be aware of the emotional state of their patients, but were obliged to consider this before attempting to elicit patient preferences regarding the provision of CPR. So although championing patient autonomy and holding that the patient should be responsible for the

DNR decision, participants considered it unproblematic that patients for whom the decision was too upsetting should not be required to make it. They also implicitly pit autonomy against hope—holding that the doctor should discuss DNR issues in order to determine the patient's wishes, but not if this would (negatively) affect their hope. These provisions implicitly legitimise not only the right of the patient not to make the decision, but also what might otherwise be deemed medical paternalism—that is, the practice of absolving or sheltering the patient from a decision that may cause harm. This harm was typically identified as psychological, but participants also drew upon prevalent Western concepts of the relationship between mind and body to impute a possibility of negative physiological consequences that further sanctioned non-involvement of the patient in the decision.

Nonetheless, any decision made by the patient—whether that was emotionally derived or not, was an actualised statement of preference, or a refusal (implicit or explicit) to state preferences—was established as acceptable. This works to identify the decision as fundamentally personal—whatever the patient wants is the best decision. However, behaviours and choices that deviated from the (traditional and dominant) ideal of decision-making were disapproved with negative evaluations and sanctions potentially applicable.

Participants thus appeared to hold two alternative notions of what constitutes an appropriate decision about CPR (or DNR orders): One derived from rational consideration of medical circumstance, and, one that accurately reflected the patient's wishes. These were not mutually exclusive, and indeed, where they produced identical results, accord between (potentially) involved parties was probable. Where they did not coincide, decisions became problematic, with an increased probability of mis-communication and dissent. Ultimately, and in keeping with the value placed upon patient autonomy, participants maintained the latter (patient's views) as pre-eminent. They appeared to have no inkling of the possibility that the patient's wishes might not direct affairs—that what the doctor writes (or does not write) within their case-notes is what ultimately dictates what will be done. The construal of the decision as personal failed to permit the possibility that autonomy might be superceded or even overlooked as doctors sought to follow appropriate medical practice or to comply with medical protocol, either mandating against CPR on the grounds of medical futility, or failing to determine whether or not the patient wanted CPR, or indeed, whether or not patients wanted to decide upon that now, or at all.

Patients' presumption that their will will be done was all-encompassing, but may fail to hold true in practice, with a number of potential causes for discrepancies between patient preference and medical practice. To give just a few illustrative examples from this study:

Events that doctor consider appropriate indicators that DNR orders are relevant, may not be so perceived by the patient; yet such a patient may (and particularly if asked) voice a preference that pertains to a hypothetical future rather than for now. The physician may deem this to constitute a current preference. Then again, a patient's preference predicated on cessation of cerebral activity might differ from one based upon heart asystole, potentially leading to confusion or inaccuracy regarding what the patient wanted. Finally, some patients in both studies had not only made a decision about CPR, but taken steps to disseminate this through formal and often legal documentation. Their presumption that this would ensure that their wishes were effected was, nonetheless, somewhat questionable, as for the majority, there was no record of such documentation within their case-notes. This poses problems for both the patient and the appointed surrogate presuming that the patient's wishes will prevail, and, should these wishes oppose those of their physician (reflecting medical circumstance etc.), for the physician and policy makers as well.

Further complicating the issue for policy makers, participants further asserted the right of the patient to decide not to decide if they did not want to—if they wanted to leave the decision to either the doctor, deeming that they would make a better decision, or to family, deeming that the family would be significantly affected by, and therefore should have a say in the decision. Both positions may be justified through assertions that they are what the patient wanted—which again works to establish the importance of the patient's wishes, and the dominance of the construal of the decision as personal. Nonetheless the former identifies the decision as at least in part medical, rendering medical knowledge of the patient most relevant, and correspondingly decreasing the suitability of any other parties to make the decision. The latter position implicating the family draws attention to the social and moral aspects of the decision, as well as the importance of emotional ties between individuals. These act to place limits upon patients' rights to do what they like—a construal that supports assertions that patient autonomy is fundamentally socialised, interrelational, and emotional in nature, rather than simply individualistic and rationalist.

Yet involvement of family in the decision becomes problematic given the symbolism participants attached to the provision of CPR, juxtaposed against their unwavering faith in its ability to restore life, however unacceptable, to the patient. Choosing to forego CPR was therefore implicitly construed as choosing to let the patient die. While the patient's right to do so was uncontested, should a family make that choice, various unpalatable moral evaluations of family or patient were therefore made relevant: Either the patient was not worth saving, or the family did not care enough to save them. On the other hand, for

the family, choosing to opt for CPR might be deemed to sentence their loved one to extended suffering, life as a 'vegetable,' and possibly to violate their autonomy if that was not what they wanted. This is a difficult dilemma for patients and families to confront, but may be minimised through emphasis on other construals of the DNR decision available to them—for example, that CPR is 'pointless because death is inevitable,' that cardiac arrest signals the appropriate time to die, is part of a natural process of life and death, or even represents God's call to them. It seems likely that recognising that CPR for the dying cannot prevent death may go some way to defusing the moral weight of this decision, indeed, will function to re-present the decision as an appropriate response to circumstance—as requiring acceptance of death, rather than a choice about it. Participants' talk on this suggests that the former is difficult enough, the latter considerably more so.

However, even though there was singular consensus regarding the inappropriateness of CPR in the dying patient, the patient's right to choose to forgo CPR could also be subject to moral opprobrium. As one of the justifications given for making the choice was poor quality of life, with the associated implication that life was worth-less, this might carry with it the implication that their attachment to their family was insufficient to prompt them to wish to carry on living. Furthermore, this choice might also connote a resignation to death, requiring that patients 'give up' their previously required and highly valued 'fight' against their disease. Determining the moment to do so may be difficult, particularly as the assessment of of others (including family and doctor) of the appropriateness of doing so may not always coincide with that of the patient. Too early, and the patient risks breaching standards of good patient behaviour centred on the fight; too late, and they risk being labelled as 'unrealistic,' or 'in denial.' Again, this attests to the fact that, patient autonomy not withstanding, these decisions have social and moral consequences that work to challenge the patient's right to just decide what they want.

On the other hand (and always on the other hand), there were several other available construals of DNR orders and CPR that worked to support a patient's decision either not to make the DNR decision, or to actually decide in favour of CPR. To deal with the former first: As noted previously, this might sometimes be justified through co-opting others in the decision, with corresponding emphasis on other aspects of the decision (e.g., medical, moral, or social)—acknowledging that these two factors (nomination and construal) are intrinsically intertwined. But even where a patient might identify the decision as their own, they could justifiably defer it to another time. Given that contemporaneous consideration of circumstance is a precursor to the valued process of rational decision-making, any

decision could be regarded as premature, therefore inappropriate, and paradoxically, as compromising their own autonomy through 'locking them in' to a choice. There was always the possibility that the patient might change their mind, particularly when the 'reality' of the situation became evident. This then constitutes grounds for holding off on the decision, again representing a push for discussing or making these decisions later. As a further consequence, this point necessarily compromises the confidence which an observer can assert that a previously voiced choice really represents the patient's wishes.

Furthermore, sometimes arguments put forward by participants to justify instantiating DNR orders were also invoked in order to achieve the opposite effect. For example, accepting that DNR orders were appropriate when a patient was 'at that stage' (i.e., had reached a particular point in their disease, typically characterised by unacceptable quality of life due to increased pain and decreased involvement in valued activities, often with others) meant that patients could assert that they were not at that stage (that their quality of life was acceptable and they could engage in valued activities with others). Similarly, arguments that DNR orders were appropriate in order to ensure the patient was not a burden meant that assertion or demonstration that they were not a burden (either in terms of interpersonal interaction or use of economic resources) acted to render these orders immediately and personally irrelevant. Therefore, the construction of the DNR category—persons who should have DNR orders and not receive CPR—enabled individuals to locate themselves outside of it and justify not having such orders, and/or a preference for CPR. This possibility was most evident within the first study: The majority of participants identified themselves as 'not at that stage,' talking hypothetically about the issue, with few having articulated their preferences, despite holding it desirable that they should do so (before they were incapable of doing so). But even in the second, some patients (who, by virtue of their inclusion in the study, were deemed within weeks of their death) also positioned themselves outside the DNR category, obviating the need to consider DNR orders, with the conclusion in favour of CPR correspondingly self-evident.

In addition, although most participants construed CPR in the dying as an inappropriate violent medical intervention, another construal of it—as indicating an appropriate resistance to death that served to value the life fought for—was also drawn upon to support a preference for CPR, even when failure was deemed likely. Again, the moral and symbolic connotations attached to CPR may mean that a range of opinions can be promoted and defended by patients. And when the dominant construal is that it is up to the patient to decide what they want, attempts to deny their preference seem destined to remain

controversial at best and reprehensible at worst. While the DNR decision is construed as a choice put to patients, some will choose in favour of CPR.

There were some other consequences of the representation of the choice of CPR as a choice between life and death, this choice then actualised by the medical profession. These assumptions—(1) that someone (usually patients) can (and generally should, given the personal, social, and philosophical reasons given to support this) choose to die through (2) forgoing intervention to prevent death, and (3) that this choice does (or should) determine medical action, resulting in the patient's death—constitute a medicalisation of the process of dying. They are also readily modified to arguments (1) that someone (usually patients) can (and possibly should, with the same reasons likely deemed relevant) choose to die through (2) requesting intervention to secure death, and (3) that this choice does (or should) determine medical action, resulting in the patient's death. Euthanasia is thus construed as a further rendition of patient's choice over life or death effected by the medical profession. It is rendered a logical extension of existing practice and correspondingly more difficult to repudiate.

Of course, some will simply not decide, with someone else inheriting the position of (surrogate) decision-maker. However, (and returning to the issue of DNR orders, but with the observation that these arguments may also transfer to the issue of euthanasia) although participants endorsed patients' right not to decide, this was typically associated with various moral strictures and negative evaluations. The DNR decision was construed as inherently difficult, but as necessary, and therefore the choice of the patient to leave others to make it was interpretable as inappropriately burdening them with a responsibility that should have been the patient's. Particularly salient in the context of familial relationships, this functioned to oblige patients to make the decision—whether or not they wanted to do so. However, attending to the social import of the decision and its potential impact on others may also act to legitimise patient moves to counter this obligation with claims to consider or defer to family (thereby enacting appropriate familial behaviour). There is consequently some potential that each party might legitimately defer to each other, both providing compelling reasons why they should do so.

Nevertheless, the construal of the DNR decision as fundamentally personal typically was drawn upon to normalise nomination of the family as surrogate, and to oblige them to take on this role—they (should) know and (should) care what the patient wanted. However, this did not exclude all others, with the possibility available that the doctor and other healthcare workers could also lay claim to having established such an interpersonal relationship with

the patient. Furthermore, enactment of good familial behaviour might also render family inappropriate surrogate decision-makers, as the very closeness required for personal knowledge was deemed likely to engender displays of emotion that might interfere with good decision-making. Curiously, this was not mentioned as likely with medical staff. Indeed, where enactment of good familial relationships both qualified and disqualified family from decision-making, enactment of the good doctor role (demonstrating both caring and competence) qualified the doctor on several fronts: Through caring, they could determine and represent the patient's wishes; through competence, they could determine the appropriate medical course of action.

But (as always) there were grounds that might be drawn upon to exclude doctors from decision-making, and indeed, many patients specifically repudiated the conclusion that doctors should make (what was dominantly construed as) a decision that belonged to the patient. One of the more frequently voiced arguments saw doctors as appropriately recognising the limits of their authority, acknowledging that they could not successfully intervene in the course of the disease, and refraining from interfering in what was no longer their concern. Paradoxically, establishing that this was the case was held to be doctors' responsibility—doctors drew upon their medical knowledge of the patient to determine that death was imminent and inevitable, but in so doing, were deemed to become less relevant to the decision and outcome. Again presenting the issue as less one of choice, but of appropriate response to circumstance, this version of doctors' involvement attributes some responsibility to the doctor, but avoids the perils of paternalism. This is not to say that all patients decried paternalism, some rejecting construal of the decision as personal, rather deeming it as medical and therefore obviously the responsibility of the doctor. Under such a construction, doctors are morally obliged to make the DNR decision, with assignation of responsibility to patients rendered as abrogation of doctors' duty to them.

This dissertation also devoted considerable space to hope, demonstrating that patients' construction of hope was not always congruent with that evident within the medical literature or medical practice. In the preceding chapter I queried the ethics or wisdom of medical practitioners assuming a shared and enduring meaning of hope with or amongst patients. It seems likely that a similar point might be made with regard to the DNR decision and associated practices (including CPR and surrogacy).

Before summarising, I wish to acknowledge some limitations of this analysis. With the exclusion criterion of non-English speakers, the population sample was exclusively Caucasian, but also predominantly Christian, and did not represent the cultural diversity

evident within Australia. Given that differences in customs, beliefs, and religions clearly influence end-of-life decisions made by physicians, patients, and their families, as well as their construction of autonomy, indiscriminate application of conclusions derived from one population to other different cultural groups is obviously inappropriate.[200, 223, 570, 597, 598] Certainly, future studies should interview similar patients from different cultural backgrounds in order to determine what discourses feature within their talk (as indeed is the intent of the greater research project of which this is a part). However, the diversity of views here re-presented suggest that even within a relatively homogenous group, any one position will always be subject to contestation, indicating a need for flexibility in approach to patients, regardless of their cultural background.

There is an obvious systematic bias towards those patients who were assessed by their carers as willing and (emotionally) capable of discussing the issues involved. It is possible that those who were not might profess different views—however, this is a common shortcoming of research with patients, and is derived from ethical directives that mandate their welfare as paramount. Nonetheless, there was, within the combined interviews of a total of 51 patients and 21 others (mostly family members) a variety of positions represented with regard to having discussed or decided upon DNR issues previously. Similarly, only patients with cancer were interviewed. Although cancer patients feature most often in other research into end-of-life decision-making, patients with, or dying from other illnesses may draw upon different discourses in considering these issues. Nonetheless, many of the discourses drawn upon by participants to support various conclusions were not specifically associated with the diagnosis of cancer (though some were), and thus may be relevant to patients with other diagnoses. Finally, patients were each interviewed only once, with the implicit suggestion that this represents their final position on the matter—a problematic assumption at best. However, as the intent of the research was to explore how patients represented the issues, and what discourses were drawn upon in this process, that patients' views may change over time or might not represent what they do, are somewhat moot. One virtue of the research was that it examined patients at different stages in the interview trajectory, revealing that similar discourses were evident across these. A further (admittedly serendipitous) strength was the inclusion of others in the interview setting, allowing for some examination of how these issues were negotiated within a family dynamic. Particularly given the role both attributed to and displayed by family in these decisions, further investigation of the process of negotiation between parties would be useful. Such studies might also usefully include a

discursive analysis of interactions between patients, families, and doctors as they attempt to formulate an acceptable outcome.

Other limitations were consequential upon the method employed. I acknowledge that this dissertation is a hybrid on (at least) two counts: Although focusing on DNR orders, it detoured into an extensive examination of hope. However, the capacity to pursue unexpected findings is one forte of qualitative research. In addition, participants' construction of hope had consequences with regard to the process of determining DNR orders, but more critically, for patient-carer interactions generally. These I considered worth exploring. Further, as I acknowledged within my discussion on method, in this thesis I have straddled two (often deemed incompatible) traditions of discourse analysis, and then attempted to make practical recommendations for healthcare policy and practice. Although I may have breached purists' tenets, by flexibly drawing upon aspects of both traditions I was able to consider both the immediate interactional context, and the wider societal and material conditions with associated discourses, to examine how these structured or affected how patients talked about and made sense of the DNR issue. My hope is that this approach facilitated clarification of patients' construction and negotiation of the DNR decision. The attempt to make tangible recommendations for policy and practice reflects my belief that researchers have an ethical obligation to consider the implications of their research.

Many of the findings herein presented are not new: For example, others have reported that patient preferences for decision-making varies, that their utilisation of advance care planning seems beset by contradiction, as patients typically say they would like to, but do not make decisions to direct their future care. Similarly, the influence of emotional and social factors in patients' decision-making has been noted, as has the disparity between patient views and either their doctor's own views, or their interpretation of those of the patient. Still others have challenged the dominant model of decision-making, and particularly its implicit assumptions of rational process and independent individualism. And others have noted the complexity of the construct of hope, and potential for miscommunication between parties. What the analysis presented in this dissertation does is show how patients' diverse positions regarding these are derived from existing discourses, how their very constructions of the DNR decision and associated practices and personnel (not to mention, hope) constitute these as embedded within a network of potentially contradictory discourses—with miscommunication almost inevitable. It further draws upon empirical data to lend support alternative models of decision-making, demonstrating how autonomy is simultaneously held pre-eminent, problematised, challenged, and re-instated,

with rationality, emotion, independence, interdependence, the medical and the personal, the individual and those caring for or cared by them, all necessary components of patient decision-making. Accordingly, although derived from talk focused on decisions at the end of life, and specifically on decisions about CPR and DNR orders, the conclusions drawn may have practical and theoretical import beyond these topics, pertaining to patient decision-making in a variety of contexts.

Ultimately, this analysis of patients' talk of CPR and DNR decisions demonstrates that they are complex and multi-faceted constructs, drawing upon diverse discourses, implicating notions of life and death, the self as the individual in a social environment, what is valued in life, the possibilities and limits of morality and medicine, and more (see Appendix N for a summary of alternative re-presentations evident in participants' talk). This very heterogeneity enabled participants to draw upon selective aspects to justify different conclusions or levels of involvement in the DNR decision. However, all participants assumed that what the patient wants to happen should determine what happens, whether that is to be resuscitated or not, to make a decision or not, to leave it to or be guided by the doctor or not, to be involved or not, to be involved early or not, to make a rational decision or not, to involve family or not… and so on. Posing a challenge for policy makers and clinicians attempting to formulate or comply with policies that pertain to a decision to forgo CPR, this sees patient autonomy as fundamental, but allows considerable leeway in the ways that it is constructed. Clearly, it seems unlikely that any presumption that a single, one-size-fits-all policy approach to patients and DNR decision-making (dictating time, place, or responsibility for decisions) will suffice. It is more likely to fail to meet all patients' needs or preferences, resulting in dissent or confusion as patients presume that their wishes will prevail.

However, one solution (explicitly stated within Study 1 and implicit within Study 2) may be derived from these participants' speech: namely, that *everyone is different and should be treated accordingly*. Such a solution encapsulates autonomy as re-presented by these participants, paradoxically allowing a single precept to account for and embrace a multiplicity of patient preferences.

Those factors that initially prompted the creation of DNR orders still hold sway. CPR is still a default measure within medical institutions but is still medically futile in dying patients; practitioners (including nurses and doctors) caring for these patients are still reluctant to interfere with the dying process; someone still needs to make the decision that directs whether or not an individual patient will receive CPR; doctors still need to write

something in patients' case-notes; and patient autonomy is still valorised within those cultures that have access to the medical technologies that support CPR. However, despite the pre-eminence accorded to autonomy by society, doctors, and patients alike, this analysis suggests that respecting patient autonomy might entail respecting their rights to make or not make the decision, to face or not face it. The challenge for the medical profession (including policy makers and practitioners) is to formulate an appropriate DNR policy, one that permits, but does not mandate that patients accept or refuse CPR, that allows patients, not policy to determine their participation in the process, but also ensures that patients are not resuscitated by default, providing individualised care and appropriate guidance for attending clinical staff.

A policy fulfilling these aims would be capable of flexibly responding to differences between patients, aiming to strike a balance between mandatory autonomy (potentially overwhelming patients with the decision) and rampant paternalism (where patients' views hold no weight in determining outcome). It would recommend that where a doctor determines that CPR is contra-indicated, but that discussions with patients have not happened, that this is recorded within their case-notes—and require that the doctor provide reasons as to why said discussions have not happened. Alternatively, if such discussions have happened, that the nature, extent, and parties involved in these similarly be documented. It would require that doctors determine whether patients have established legal documentation of their wishes regarding future treatment, and the nature of and parties involved in these. It would be readily and obviously identifiable to attending clinical staff, as well as capable of accommodating changing circumstance. While not solving the problem of potential differences between doctor and patient views regarding the desirability of CPR in any individual case, such a policy would recognise that doctors do have responsibility for stipulating the care of their patients, but hold them accountable for this, and maximise the probability that patient participation in the DNR decision will be determined by patient preferences. Moreover, with potential differences clearly articulated and justified, it seems more likely that resolution of conflict may be attainable, perhaps through agreeing to a time-limited trial of CPR, recognising the social, economic, moral, or legal consequences or parameters of decision-making that might temper a patient's exercise of autonomy, or finding other ways to fulfil the symbolic function that a physiologically inefficacious intervention might offer. Either way, the process would be clearly transparent, maximally flexible, and responsive to individual circumstance, further facilitating review of process and outcome for all involved parties—including patients, families, healthcare workers (doctors and nurses), and policy makers. Such a policy is, at

the time of writing, in draft form at the site for this research (see Appendix O), and will be reviewed one year after its institution. Determining the effect of this policy is one further step in the research program of which this dissertation is one part.

Appendix A

ROYAL ADELAIDE HOSPITAL
MEDICAL POLICIES & PROCEDURES MANUAL

CONSENT TO MEDICAL TREATMENT

CONSENT TO MEDICAL TREATMENT OF A PERSON WITH MENTAL INCAPACITY

Mental incapacity may be temporary or permanent. Under the Guardianship and Administration Act 1993, mental incapacity is defined as - *'the inability of a person to look after his or her own health, safety or welfare or to manage his or her own affairs, as a result of -*

a. *any damage to, or any illness, disorder, imperfect or delayed development, impairment or deterioration, of the brain or mind, or*

b. *any physical illness or condition that renders the person unable to communicate his or her intentions or wishes in any manner whatsoever'.*

There are two laws that deal with the issue of who has the legal authority to consent to medical and dental treatment where a person, because of reduced mental capacity, is unable to provide their own consent:

- Consent to Medical Treatment and Palliative Care Act 1995
- Guardianship and Administration Act 1993

Consent to Medical Treatment and Palliative Care Act 1995

Under this Act, a person who is 18 years or over and of sound mind, make an **Anticipatory Direction** (in relation to future medical treatment and palliative care for the situation where they may be in the terminal phase of a terminal illness or in a persistent vegetative state and are incapable of making decisions about their medical treatment) or can appoint a **Medical Agent** (under a Medical Power of Attorney).

If a person, who has made an Anticipatory Direction, is in the terminal phase of a terminal illness or in a persistent vegetative state and is incapable of making decisions about medical treatment, the wishes expressed in the Anticipatory Direction must be acted upon.

If a Medical Agent has been appointed and the medical/dental practitioner responsible for the treatment is aware of the appointment (and the Medical Agent produces a copy of the Medical Power of Attorney for inspection by the medical/dental practitioner), then the consent of the Medical Agent must be sought before any medical or dental treatment can be administered. A person can appoint one or more Medical Agents, and the order of appointment must be indicated so that if the first agent is unavailable, the second can be consulted, and so on. If a person has appointed both a Medical Agent and Enduring Guardian (under the

Guardianship and Administration Act), the Medical Agent has precedence for medical decisions.

Guardianship and Administration Act 1993

If a person has lost mental capacity and has not appointed a Medical Agent (or the Medical Agent is not reasonably available or willing to make a decision), or the patient has made an Anticipatory Direction but is not in the terminal phase of a terminal illness or in a persistent vegetative state, then the provisions of Section 59 of the Guardianship and Administration Act 1993 apply. Under this Section, consent to medical or dental treatment for a person with a mental incapacity must be sought from:

- an **Enduring Guardian**, who is a guardian appointed, under the Guardianship and Administration Act, by a person, prior to mental incapacity occurring, to make medical decisions should the need arise.

- a **Guardian** appointed by the Guardianship Board under a Guardianship Order. The written order will specify the areas in which the guardian is empowered to make decisions.

- where there is no Enduring Guardian or Guardian, then the following **specified relatives** can give consent:

- a spouse, including legal defacto spouse;

- a parent;

- a sister or brother of or over 18 years;

- a daughter or son of or over 18 years;

- a person (not being a guardian) who acts in 'loco parentis'. This means a person who provides the day-to-day care and supervision of the person, and can include a live-in carer or the director of a nursing home or hostel.

Under the Guardianship and Administration Act, there is no hierarchy for relatives. The Act contains a provision which covers the medical staff for situations where someone may have misrepresented themselves as a person eligible to give consent, if it was reasonable to believe that they were such a person.

Where there are concerns about a relative not making a decision in the best interests of the patient, or if relatives disagree, the Guardianship Board should be contacted.

Under the Guardianship and Administration (Miscellaneous) Amendment Act 1999 the definition of medical treatment has been expanded to include treatment by physiotherapists, chiropractors and chiropodists.

- the **Guardianship Board**, on application, can provide consent to necessary medical or dental treatment where a person is not able to give informed and effective consent and who does not have a guardian, enduring guardian, a medical agent or any appropriate family member or carer available, or where there is dispute between relatives. This will involve a hearing before the Board. (information regarding applications to the Guardianship Board is available from the Social Work Department, ext. 24025). (The Guardianship Board is available 24 hours per day by telephoning (08) 83685600, toll free 1800 800501, fax (08) 83685699).

CONSENT TO EMERGENCY MEDICAL TREATMENT

The provisions relating to emergency medical treatment for a patient incapable of giving their own consent are contained in Section 13 of the Consent to Medical Treatment and Palliative Care Act 1995. If treatment is needed urgently to save a person's life or to prevent serious damage to the person's health and:

- the treating medical practitioner (or dentist) does not have any knowledge of a prior refusal by the patient to the treatment,
- the patient has not appointed a **Medical Agent** (or the Medical Agent is unavailable);
- the patient has not appointed an **Enduring Guardian** (or the Enduring Guardian is unavailable);
- there is not a **Guardian** appointed by the Guardianship Board (or the Guardian is unavailable);

then a medical practitioner (or dentist) can proceed without obtaining consent.

In such cases the medical practitioner's opinion to provide treatment should be supported, unless it is not practical to do so, by the written opinion of another medical practitioner who has also personally examined the patient

It should be noted that where a person has made an Anticipatory Direction and they are in the terminal phase of a terminal illness or in a persistent vegetative state then their Anticipatory Direction must be followed. Where a person has appointed a Medical Agent (if the treating doctor is aware of this appointment and the conditions and terms of the Medical Power of Attorney) and the Medical Agent is available, then the treatment must not be administered without the consent of the Medical Agent. If no Medical Agent is available, but the person has an Enduring Guardian or Guardian who is available, then the treating medical practitioner should obtain the consent of the Enduring Guardian / Guardian.

If the patient is a child (under 16 years), and a parent or guardian of the child is available to decide whether the medical treatment should be administered, the parent's or guardian's consent to the treatment must be sought but the child's health and well-being are paramount and if the parent or guardian refuses consent, the treatment may be administered despite the refusal if it is in the best interest of the child's health.

Appendix A cont'd

Approved by - Operations Committee
RAH Contact Person -Director, Medical Administration & Services
Date Version 2 Issued - August 2002

Down-loaded10:51 a.m., 17-11-02, from the Royal Adelaide Hospital, Intranet, Home.

Appendix B

An examination of South Australian legislation and policies in effect at The Royal Adelaide Hospital during data collection for the present research

South Australian Policy: The Consent to Medical Treatment and Palliative Care Act 1995 No. 26 of 1995[o]

Within South Australia, the Consent to Medical Treatment and Palliative Care Act 1995[264] (1995 CA) came into effect in November 1995. One of the stated aims of the 1995 CA was "to allow for the provision of palliative care, in accordance with proper standards to people who are dying and to protect them from medical treatment that is intrusive, burdensome and futile" (Section 3 (c)). This seems consonant with a desire to legitimise and legalise the intent to refrain from initiation of CPR on the dying patient.

The document supplied by the South Australian Department of Human Services (SADHS) entitled *An explanation of the key provisions of the Consent to Medical Treatment and Palliative Care Act 1995* (SADHS Explanatory Document) is intended to provide information about the 1995 CA for the general public. As the most publicly accessible source of information regarding the 1995 CA, it provides a summary of the 1995 Act's key new provisions. I now discuss some of the details of this.

Point 6 of the SADHS Explanatory Document reads: "Medical Practitioners caring for people who are dying are not obliged to use life-sustaining measures if there is no prospect of recovery" (p. 2). Citing the 1995 CA Section 4, life-sustaining measures are defined as

> medical treatment that supplants or maintains the operation of vital bodily functions that are temporarily or permanently incapable of independent operations, and include assisted ventilations, artificial nutrition and hydration and cardiopulmonary resuscitation. (p. 5 of the SADHS Explanatory Document)

The conclusion would appear to be that, as included in the definition of life-sustaining measures, the provision of CPR is not obligatory for the dying person. Moreover, as determining a patient's prospects of recovery is the province of the medical practitioner, and the terminology employed to define the situation is medical, the decision not to provide CPR is presented to the lay person as a medical decision. Thus the SADHS Explanatory

[o] This commentary is not intended to be a comprehensive legal analysis of the intricacies of the law, but to provide background for this study, with some comment upon relevant aspects of existing legislation.

Document would seem to sanction the medical practitioner unilaterally making a decision without agreement of the patient or the patient's representative. In this interpretation, a request from a dying patient or their representative that CPR be attempted, possesses minimal force, and may legitimately be repealed.

Within the 1995 CA, Section 16 provides some legal protection for the medical practitioner who refrains from CPR, stating that they will incur

> no civil or criminal liability for an act or omission done or made (a) with the consent of the patient or the patient's representative or without consent ... [when performed] (b) in good faith and without negligence; and (c) in accordance with proper professional standards of medical practice; and (d) in order to preserve or improve the quality of life.

This leaves some room, however, for differences of interpretation, for two reasons: First, refraining from intervention intended to prevent death may be deemed by some (for example, a patient's relatives) as negligent; and second, the status of an "omission" with regard to "proper professional standards of medical practice" appears ill-defined, as attested to by the fact that CPR continues to be performed upon at least some patients who suffer cardiac arrest at the end of a terminal illness.

Section 17(3.b) of the 1995 CA (covering the care of people who are dying) goes some way to further indemnifying the medical practitioner, affirming that "the non-application or discontinuance of life-sustaining measures in accordance with subsection (2) does not constitute an intervening cause of death." The details of this subsection 17(2) are addressed below, but the conclusion to be drawn from s.17(3.b) is that medical practitioners cannot legally be held responsible for the death of the patient. This addresses a legal ambiguity which has been held to contribute to the continuing blanket application of CPR in Australian hospitals. Again, the conclusion is that doctors may refrain from CPR with or without the consent of the patient or patient's representative.

This conclusion is, however, rendered somewhat less unassailable when other parts of the 1995 CA are consulted. According to the SADHS Explanatory Document, Point 6 cited above is based upon s.17(2) of the 1995 CA, which reads:

> A medical practitioner responsible for the treatment or care of a patient in the terminal phase of a terminal illness, or a person participating in the treatment or care of the patient under the medical practitioner's supervision, is, *in the absence of an*

> *express direction by the patient or the patient's representative to the contrary*, under no duty to use, or to continue to use, life sustaining measures in treating the patient if the effect of doing so would be merely to prolong life in a moribund state without any real prospect of recovery or in a persistent vegetative state. (italics mine)

The inclusion of the clause "in the absence of an express direction by the patient or the patient's representative to the contrary" introduces an element of ambiguity. The question arises—What is the duty of the medical practitioner should the patient or the patient's representative provide an express direction in favour of CPR even though the outcome might be considered "merely to prolong life" etc? Normal principles of statutory construction allow that if "no duty exists in the absence of a direction, the inference would be that a duty does exist if there is a direction" (as stated in a legal opinion accessed within the RAH,[266] section 4.2, p. 7). Section 17(2) of the 1995 CA would thus appear to contradict the earlier cited Point 6 of the SADHS Explanatory Document, implying that should the patient (or their representative) express a wish for life-sustaining measures, the medical practitioner is obliged to provide this, regardless of medical opinion on the outcome.

A further ambiguity exists with regard to the extent to which the medical practitioner is obligated to elicit an "express direction" regarding the wishes of the patient? There are a number of reasons why this is pertinent. The ethical principle of respect for patient autonomy, and the practice of informed consent both emphasise that medical practitioners should determine the patient's views about what may or may not happen to them at the end of their life. Indeed, in summarising Section 15 of the 1995 CA, Point 1 of the SADH Explanatory Document states that

> Medical Practitioners have a **duty to explain** the nature, consequences and risks of proposed medical treatment; the likely consequences of not undertaking the treatment and any alternative treatment that might be reasonably considered in the circumstances of the particular case (p. 2) (bold in the original)

Although CPR (and DNR orders) represents a unique case in that consent would be required for refraining from providing treatment rather than the converse, if doctors fail to determine the patient's wishes regarding a procedure that is otherwise routine, then they may be vulnerable to the charge of paternalism. It cannot be assumed that all patients will either desire or reject attempts to resuscitate them, and indeed, given that the default mechanism within a medical institution is to proceed with CPR, it could be argued that

many might expect it. For the medical practitioner to decide unilaterally against providing an expected treatment, or to inform the patient that they may not be resuscitated should they experience cardiopulmonary failure—to fail to elicit or consider the patient's views—may constitute a breach of trust, and is not consonant with the priority placed upon patient autonomy.

In addition, in the immediate circumstances that arise following the arrest of a patient, the 1995 CA also fails to provide adequate directives for those other than the "medical practitioner," a category which legally excludes those most often first on the scene of a cardiac arrest, namely, nursing practitioners. Without explicit instruction as to their responsibilities in the absence of either a directive from the patient, or the medical practitioner, nurses remain in an invidious position, legally and morally vulnerable. Neither is it clear as to the appropriate course of action for the nurse at hand when the patient has expressed a wish to nursing staff, but this has not been ratified or approved of by the medical practitioner.

Another aim of the 1995 CA was to further the "patient's right to self determination" (SADH Explanatory Document, p. 1), an aim that promotes the patient's autonomy as fundamental. Following this rationale, two documents were created and disseminated. These were both intended to allow the patient to "determine" what treatment might be carried out upon them when they were no longer able to consent to such treatment, namely when they were incompetent. Schedule 1 is designed to enable the patient either to appoint a representative (or Medical Agent) to make decisions on their behalf if they are incapable of so doing. Schedule 2 allows patients to document their advance decisions, through written Advance Directives that stipulate what treatment options they desire when they are not able to voice decisions or preferences. The implication behind both these documents would seem to be that patient autonomy, and the patient's desires should determine treatment in these circumstances, whether in the guise of representation from their appointed Medical Agent or through Advance Directives.

The first point I wish to make with respect to these Schedules is that they constitute these decisions made at the end of life as a legal process. The documents are couched in legalese, with language potentially alienating or confusing for the non-expert—patients and their families. As they refer to future events, they require that the patient (or their representative)

understand and cover in the documents all possible medical eventualities that may arise at the end of life. Whether patients and representatives will always do so is at least questionable, and the presence of a document in instances unforeseen may increase, rather than decrease, the potential for confusion and dissent over what the patient's "real" wishes might have been. In addition, completing the Schedules correctly may not be necessarily straightforward for patients and relatives, necessitating obtaining signatures from a "JP, solicitor, clergy" or other worthy individuals.

Even when comprehensively completed, the Schedules are still subject to many of the problems mentioned above. What if the wishes expressed according to either Schedule (via patient directly in Schedule 2, or more indirectly in Schedule 1) conflict with the recommendations of the medical practitioner? What are obligations of the medical practitioner with regard to consultation about the possibility of, and practices involved with CPR? In addition to the understanding that the competent patient has the right to determine their own treatment, s.13(3) of the 1995 CA states that when the medical practitioner is aware that the patient has appointed a medical agent who is at hand "medical treatment may not be administered without the agent's consent," which would seem to shift both rights and responsibilities for decision making away from the medical practitioner. Again, whether or not this includes the right of the patient or their representative to request life-sustaining measures is a matter yet to be clarified.[266] Although the intent of the Act was to authorise medical practitioners to limit "futile" treatment, and the common-law position "probably" supports this view, legal advice regarding this states that at least one interpretation of the Act does not support that position, with the possibility that to do so may "give rise to civil liability and may constitute a criminal offence" ([266] section 5, p. 12).

The further question arises, what if the patient does not utilise either Schedule 1 or 2? In such circumstances, the edicts of the Guardianship and Administration Act, 1993[265] (1993 GA) apply. In the first instance, a patient may have appointed an Enduring Guardian who is then empowered to make decisions for that patient if they lose mental capacity. If, however, the patient has not taken any legal steps to direct their future medical treatment, s.59(1) of the GA directs that "the appropriate authority" can give consent in circumstances where it is proposed to "give medical … treatment." This category specifically includes a "relative of the person" (s.59(1)), defined in s.3(1) as including spouse, parent, sibling or child (over

18 years). It appears an oversight that no hierarchy for these relatives is stipulated, presenting a problem in precisely those situations when the consent from other than the patient may be necessary—at critical moments for life and death. Consensus with regard to treatment or no treatment is by no means assured amongst family members. Although the GA stipulates that the matter should be resolved by the Guardianship Board, such an option is not always practical or helpful given the inherent immediacy of response required for CPR.

Although the GA specifically identifies itself as subservient to the terms of the 1995 CA (s.2.b), allowing that the powers of a Medical Agent might supercede those of an Enduring Guardian, other difficulties might arise with regard to the role of the patient's relatives when considering Acts in tandem. The 1995 CA does not specify that the patient's relatives are deemed to be the patient's representative, and therefore whether entitled, according to Section 17(2), to "give express direction to the contrary" regarding cessation of medical treatment. It defines "representative" in s.4 to be those with medical power of attorney "or some other lawful authority" to make decisions. The 1993 GA would seem to include relatives in the category of "other lawful authority," but this conclusion is by no means indisputable ([266] section 3, p. 3). Nonetheless, the 1993 GA s.59(1) asserts that the relative is only empowered to consent to the *giving* (not refusing) of medical treatment. Within such a ruling, the DNR decision not to instigate CPR may not be considered to constitute medical treatment, and thus the relative would not be authorised to make such decision. Alternatively, however, it could be argued that where the DNR decision is part of a palliative plan of treatment, it represents part of the treatment decisions that would need to be authorised by the patient's representative.

To further confuse matters, where the 1993 GA (s.59.1) proclaims the right of the "appropriate authority" (the patient's relative) to consent to the giving of medical treatment, the 1995 CA (s.4) speaks of the "lawful authority to make decisions about the medical treatment" of the incompetent patient, with no distinctions made between giving, withdrawing, or withholding treatment. Thus consultation and consideration of both Acts will not clarify for the medical practitioner precisely what the limits of their own jurisdiction might be when the now incompetent patient has not made their wishes known

and their relatives request treatment options other than those recommended by the medical practitioner, for example, requesting CPR.

Theoretically at least, according to Section 13 of the 1995 CA, the medical practitioner who has no inkling of what the patient might desire in a given situation is empowered to provide "emergency medical treatment" without consent in order to "meet an imminent risk to life or health" (s.13.1.b). The problem for CPR, and DNR orders lie in the difficulty of adequate definitions: CPR is *ipso facto* intended to meet an imminent risk to life or health—whether it is appropriate to attempt to do so is the issue that is not here addressed, and this is potentially a cause for disagreement between interested parties. And again, the status of a medical decision to refrain from initiating such treatment remains unclear.

Despite the intent to clarify the legal situation with regard to CPR, and the authority of the medical practitioner not to provide it for dying patients, the 1995 CA fails to address a number of dilemmas for those deciding on such matters in advance, or attempting to instigate DNR orders. Neither, in circumstances wherein authority has not been given by patients, relatives, or medical practitioners, does it give sufficient guidance for those who may be the probable actors on those decisions, namely nursing staff. Given these deficiencies, establishing credible, consistent, and workable guidelines with respect to CPR is severely compromised, and I now turn briefly to discuss those established by the Royal Adelaide Hospital—the site for the present studies

The Royal Adelaide Hospital (RAH) policy

The following discussion is based upon the Royal Adelaide Hospital Medical Policies and procedures Manual "Guidelines for 'No Cardio-pulmonary Resuscitation Order'"[p] (RAH 2000 CPR Policy) available within the RAH (and reproduced in Appendix A). These guidelines were first available in draft form in July 2000 (the same month that the RAH received legal opinion on the interpretation of the relevant Acts),[266] and reviewed and reissued with no change in August 2002.

[p] Although the RAH uses the term 'No Cardio-pulmonary Resuscitation Orders', I take the term 'Do Not Resuscitate Orders' to be synonymous, and, as it is the term more commonly employed within the literature pertaining to this practice, and used within this dissertation, shall continue to use the latter.

These guidelines were predated by the Royal Adelaide Hospital 1994 Policy Statement, the "Natural Death Act—guidelines for implementing "No Cardiopulmonary Resuscitation' within the hospital" (RAH 1994 CPR Policy). This statement (numbered 6.36(h)) issued in October 1994 was obviously subject to the changes in law given in the 1995 CA, but although under review, it was current hospital policy at the time of the first study. Legally, the tenets of the 1995 CA may be considered to be active at this time (as well as during the latter study), and the ambiguities previously identified were therefore a consideration for those attempting to develop RAH policy on this matter. This presumably prompted the hospital to seek legal clarification in early 2000 regarding the withdrawal or withholding of life-sustaining measures.[266]

There are some similarities between the 1994 and 2000 RAH policy guidelines. Both assert that the purpose or intent of the guidelines is the welfare of the patient—in the latter document, to protect patients from "unnecessary and intrusive interventions." Although such a direction may appear uncontroversial, what constitutes an unnecessary and intrusive intervention is somewhat subjectively determined: For some patients, even when deemed medically futile (or unnecessary according to medical criteria), the provision of CPR may fulfill some symbolic function, indicating that death has been resisted to the very end. Furthermore, intrusive can only refer to something that is unwelcomed, which may not be the case for all patients.

A further point of similarity between the two policy statements is the omission of a definition regarding CPR itself. Although there are a number of different interventions potentially involved in CPR these distinctions are not alluded to within the document, an omission which maintains the pre-eminence, acceptance, and mystique accorded to CPR. Neither does either document contain any statement regarding the default nature of CPR, that (as sanctioned by the 1995 CA, 13.1.b discussed above) CPR is routine hospital policy following cardiac or pulmonary failure in a patient. This again points to the taken for granted status of the CPR procedure within the hospital environment, and the unquestioned imperative to perform CPR constitutes significant difficulties for those seeking to limit its application.

There are a number of significant differences between the two policy documents, some of which I shall here comment on. Unlike the more recent RAH 2000 CPR Policy, the 1994

guidelines explicitly state the importance of a written DNR order in providing "guidance of those staff members most likely to find deceased patients—nursing staff and trainee medical officers." In accordance with the 1995 CA operative at the time, the onus was upon the senior medical officer to make and write the order, although it was stipulated that "medical and nursing members of the team should have the right to have some input into the decision to withhold CPR" (RAH 1994 CPR Policy, Point 5). As a historical record, this attests to the impetus for the development of hospital policy in part deriving from the vulnerability of staff at hand at the time of a patient's arrest. Although the later version also recommends the involvement of "appropriate members of the health care team" and asserts that the final responsibility was that of the "senior attending medical officer" (p.3), any notion of the importance of a DNR order to less senior staff is no longer present.

The 1994 guidelines further differ in that they specify that they are intended to provide "guidelines only" and that the "consultant responsible will still have to use his or her discretion in applying them" (RAH 1994 CPR Policy, p. 1). Perhaps as a result of the increased emphasis on avoiding any assertions of paternalism, and a concomitant increase in bureaucratic and legal restructuring of medical practice, the 2000 version has no mention of the "discretion" of the medical practitioner. Rather it makes substantial reference to "Legal Issues" informing the guidelines established, referring to or quoting from three separate Acts that pertain to the dying patient, and speaking of the "legal duty of care of a medical practitioner to a patient who is dying" (RAH 2000 CPR Policy, p. 3).[q] No legal injunction is mentioned in the earlier document, and "the legal guardian" of a non-competent patient is the only time that a legal aspect to the issue is discussed within it. This further affirms the increasing influence of the legal over the medical, a situation which some have decried as inappropriate, particularly with regard to the care of the dying.

Both guidelines list possible indications for an order to withhold CPR, which in 1994 were

- that there was no specific patient request
- no medical benefit (CPR either prolonging a dying process that would bring death in days or weeks, and/or that "would be bound to be unsuccessful in producing survival to discharge"), or

[q] In fact, the Legal Issues section of the RAH 2000 document constitutes 1½ pages of its 5½ pages, equivalent to the total length of the 1995 document.

- when it would result in a poor quality of life (e.g., a chronic vegetative state) (RAH 1994 CPR Policy, p. 1).

In the later version, the criteria were

- that the patient does not wish for CPR, or
- that it was "medically … deemed that it would be unlikely that cardio-pulmonary resuscitation would restore circulation or spontaneous ventilation" (RAH 2000 CPR Policy, Introductory Information, p. 1).

It is worth noting that 1994 clause mentioning "survival to discharge" is omitted from the 2000 version. Survival to discharge is one of the conditions most cited in discussions regarding the efficacy of CPR in particular populations of patients (including those with terminal cancer), and the statistical information therein contained is often considered the least subjective, and therefore most justifiable grounds upon which to base any decision.

In the 2000 document, as might be expected given the difficulties in interpreting the law regarding these issues, there is some ambiguity regarding situations wherein patient and medical opinion differ. The opening paragraph in the "Legal Issues" section states that the competent adult patient can legally decide whether to accept or refuse medical treatment, and can therefore decide whether CPR should occur. Yet it later cites s.17.2 of the 1995 CA (discussed above) stating that the medical practitioner is not obliged to use life-sustaining measures etc, with no clear indication as to appropriate procedure when the patient requests CPR deemed medically futile. It is thus subject to the same criticisms that may be directed at the current legislation. Similarly, the document provides no clear guidelines for nursing staff when no DNR order exists for a patient for whom CPR might be unlikely to succeed, and as such fails to succeed in the original aim to provide such guidance.

With respect to situations where a patient has not made specific provision or expressed a preference regarding CPR, the 2000 guidelines do not clarify the role of the family in authorisation of DNR orders. Indeed, it states that the purpose of the DNR order is to protect the patient from CPR deemed unlikely to "restore circulation or spontaneous ventilation (and such a view is shared and accepted by the patient's family/surrogate)" (p. 1). This would seem to imply that, even in situations where CPR would be deemed

medically futile, the consent of the family is necessary. In contrast, however, it later states only that it would be "prudent" for medical staff "to discuss any proposed [DNR order] … with the patient's family/surrogate" (p. 2), which does not seem to suggest that either a discussion with, or consent from a patient's family is mandatory.

Beyond these difficulties (arguably contingent upon the aforementioned deficiencies in legislation underpinning RAH policy), a further problematic aspect of the 2000 guidelines lies in the introduction of the term "the patient's family/surrogate." Such a term is mentioned neither in the 1993 GA, nor the 1995 CA, and cannot therefore be deemed to have any legal status. The net effect is thus to further confound the issue of establishing precisely who should have the ultimate responsibility for authorisation of orders to perform or refrain from CPR on a non-competent patient.

Appendix C

Interview Schedule: Study 1

ASSESSING CANCER PATIENTS' VIEWS ON HOW TO FORMULATE POLICY ON END OF LIFE DECISIONS

1. What do you understand by the concept of DNR?
2. What do YOU think patients want to know about a DNR decision?
3. Would the patient want to know of the decision?
4. Do patients always need to be told of a DNR decision? IF NO
5. If not, under what circumstances would it be appropriate not to communicate that information?
6. Also if not, then who should be informed about the decision?
7. If a patient is not capable of making the decision or does not wish to do so, who should make the decision?
8. Should a DNR order be referred to as 'a do not resuscitate' order or 'a good palliative care' order?
9. What do you think patients understand about the difference between the two concepts?
10. When should such orders be discussed?
    Early in the disease?
    When active treatment is clearly having no effect, or
    Only at the time that the treatment is required?
    That is, when the aggressiveness of treatment needs to be defined? eg. When the patient is dying?
11. Who should be involved in decision making, the patient only, the doctor, patient and best friend/partner/spouse, or family?
12. How do you think a DNR decision should be recorded? Should a DNR decision by a patient be a verbal directive (which would be documented in the case notes) or should a written form be developed and completed by the patient or relative?
13. What do you think of the idea of the patient saying what they want before they die? When should this be discussed? Early in the illness? Toward the end? Would it be frightening during active treatment, or even more frightening at the end of active treatment?

Appendix D

Interview Schedule: Study 2, v.1

END OF LIFE ISSUES: ASSESSING THE VIEWS OF PATIENTS WITH CANCER IN THE TERMINAL PHASE OF THEIR ILLNESS

1. What do you understand by 'do-not-resuscitate' orders?
2. Who should make a decision to apply DNR orders?
3. Why would someone make a DNR decision?
4. What would a patient want to know before thinking about a DNR decision?
5. When is the best time to talk about those things (the end of life and DNR orders)?
6. When should we not talk about them?
7. Who should be involved in the decision-making process? (family; medical staff?)
8. Is there ever a time when the patient shouldn't make the DNR decision?
9. If someone makes a DNR decision, what happens then (recording it)?
10. Sometimes people talk of 'good palliative care' orders – what does that mean to you?
11. What sort of difference is there between the two?
12. Do you think people know when they are approaching the end of their life?
13. What do you think about euthanasia?
14. What do you think about 'alternative' treatments for cancer?
15. Tell me about hope?
16. Is there anything else we/doctors should know?
17. Can I just check a few details with you?

Appendix E

Interview Schedule: Study 2, final version

END OF LIFE ISSUES:
ASSESSING THE VIEWS OF PATIENTS WITH CANCER
IN THE FINAL PHASE OF THEIR ILLNESS

1. Can you tell me a little about what has happened for you since your diagnosis?
2. One term that the medicos use is 'do not resuscitate'
    - Have you heard of that?
    - Can you tell me your thoughts on it?
3. Why would someone make a decision not to resuscitate, or to be resuscitated?
4. What things are important in deciding what to do?
5. Do you think it's a good idea to discuss it with somebody else?
    - Who have you discussed it with?
6. When did you first think about these sorts of things?
    - Would you have wanted the doctor to talk to you about it then?
    - Is there ever a time when should we not talk about them?
7. What could a doctor tell the patient to help them to think about a DNR decision?
8. What is the doctor's role in making these sorts of decisions near the end of a patient's life?
9. Who should make a decision to apply DNR orders?
    - Should anyone not make the decision?
10. If someone makes a DNR decision, who should know?
    - How?
11. Sometimes people talk of 'good palliative care' orders – what does that mean to you?
12. What sort of difference is there between the term 'do not resuscitate' orders, and 'good palliative care' orders?

Appendix E cont'd

13. What do you think about 'alternative' treatments for cancer?
    - What types do you mean?
    - How do you see their role in cancer?
14. Have any of your family died in hospital?
    - Of an illness? Of cancer?
    - Can you tell me about it?
15. Do you think that people know when death is near?
16. Some people have mentioned euthanasia?
    - What are your thoughts on that?
17. Tell me about hope?
    - and hoping?
    - What does hope mean for you now?
18. There are just a few demographic details to complete
    - Complete list on form
19. Is there anything else you'd like to say about all this?

Checklist

Definition	Responsibility	Factors
Involved	Doctors' role	Timing
Recording	Awareness	Euthanasia
GPC	Alternative treatments	Hope

Appendix F

Demographic/disease/treatment information form: Study 2

Participant No:

1. Date of Interview
2. Time commenced
3. Time finished
4. Length
5. Present at interview
6. Patient condition
7. Department referral
8. Ward
9. Name
10. Sex
11. Age
12. Date of birth
13. Marital status
14. Currently living (location, with):
15. Religion: Active/passive:
16. Work history: Retired Full/part-time.
17. Birthplace
18. Residency in Australia
19. Highest level of education (number of years of schooling)
20. Primary disease site
21. Date of original diagnosis
22. Current treatment
23. Current DNR order – Red dot alert
24. Current DNR order – wording:
25. Patient died: Date
26. Patient died: Place:

Appendix G

ASSESSING CANCER PATIENTS' VIEWS ON HOW TO FORMULATE POLICY ON END OF LIFE DECISIONS

I. N. Olver and J. S. Blake-Mortimer

STUDY NUMBER ☐☐☐☐

UR NUMBER ☐☐☐☐

SURNAME ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

FIRST NAME ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

DATE OF BIRTH ☐☐-☐☐-☐☐☐☐

SEX (M/F) ☐

RELIGION ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

SITE OF DISEASE

○ Breast ○ Lung ○ Colorectoral ○ Ovary

○ Lymphoma ○ Prostate ○ Other (Specify)

DATE OF ORIGINAL DIAGNOSIS

☐☐-☐☐-☐☐☐☐

STAGE OF DISEASE AT THE PRESENT TIME

○ I ○ II ○ III ○ IV

TREATMENT INTENT

○ Cure ○ Prolong survival ○ Palliation

CURRENT TREATMENT

☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

ASSESSING CANCER PATIENTS' VIEWS ON HOW TO FORMULATE POLICY ON END OF LIFE DECISIONS

I. N. Olver and J. S. Blake-Mortimer

MARITAL STATUS

- ○ Never married
- ○ Married
- ○ Separated or divorced
- ○ Defacto
- ○ Widowed

WORK STATUS

- ○ Full time work
- ○ Part time work
- ○ Voluntary work
- ○ Home duties
- ○ Unemployed
- ○ Student
- ○ Retired
- ○ Other

WHERE WERE YOU BORN?

- ○ Australia
- ○ New Zealand
- ○ United Kingdom and Ireland
- ○ Italy
- ○ Africa
- ○ Asia
- ○ Greece
- ○ Holland
- ○ South America
- ○ Yugoslavia
- ○ Germany
- ○ Poland
- ○ North America
- ○ Other (please specify)

HOW LONG HAVE YOU LIVE IN AUSTRALIA?

- ○ Less than 1 year
- ○ From 1 to 5 years
- ○ From 6 to 10 years
- ○ More than 10 years

WHAT IS THE HIGHEST LEVEL OF EDUCATION THAT YOU HAVE ATTENDED?

- ○ Grade 7 or less
- ○ Some high school
- ○ Year 11 or 12
- ○ TAFE
- ○ University

WHAT IS THE INTENT OF YOUR TREATMENT?

- ○ Cure
- ○ Prolong survival
- ○ Palliation

HAVE ANY OF YOUR FAMILY OR FRIENDS BEEN DIAGNOSED WITH CANCER?

- ○ Mother
- ○ Father
- ○ Daughter
- ○ Son
- ○ Friend
- ○ Uncle
- ○ Aunt
- ○ Niece
- ○ Nephew
- ○ Grandmother
- ○ Grandfather
- ○ None
- ○ Other

Appendix H

PATIENT INFORMATION FORM (Study 1)
TITLE: ASSESSING CANCER PATIENTS' VIEWS ON HOW TO FORMULATE POLICY ON END OF LIFE DECISIONS

INVESTIGATORS:
I.N. Olver and J.S. Blake-Mortimer

This is a study to find out patients' views on how they would like information required to make decisions at the end of life to be presented to them. It will focus on the 'do not resuscitate' decision in the final phase of an illness, that is, a decision to not attempt to restart the heart if it stops which would otherwise be the routine in a hospital setting.

We wish to find out what patients would want to know before making such a decision, who should be involved in the decision and at what stage all this information should be given to a patient.

We are trying to find out this information from patients who have had a diagnosis of cancer but who are not at the stage where they would have to make such decisions. You must understand that you have not been chose because it is thought that this will apply to you, but we are questioning consecutive patients who have been diagnosed with cancer.

If you agree to participate in this trial, Dr Jan Blake-Mortimer a clinical psychologist will interview you to determine your thought on questions of 'do not resuscitate orders'. The interviews will take 1 to 1½ hours and will be recorded on tape so that they can be analysed by a research assistant subsequently. Details including your name, date of birth, ethnic origin, religion, number of dependents and highest educational standard will be recorded as well as details of your type of cancer and its treatment and the intent of treatment. Any prior contact with cancer or prior experiences with friends and relatives with this disease will be recorded. Also you will be asked to complete some standardised questionnaires.

If the interview process causes you any distress the interview will be stopped and follow-up interviews will be conducted to ensure that no issues have arisen from the initial interview which have not been satisfactorily resolved.

If you do not wish to participate in the interview it will not affect any aspect of your care by doctors in this hospital.

All information will be confidential. The results from a series of interviews will be pooled and no individual patient responses will be able to be identified.

If you require any further information about this trial, you may contact the principal investigator Dr Ian Olver, telephone number work 8224 5566, home 8379 1066.

If you have questions about the ethical nature of this study. You may contact Dr Michael James, Chairperson Research Ethics Committee, Royal Adelaide Hospital, work telephone number 8224 5355.

8 October, 1996

Appendix I

PATIENT INFORMATION FORM (Study 2, v.1)
TITLE: END OF LIFE ISSUES:
ASSESSING THE VIEWS OF PATIENTS WITH CANCER
IN THE TERMINAL PHASE OF THEIR ILLNESS

INVESTIGATORS: I.N. Olver and J.A. Eliott

In this study, we want to talk to you to find out your views on important end-of-life issues. We will focus on things like the 'do-not-resuscitate' decision that can be made in the final stage of an illness; that is, a decision not to attempt to restart the heart if it stops, which is otherwise the routine in a medical setting.

We wish to find out things like what you would want to know before making such a decision, who you think should be involved in the decision and when you think these things should be talked about. But you can talk about any issues that you think are important for us to know about the time near the end of life.

If you agree to participate in this program, Jaklin Eliott, a hospital researcher, will interview you to determine your thoughts about these issues. If you wish, a family member or close friend may also be present. The interviews will last as long as you feel comfortable, but usually between half an hour and an hour. We will record the interviews on tape, so that we can analyse them later. Details such as your name, age, religion and marital status, will be recorded as well as details of your type of cancer, and past and present treatment. We will also ask you about any prior contact with cancer, especially within your family.

All information will be confidential, and names will be changed so that you will never be able to be personally identified as having contributed to this program. If you do not wish to be interviewed, it will not affect any aspect of your care by medical staff.

If the interview process causes you distress at any stage, the interview will be stopped, and follow-up interviews by a clinical psychologist will be available to ensure that no issues have arisen that have not been satisfactorily resolved. This service will also be available to you even if the interview was not stopped, should you so request.

If you require any further information about this program, you may contact the principal investigator, Dr. Ian Olver: telephone number (work) 82245577; (home) 8379 1066. If you have any questions about the ethical nature of this study, you may contact Dr. Michael James, Chair of Research Ethics Committee on 82225761.

Appendix J

PATIENT INFORMATION FORM (Study 2, v.2)

TITLE: END OF LIFE ISSUES: ASSESSING THE VIEWS OF PATIENTS WITH CANCER IN THE FINAL PHASE OF THEIR ILLNESS

INVESTIGATORS: I.N. Olver and J.A. Eliott

In this study, we want to talk to you to find out your views on important end-of-life issues. We will focus on things like the 'do-not-resuscitate' decision that can be made in the final stage of an illness; that is, a decision not to attempt to restart the heart if it stops, which is otherwise the routine in a medical setting.

We wish to find out things like what you would want to know before making such a decision, who you think should be involved in the decision and when you think these things should be talked about. But you can talk about any issues that you think are important for us to know about the time near the end of life.

If you agree to participate in this program, Jaklin Eliott, a hospital researcher, will interview you to determine your thoughts about these issues. If you wish, a family member or close friend may also be present. The interviews will last as long as you feel comfortable, but usually between half an hour and an hour. We will record the interviews on tape, so that we can analyse them later. Details such as your name, age, religion and marital status, will be recorded as well as details of your type of cancer, and past and present treatment. We will also ask you about any prior contact with cancer, especially within your family.

All information will be confidential, and names will be changed so that you will never be able to be personally identified as having contributed to this program. If you do not wish to be interviewed, it will not affect any aspect of your care by medical staff.

If the interview process causes you distress at any stage, the interview will be stopped, and follow-up interviews by a clinical psychologist will be available to ensure that no issues have arisen that have not been satisfactorily resolved. This service will also be available to you even if the interview was not stopped, should you so request.

If you require any further information about this program, you may contact the principal investigator, Dr. Ian Olver: telephone number (work) 82245577; (home) 8379 1066. If you have any questions about the ethical nature of this study, you may contact Dr. Michael James, Chair of Research Ethics Committee on 82225761.

Appendix K

CONSENT FORM (Study 1)
TITLE: ASSESSING CANCER PATIENTS' VIEWS ON HOW TO FORMULATE POLICY ON END OF LIFE DECISIONS.

INVESTIGATORS:
I.N. OLVER
J.S. BLAKE-MORTIMER

1. The nature and purpose of the research project has been explained to me. I understand it, and agree to take part.

2. I understand that I may not directly benefit from taking part in the trial.

3. I understand that, while information gained during the study may be published, I will not be identified and my personal results will remain confidential.

4. I understand that I can withdraw from the study at any stage and that this will not affect my medical care, now or in the future.

5. I have not been a volunteer in any other research projects which have involved radiation exposure in the last twelve months.

6. I have had the opportunity to discuss taking part in this investigation with a family member or friend.

Name of Subject .....

Signed .....

Dated.....

Signed .....

I certify that I have explained the study to the patient/volunteer and consider that he/she understands what is involved.

Signed .....
(investigator)

Appendix L

PATIENT CONSENT FORM (Study 2, v.1)

TITLE: END OF LIFE ISSUES: ASSESSING THE VIEWS OF PATIENTS WITH CANCER IN THE TERMINAL PHASE OF THEIR ILLNESS

INVESTIGATORS: I.N. Olver and J.A. Eliott

1. The nature and purpose of the research project has been explained to me. I understand it, and agree to take part.

2. I understand that I may not directly benefit from taking part in this program.

3. I understand that I will be interviewed and this interview will be recorded on audio-tape.

4. I understand that, while information gained during the project may be published, I will not be identified, and anything I said will remain confidential.

5. I understand that I can withdraw from the project at any stage, and that this will not affect my medical care, now or in the future.

6. I have had the opportunity to discuss taking part in this investigation with a family member, or a close friend.

Your name (please print).....

Signature.....

Date.....

Appendix M

PATIENT CONSENT FORM (Study 2, v.2)

TITLE: END OF LIFE ISSUES: ASSESSING THE VIEWS OF PATIENTS WITH CANCER IN THE FINAL PHASE OF THEIR ILLNESS

INVESTIGATORS: I.N. Olver and J.A. Eliott

1. The nature and purpose of the research project has been explained to me. I understand it, and agree to take part.

2. I understand that I may not directly benefit from taking part in this program.

3. I understand that I will be interviewed and this interview will be recorded on audio-tape.

4. I understand that, while information gained during the project may be published, I will not be identified, and anything I said will remain confidential.

5. I understand that I can withdraw from the project at any stage, and that this will not affect my medical care, now or in the future.

6. I have had the opportunity to discuss taking part in this investigation with a family member, or a close friend.

Your name (please print).....

Signature.....

Date.....

Appendix N

Alternative arguments re-presented by 51 patients with cancer and 21 family or friends in interviews focused on the DNR decision

Patient should make the decision	Patient does not have to make the decision
Patients except cognitively compromised people make decisions	Patients except emotionally unstable people make the decision
Patients can decide what they like, even if it has consequences for others	Patients should consider the economic and emotional consequences of the decision on others
Patients should make the decision early before they are mentally incompetent	Patients should make the decision as late as possible so they consider everything
Patients should decide in advance what they want so everyone knows	Patients should not decide in advance because they might change their mind
Patients should make decisions rationally	Patients can decide what they like even if it is irrational
A patient's decision is always the right one	A patient's decision can be wrong
The best decision is what the patient want	The best decision is dictated by medical fact
The DNR decision is basically personal	The DNR decision is basically medical
Patients will not get resuscitate if they do not want to	Patients will get resuscitated if they want to
Doctors should ask patients what they want	Doctors should not ask patients what they want
Doctors should prioritise patient autonomy and ask about CPR	Doctors should prioritise a patient's hope and not ask about CPR
A patient's refusal to make the decision means they want to be resuscitated	A patient's refusal to make the decision means they want others to make the decision
CPR is about your heart	CPR prevents brain death
CPR is a violent intervention in natural death	CPR is an appropriate resistance to death
Cardiac arrest has nothing to do with my disease and should be reversed	Cardiac arrest says that it is time to die and should not be interfered with
CPR in the dying is morally reprehensible	CPR shows the moral worth of all parties

Appendix N cont'd

Alternative arguments re-presented by 51 patients with cancer and 21 family or friends in interviews focused on the DNR decision, con'td

Not wanting to live on a machine means you do not want CPR	Not wanting to live on a machine means give CPR a try, but then stop
CPR will stop the patient dying and that's good	CPR will stop the patient dying and that's bad
Dying is part of life and should be accepted	Dying represents failure and should be resisted
DNR orders represent an active choice to die, and medicine achieves this	DNR orders represent the limits of medical intervention and acknowledgement of the inevitability of death
Patients who are incurable, for whom death is inevitable, are at that stage and should not receive CPR	I am incurable, death is inevitable, but I am not at that stage, and I want CPR
If the patient does not decide, the family should	If the patient does not decide, the doctor should
Patients should not burden the family with the decision	Family should take on the decision if the patient wants them to
Family are appropriate surrogate decision-makers because they care about the patient	Family are not appropriate decision-makers because they care about the patient
Doctors are appropriate surrogate decision-makers because they know the patient's medical circumstances	Doctors are appropriate surrogate decision-makers because they know what the patient wants
Doctors should make the DNR decision	Doctors should not make the DNR decision
Doctors can be trusted with the DNR decision	Doctors cannot be trusted with the DNR decision

Appendix O: Advance Care Plan

(including resuscitation status)

Unit Record No:

Surname:

Given Names:

Date of Birth:

Advance Care Plan (including resuscitation status)

MR 0.30

It is accepted practice under appropriate circumstances† to withhold or withdraw aspects of medical treatment. A competent adult patient is entitled to withhold or withdraw consent for any treatment at any time, even if this may shorten their life. Patients may have completed one of a range of advance directives while they were competent and then subsequently lost capacity to make their own decisions. Where the person has completed an Anticipatory Direction, this guides treatment decisions when the patient becomes incompetent. If the person has appointed a legal representative (a Medical Agent or an Enduring Guardian) or the Guardianship Board has appointed a legal Guardian, the relevant clinical staff should seek agreement to treatment decisions from this person when the patient has lost capacity.

If none of these exist, as is commonly the case, agreement should be between the relevant clinical staff and relatives, carers or friends deemed the most appropriate to represent the patient. Details of the progression of the discussions and rationale for any decisions should be recorded in this plan. The overriding principle is to act in the best interests of the patient and to try to do what the patient would have wished, had they been competent.

Where a competent patient indicates they do not wish to discuss withholding or withdrawing aspects of treatment, such as in certain palliative care and advanced chronic disease circumstances, and relatives, carers or friends are unavailable for discussion, a plan may be made with respect to withholding or withdrawing aspects of treatment. The rationale underlying this plan must be recorded together with a description of the extent of medical treatment to be offered.

The extent of medical treatment that is to be offered, including comfort care measures and any treatment that is to be withheld or withdrawn, needs to be recorded on the Advance Care Plan in a clear and unambiguous manner*. The focus should be on respect for the dignity and comfort of the patient as well as support and care for their relatives, carers or friends. It should be noted that the use of medication for the control of patient symptoms in this setting is appropriate, even if this may shorten life. All aspects of treatment to be withheld or withdrawn must be discussed and agreed upon by the parties listed in this Advance Care Plan.

If the patient is in the Intensive Care Unit, the relevant orders to enact these measures must be made by the Intensive Care Consultant on duty [see over page (3)]. When a patient is transferred elsewhere from the Intensive Care Unit after aspects of treatment have been withdrawn, the measures that are or are not to be undertaken must be clearly documented in the discharge summary. Communication with the home clinic medical team needs to occur to ensure that the team understands and accepts the plan. A member of the Intensive Care Unit caring team should hand-over and introduce any available relatives, carers or friends of the patient to the new caring team.

† The "Statement on Withholding and Withdrawing Treatment" of the Australian & New Zealand Intensive Care Society and the Joint Faculty of Intensive Care Medicine provide a synopsis of the principles underlying this document.

* Descriptive examples are provided in the '*Guidelines for an Advance Care Plan*' found in the Clinical Practice Manual on the RAH IntraNet. These guidelines are informed by the Statement on Withdrawing and Withholding Treatment, Consent to Medical Treatment and Palliative Care Act 1995 and Guardianship and Administration Act 1993.

The following information from the agreeing parties is required. Discussion and agreement should occur and be obtained in the sequence listed below to ensure that there is medical and nursing consensus before patients and their representatives are approached.

Before proceeding, determine if any of the following are in place as these take legal precedent (refer Guidelines):

Anticipatory Direction Y / N Medical Agent Y / N
Enduring Guardian Y / N Guardian appointed by Guardianship Board Y / N
Copy placed within the patients medical record Y / N

REQUIRED DETAILS:

(1) A senior medical representative (consultant or registrar/advanced trainee) from the 'home' medical clinic.
Print name: ..... Signature: .....
Date/time: .....
Details of contact:.....
.....
.....

DESIRABLE DETAILS: where appropriate - refer local processes or procedure

(2) The registered nurse responsible for the ward in consultation with the nurse(s) assigned to the care of the patient.
NB. This is to document nursing concurrence and witness that appropriate discussions have involved the patient and/or guardian/relatives/carers/friends and that the nurses involved understand and accept the plan.
Print name: ..... Signature:.....
Date/time: .....

(3) The Intensive Care medical consultant on duty who is responsible for the clinical care of the patient, has had discussions with the relevant medical and nursing staff and the patient and/or guardian/relatives/carers/friends and is cognisant that they understand and accept all aspects of the plan to withhold or withdraw aspects of treatment.
Print name: ..... Signature:.....
Date/time: .....

(4) A second Intensive Care medical consultant to confirm that the plan is appropriate.
Print name: ..... Signature:.....
Date/time: .....

NB. For patients in Intensive Care (2), (3) and (4) must be completed.

(5) The patient, whenever possible, or an agreed spokesperson for the guardians, relatives, carers or friends of the patient whoever is deemed most appropriate.
NB. This is to acknowledge that discussions with staff have involved the patient and/or guardians/relatives/carers/friends and that they understand and accept the plan.
Print name: ..... *Signature (optional):* .....
Date/time: .....
Relationship with patient:.....
.....

Record details of the Advance Care Plan on the following Advance Care Plan Continuation Sheet. Any changes or revisions to the plan also need to be recorded here.

Advance Care Plan

(including resuscitation status)

Continuation Sheet

Unit Record No:
Surname:
Given Names:
Date of Birth:

Please record details* of the Advance Care Plan here following agreement from all parties:

* Descriptive examples are provided in the '*Guidelines for an Advance Care Plan*' found in the Clinical Practice Manual on the RAH IntraNet.

289

Advance Care Plan – Continuation Sheet

MR 0.31

References

1. Burns, J. P., Edwards, J., Johnson, J., Cassem, N. H. & Truog, R. D. Do-not-resuscitate order after 25 years. *Crit Care Med* **31**, 1543-50 (2003).
2. Ebell, M. H., Doukas, D. J. & Smith, M. A. The do-not-resuscitate order: a comparison of physician and patient preferences and decision-making. *Am J Med* **91**, 255-60 (1991).
3. Miles, S., Cranford, R. & Schultz, A. The do-not-resuscitate order in a teaching hospital: consideration and a suggested policy. *Ann Intern Med* **96**, 660-4 (1982).
4. Sulmasy, D. P., Geller, G., Faden, R. & Levine, D. M. The quality of mercy: caring for patients with 'Do Not Resuscitate' orders. *JAMA* **267**, 682-6 (1992).
5. Bains, J. From reviving the living to raising the dead: the making of cardiac resuscitation. *Soc Sci Med* **47**, 1341-9 (1998).
6. Rabkin, M. T., Gillerman, G. & Rice, M. R. Orders not to resuscitate. *N Engl J Med* **295**, 364-6 (1976).
7. Scofield, G. R. Is consent useful when resuscitation isn't? in *Life choices: a Hastings Center introduction to bioethics.* (eds. Howell, J. H. & Sale, W. F.) (Georgetown University Press, Washington, D.C., 1995).
8. Niemann, J. T. Cardiopulmonary resuscitation. *N Engl J Med* **327**, 1075-80 (1992).
9. Hayward, M. Cardiopulmonary resuscitation: Are practitioners being realistic? *Brit J Nursing* **8**, 810-4 (1999).
10. Kouwenhoven, W. B., Jude, J. R. & Knickerbocker, G. G. Closed-chest cardiac massage. *JAMA* **173**, 1064-7 (1960).
11. Elam, J. O. The development of cardiac resuscitation: 1963 classical article. *Int Anesthesiol Clin* **37**, 87-117 (1999).
12. Lo, B. Unanswered questions about DNR orders. *JAMA* **265**, 1874-5 (1991).
13. Schulz, L. Not for resuscitation: two decades of challenge for nursing ethics and practice. *Nurs Ethics* **4**, 227-38 (1997).
14. Blackhall, L. Must we always use CPR? *N Engl J Med* **317**, 1281-5 (1987).
15. Montelibano, L. Cardiopulmonary resuscitation and medical ethics [Abstract]. *J La State Med Soc* **152**, 642-8 (2000).
16. Nolan, K. In death's shadow: the meanings of withholding resuscitation, in *Life choices: A Hastings Center introduction to bioethics.* (eds. Howell, J. H. & Sale, W. F.) (Georgetown University Press, Washington, DC, 1995).
17. Stanley, D. P. & Reid, D. P. Withholding cardiopulmonary resuscitation: one hospital's policy. *Med J Aust* **151**, 257, 260-2 (1989).

18. Bedell, S. E., Delbanco, H. L., Cook, F. & Epstein, F. H. Survival after cardiopulmonary resuscitation in hospital. *N Engl J Med* **309**, 569-73 (1983).
19. Brown, C. Limiting care: Is CPR for everyone? *ACCN Clin Issues Crit Care Nurs* **1**, 161-8 (1990).
20. Faber-Langendoen, K. Resuscitation of patients with metastatic cancer. Is transient benefit still futile? *Arch Intern Med* **151**, 235-9 (1991).
21. Haines, I. E., Zalcberg, J. & Buchanan, J. D. Not-for-resuscitation orders in cancer patients--principles of decision-making. *Med J Aust* **153**, 225-9 (1990).
22. Johnson, A. L. Towards a modified cardiopulmonary resuscitation policy. *Can J Cardiol* **14**, 203-8 (1998).
23. Peatfield, R. C., Sillett, R. W., Taylor, D. & McNicol, M. W. Survival after cardiac arrest in hospital. *Lancet* **1**, 1223-5 (1977).
24. Bjork, R. J., Snyder, B. D., Campion, B. C. & Loewenson, R. B. Medical complications of cardiopulmonary arrest. *Arch Intern Med* **142**, 500-3 (1982).
25. Youngner, S. J. Futility in context. *JAMA* **264**, 1295-6 (1990).
26. Luce, J. M. Special article: Physicians do not have a responsibility to provide futile or unreasonable care if a patient or family insists. *Crit Care Med* **23**, 760-6 (1995).
27. Symmers, W. S., Sr. Not allowed to die. *BMJ* **1**, 442 (1968).
28. Weiss, G. L. & Hite, C. A. The do-not-resuscitate decision: the context, process, and consequences of DNR orders. *Death Stud* **24**, 307-23 (2000).
29. Baskett, P. J. F. Ethics in cardiopulmonary resuscitation. *Resuscitation* **25**, 1-8 (1993).
30. Marik, P. E. & Zaloga, G. P. Case report: CPR in terminally ill patients? *Resuscitation* **49**, 99-103 (2001).
31. Davies, J. M. & Reynolds, B. M. The ethics of cardiopulmonary resuscitation. 1. Background to decision making. *Arch Dis Child* **67**, 1498-501 (1992).
32. Ditillo, B. A. Should there be a choice for cardiopulmonary resuscitation when death is expected? Revisiting an old idea whose time is yet to come. *J Pall Med* **5**, 107-16 (2002).
33. Baker, R. The legitimation and regulation of DNR orders, in *Legislating medical ethics: a study of the New York State's do not resuscitate law.* (eds. Baker, R. & Strosberg, M. A.) (Kluwer Academic, Boston, 1995).
34. Emergency Cardiac Care Committee and Subcommittees, A. H. A. Guidelines for cardiopulmonary resuscitation and emergency cardiac care, VIII: Ethical considerations in resuscitation. *JAMA* **268**, 2282-8 (1992).

35. Dodds, S. Choice and control in feminist bioethics, in *Relational autonomy: Feminist perspectives on autonomy, agency, and the social self.* (eds. Mackenzie, C. & Stoljar, N.) (Oxford University Press, New York, 2000).
36. Jonsen, A. R. *The birth of bioethics*. (Oxford, New York, 1998).
37. Schneider, C. E. *The practice of autonomy: patients, doctors, and medical decisions*. (Oxford University Press, New York, 1998).
38. Kerridge, I., Pearson, S. A., Rolfe, I. E. & Lowe, J. Decision making in CPR: attitudes of hospital patients and healthcare professionals. *Med J Aust* **169**, 128-31 (1998).
39. McClung, J. A. & Kamer, R. S. Implications of New York's do-not-resuscitate law. *N Engl J Med* **323**, 270-2 (1990).
40. Sharp, J. Q. & Frederick, B. J. Developing do not resuscitate policies. *J Nurs Adm* **19**, 25-9 (1989).
41. Tomlinson, T. & Brody, H. Ethics and communication in do-not-resuscitate orders. *N Engl J Med* **318**, 43-6 (1988).
42. Biegler, P., Stewart, C., Savulescu, J. & Skene, L. Determining the validity of advance directives. *Med J Aust* **172**, 545-8 (2000).
43. Norton, S. A. & Talerico, K. A. Facilitating end-of-life decision-making: strategies for communicating and assessing. *J Gerontol Nurs* **26**, 6-13 (2000).
44. Doyal, L. & Wilsher, D. Withholding CPR: proposals for formal guidelines. *BMJ* **306**, 1593-6 (1993).
45. Aarons, E. J. & Beeching, N. F. Do not resuscitate orders: use and abuse. *Crit Care Ill* **8**, 265-8 (1992).
46. Biegler, P. Should patient consent be required to write a do not resuscitate order? *J Med Ethics* **29**, 359-63 (2003).
47. Handley, A. J. Editorial: Do not resuscitate. *Heart* **86**, 1-2 (2001).
48. Ott, B. B. & Neiswiadomy, R. M. Support of patient autonomy in the do-not-resuscitate decision. *Heart Lung* **20**, 66-72 (1991).
49. Nyman, D. J. & Sprung, C. L. End-of-life decision making in the intensive care unit. *Intensive Care Med* **26**, 1414-20 (2000).
50. Manias, E. Australian nurses' experiences and attitudes in the 'do not resuscitate' decision. *Res Nurs Health* **21**, 429-41 (1998).
51. Lofmark, R. & Nilstun, T. Do-not-resuscitate orders—should the patient be informed? *J Intern Med* **241**, 421-5 (1997).
52. Dwyer, T. & Williams, L. M. Nurses' behaviour regarding CPR and the theories of reasoned action and planned behaviour. *Resuscitation* **52**, 85-90 (2002).

53. Aaron, E. J. & Beeching, N. J. Survey of 'do not resuscitate' orders in a district general hospital. *BMJ* **303**, 1504-6 (1991).

54. Headley, J. A. The DNR decision—Part II: ethical principles and application. *Dimens Oncol Nurs* **5**, 34-7 (1991).

55. Pearlman, R. A., Miles, S. H. & Arnold, R. M. Contributions of empirical research to medical ethics. *Theor Med* **14**, 197-210 (1993).

56. Perry, S. W., Schwartz, H. I. & Amchin, J. Determining resuscitation status: a survey of medical professionals. *Gen Hosp Psychiatry* **8**, 198-202 (1986).

57. Hackler, J. C. & Hiller, F. C. Family consent to orders not to resuscitate: reconsidering hospital policy. *JAMA* **264**, 1281-3 (1990).

58. Torda, T. A. & Gerber, P. To resuscitate or not to resuscitate, that is the question. *Med J Aust* **151**, 243-5 (1989).

59. Brett, A. S. & McCullough, L. B. When patients request specific interventions: defining the limits of the physician's obligation. *N Engl J Med* **315**, 1347-51 (1986).

60. DiVitto, S. Giving hope, she found hope. *Reflect Nurs Leadersh* **28**, 21 (2002).

61. Mello, M. & Jenkinson, C. Comparison of medical and nursing attitudes to resuscitation and patient autonomy between a British and an American teaching hospital. *Soc Sci Med* **46**, 15-24 (1998).

62. Asch, D. A., Hansen-Flaschen, J. & Lanken, P. N. Decisions to limit or continue life-sustaining treatment by critical care physicians in the United States: conflicts between physicians' practices and patients' wishes. *Am J Respir Crit Care Med* **151**, 288-92 (1995).

63. Farber, N. J., Bowman, S. M., Major, D. A. & Green, W. P. Cardiopulmonary resuscitation: patient factors and decision making. *Arch Intern Med* **144**, 2229-32 (1984).

64. Kelly, W. F., Eliasson, M. D., Stocker, D. J. & Hnatiuk, O. W. Do specialists differ on do-not-resuscitate decisions? *Chest* **121**, 957-63 (2002).

65. Lipton, H. L. Physicians' do-not-resuscitate decisions and documentation in a community hospital. *QRB Qual Rev Bull* **15**, 108-13 (1989).

66. Owen, C., Tennant, C., Levi, J. & Jones, M. Resuscitation in cancer. Comparison of patient and health staff preferences. *Gen Hosp Psychiatry* **16**, 277-85 (1994).

67. Ventres, W., Nichter, M., Reed, R. & Frankel, R. Limitation of medical care: an ethnographic analysis. *J Clin Ethics* **4**, 134-45 (1993).

68. Vincent, J. L. Forgoing life support in Western Europe intensive care units: the results of an ethical questionnaire. *Crit Care Med* **27**, 1686-7 (1999).

69. Watcher, R. M., Luce, J. M., Hearst, N. & Lo, B. Decisions about resuscitation: inequities among patients with different diseases but similar prognoses. *Ann Intern Med* **111**, 525-32 (1989).

70. van der Heide, A., Vrakking, A., van Delden, H., Looman, C. & van der Maas, P. Medical and nonmedical determinants of decision making about potentially life-prolonging interventions. *Med Decis Making* **24**, 518-24 (2004).

71. Wenger, N. S. et al. Epidemiology of do-not-resuscitate orders. Disparity by age, diagnosis, gender, race, and functional impairment. *Arch Intern Med* **155**, 2056-62 (1995).

72. Ventres, W., Nichter, M., Reed, R. & Frankel, R. Do-not-resuscitate discussions: a qualitative analysis. *Fam Pract Res J* **12**, 157-69 (1992).

73. Kerridge, I. H., Pearson, S. A., Rolfe, I. E., Lowe, M. & McPhee, J. R. Impact of written information on knowledge and preferences for cardiopulmonary resuscitation. *Med J Aust* **171**, 239-42 (1999).

74. Miller, D. L., Gorbien, M. J., Simbartl, L. A. & Jahnigen, D. W. Factors influencing physicians in recommending in-hospital cardiopulmonary resuscitation. *Arch Intern Med* **153**, 199-203 (1993).

75. Beach, M. C. & Morrison, R. S. The effect of do-not-resuscitate orders on physician decision-making. *J Am Geriatr Soc* **50**, 2057-61 (2002).

76. Evans, A. & Brody, B. The do-not-resuscitate order in teaching hospitals. *JAMA* **253**, 2236-9 (1985).

77. La Puma, J., Silverstein, M., Stocking, C., Roland, D. & Siegler, M. Life-sustaining treatment: a prospective study of patients with DNR orders in a teaching hospital. *Arch Intern Med* **148**, 2193-8 (1988).

78. Resnick, L., Cowart, M. E. & Kubrin, A. Perceptions of do-not-resuscitate orders. *Soc Work Health Care* **26**, 1-21 (1998).

79. Youngner, S. Do-not-resuscitate orders: no longer secret, but still a problem. *Hastings Center Rep* **17**, 24-33 (1987).

80. Sanders, A. B. When are resuscitation attempts futile? *Acad Emerg Med* **4**, 852-3 (1997).

81. Schneiderman, L. J., Jecker, N. S. & Jonsen, A. Medical futility: its meaning and ethical implications. *Ann Intern Med* **112**, 949-54 (1990).

82. Bruce-Jones, P. N. Resuscitation decisions in the elderly: a discussion of current thinking. *J Med Ethics* **22**, 286-91 (1996).

83. Marchette, L. et al. Nurses' perceptions of the support of patient autonomy in do-not-resuscitate (DNR) decisions. *Int J Nurs Stud* **30**, 37-49 (1993).

84. Emanuel, E. J. & Emanuel, L. L. Four models of the physician-patient relationship. *JAMA* **267**, 2221-6 (1992).

85. Cook, D. Patient autonomy versus parentalism. *Crit Care Med* **29**, 24-5 (2001).

86. Wallace, K., Ewer, M. S., Price, K. J. & Feeley, T. W. Outcome and cost implications of cardiopulmonary resuscitation in the medical intensive care unit of a comprehensive cancer center. *Support Care Cancer* **10**, 425-9 (2001).

87. Teno, J. M. et al. Preferences for cardiopulmonary resuscitation: physician-patient agreement and hospital resource use. The SUPPORT Investigators. *J Gen Intern Med* **10**, 179-86 (1995).

88. Chambers, C. V., Diamond, J. J., Perkel, R. L. & Lasch, L. A. Relationship of advance directives to hospital charges in a Medicare population. *Arch Intern Med* **154**, 541-7 (1994).

89. Gillick, M. The high costs of dying. *Arch Intern Med* **154**, 2134-7 (1994).

90. Bock, K. R., Teres, D. & Rapoport, J. Economic implications of the timing of do-not-resuscitate orders for ICU patients. *New Horiz* **5**, 51-5 (New Horiz).

91. Rapoport, J., Teres, D. & Lemeshow, S. Resource use implications of do not resuscitate orders for intensive care unit patients. *Am J Respir Crit Care Med* **153**, 185-90 (1996).

92. Edwards, B. S. Does the DNR patient belong in the ICU? *Crit Care Nurs Clin North Am* **2**, 473-80 (1990).

93. Hardwig, J. Is there a duty to die? in *Life choices: A Hastings Center introduction to bioethics.* (eds. Howell, J. H. & Sale, W. F.) (Georgetown University Press, Washington, DC, 1995).

94. Lo, B. *Resolving ethical dilemmas: a guide for clinicians.* (Williams & Wilkins, Baltimore, 1995).

95. Reust, C. E. & Mattingly, S. Family involvement in medical decision making. *Fam Med* **28**, 39-45 (1996).

96. Campbell, M. L. & Frank, R. R. Experience with end of life practice at a university hospital. *Crit Care Med* **25**, 197-202 (1997).

97. Kerridge, I. H., Pearson, S., Rolfe, I. E. & Lowe, M. Letters to the editor: in reply. *Med J Aust* **170**, 45-6 (1999).

98. Marco, C. A., Bessman, E. S., Schoenfeld, C. N. & Kelen, G. D. Ethical issues of cardiopulmonary resuscitation: current practice among emergency physicians. *Acad Emerg Med* **49**, 898-904 (1997).

99. Ashby, M. & Maddocks, I. Not for (cardio-pulmonary) resuscitation and palliative care: a gentler way forward? Paper presented at the 1st Bioethics Meeting (Sydney, Australia, 1990).

100. Pacheco, R., Osuna, E., Gomez-Zapata, M. & Luna, A. Medicolegal problems associated with do not resuscitate orders. *Med Law* **13**, 461-6 (1994).

101. Richter, J., Eisemann, M., Bauer, B. & Kreibeck, H. Decisions and attitudes in treatment of incompetent, chronically ill, aged patients: a comparison between nurses and physicians: Why does no one ask the nurse? [Abstract]. *Z Gerontol Geriatr* **32**, 131-9 (1999).

102. Barnes, D. J. No-CPR orders in a teaching hospital. *Aust N Z J Med* **27**, 708 (1997).

103. Enderlin, A. & Wilhite, M. J. Establishing incidence and administrative protocols for do not resuscitate orders. *J Gerontol Nurs* **17**, 12-6 (1991).

104. Fields, F. R. & McKenna, J. T. Practical guidelines for action regarding application of CPR/DNR. *Death Stud* **12**, 319-28 (1988).

105. Gordon, M. & Schwartz, B. E. Do-not-resuscitate practice, guidelines and policies in long term care in Ontario: results of a survey. *Ann R Coll Physicians Surg Can* **14**, 332-5 (1996).

106. Middlewood, S., Gardner, G. & Gardner, A. Dying in hospital: medical failure or natural outcome? *J Pain Symptom Manage* **22**, 1035-41 (2001).

107. Webster, G. C., Mazer, C. D., Potvin, C. A., Fisher, A. & Byrick, R. J. Evaluation of a do not resuscitate' policy in intensive care. *Can J Anaesth* **38**, 553-63 (1991).

108. Williams, R. The 'do not resuscitate' decision: guidelines for policy in the adult. *J R Coll Physicians Lond* **27**, 139-40 (1993).

109. Zimmerman, J. E. et al. The use and implications of do not resuscitate orders in intensive care units. *JAMA* **255**, 351-6 (1986).

110. Back, A. R., Arnold, R. & Quill, T. Hope for the best, and prepare for the worst. *Ann Intern Med* **138**, 439-44 (2003).

111. Blustein, J. The family in medical decisionmaking, in *Life choices: A Hastings Center introduction to bioethics.* (eds. Howell, J. H. & Sale, W. F.) (Georgetown University Press, Washington, DC, 1995).

112. Brock, D. W. What is the moral basis of the authority of family members to act as surrogates for incompetent patients? *J Clin Ethics* **3**, 121-3 (1992).

113. Loewy, E. H. Patient, family, physician: agreement, disagreement, and resolution. *Fam Med* **18**, 375-8 (1986).

114. Mappes, T. A. & Zembaty, J. S. Patient choices, family interests, and physician obligations. *Kennedy Inst Ethics J* **4**, 27-46 (1994).

115. Bailey, S. Decision making in health care: limitations of the substituted judgement principle. *Nurs Ethics* **9**, 483-93 (2002).

116. Rhoden, N. Litigating life and death. *Harv Law Rev* **102**, 375-446 (1988).

117. Nelson, H. L. & Nelson, J. L. *The patient in the family: an ethics of medicine and families*. (Routledge, New York, 1995).

118. Hardwig, J. What about the family? in *Life choices: a Hastings Center introduction to bioethics.* (eds. Howell, J. H. & Sale, W. F.) (Georgetown University Press, Washington, DC, 1995).

119. Council on Ethical and Judicial Affairs, American Medical Association. Decisions near the end of life. *JAMA* **267**, 2229-33 (1992).

120. Cassell, E. J. The changing concept of the ideal physician. *Daedalus* **15**, 185-208 (1986).

121. Drought, T. S. & Koenig, B. A. "Choice" in end-of-life decision making: researching fact or fiction. *Gerontologist* **42**, 114-28 (2002).

122. Beauchamp, T. L. & Childress, J. F. *Principles of biomedical ethics*. (Oxford, New York, 1994).

123. Donchin, A. Autonomy and interdependence: quandaries in genetic decision making, in *Relational autonomy: feminist perspectives on autonomy, agency, and the social self.* (eds. Mackenzie, C. & Stoljar, N.) (Oxford University Press, New York, 2000).

124. Howell, J. H. & Sale, W. F. Foreword to Part II: Biomedicine, rights, and responsibilities, in *Life choices: a Hastings Center introduction to bioethics.* (eds. Howell, J. H. & Sale, W. F.) (Georgetown University Press, Washington, D.C., 1995).

125. Wolpe, P. R. The triumph of autonomy in American medical ethics, in *Bioethics and society: sociological investigations of the enterprise of bioethics.* (eds. DeVries, R. & Subedi, H.) (Prentice-Hall, New York, 1998).

126. Gattellari, M., Butow, P. N. & Tattersall, M. H. N. Sharing decisions in cancer care. *Soc Sci Med* **52**, 1865-78 (2001).

127. Lewins, F. *Bioethics for health professionals: an introduction and critical approach*. (MacMillan Education Australia, South Melbourne, 1996).

128. Ankeny, R. A., Clifford, R., Jordens, C. F. C., Kerridge, I. H. & Benson, R. Religious perspectives on withdrawal of treatment from patients with multiple organ failure. *Med J Aust* **183**, 616-21 (2005).

129. Mackenzie, C. & Stoljar, N. Introduction: autonomy refigured, in *Relational autonomy: feminist perspectives on autonomy, agency, and the social self.* (eds. Mackenzie, C. & Stoljar, N.) (Oxford University Press, New York, 2000).

130. Hill Jr, T. E. The importance of autonomy, in *Women and moral theory.* (eds. Kittay, E. F. & Meyers, D. T.) (Rowan & Littlefield, USA, 1987).

131. Meyers, D. T. The socialized individual and individual autonomy: an intersection between philosophy and psychology, in *Women and moral theory.* (eds. Kittay, E. F. & Meyers, D. T.) (Rowan & Littlefield, USA, 1987).

132. Sherwin, S. A relational approach to autonomy in health-care, in *The politics of women's health: exploring agency and autonomy.* (ed. Sherwin, S.) (Temple University Press, Philadelphia, 1998).

133. Young, R. *Personal autonomy.* (Croom Helm, London, 1986).

134. Rainbolt, G. W. Prescription drugs laws: justified hard paternalism. *Bioethics* **3**, 45-58 (1989).

135. Hardwig, J. SUPPORT and the invisible family. *Hastings Center Rep* **25**, S23-5 (1995).

136. Schneider, C. E. From consumer choice to consumer welfare. *Hastings Center Report* **25**, S25-8 (1995).

137. Janis, I. L. The patient as decision maker, in *Handbook of behavioral medicine.* (ed. Gentry, W. D.) (Guilford Press, New York, 1984).

138. Savulescu, J. & Momeyer, R. W. Should informed consent be based on rational beliefs? *J Med Ethics* **23**, 282-8 (1997).

139. Simon, H. A. Alternative visions of rationality, in *Rationality in action: contemporary approaches.* (ed. Moser, P. K.) (Cambridge University Press, Cambridge, 1990).

140. Fan, R. Self-determination vs. family-determination: two incommensurable principles of autonomy. *Bioethics* **11**, 309-22 (1997).

141. Pang, M. C. Protective truthfulness: the Chinese way of safeguarding patients in informed treatment decisions. *J Med Ethics* **25**, 247-53 (1999).

142. Friedman, M. Autonomy, social disruption, and women, in *Relational autonomy: feminist perspectives on autonomy, agency, and the social self.* (eds. Mackenzie, C. & Stoljar, N.) (Oxford University Press, New York, 2000).

143. Barnes, B. *Understanding agency: social theory and responsible action.* (Sage, London, 2000).

144. Tversky, A. & Kahneman, D. Judgment under uncertainty: heuristics and biases. *Science* **185**, 1124-30 (1974).

145. Tversky, A. & Kahneman, D. The framing of decisions and the psychology of choice. *Science* **211**, 453-8 (1981).

146. Nisbett, R. & Ross, L. *Human inference: strategies and shortcomings of social judgment.* (Prentice-Hall, Englewood Cliffs, N.J., 1980).

147. Janis, I. L. & Mann, L. *Decision making: a psychological analysis of conflict, choice, and commitment.* (Free Press, New York, 1977).

148. Dawes, R. M. *Rational choice in an uncertain world.* (Harcourt Brace Jovanovich, New York, 1988).

149. Marta, J. Whose consent is it anyway? A Poststructuralist framing of the person in medical decision-making. *Theor Med Bioeth* **19**, 353-70 (1998).

150. Gergen, K. J. *An invitation to social construction.* (Sage, London, 1999).

151. Gergen, K. J. *The saturated self: dilemmas of identity in contemporary life.* (Basic Books, New York, 1991).

152. Lupton, D. *The emotional self.* (Sage, London, 1998).

153. Askehave, I. If language are a game—these are the rules: a search into the rhetoric of the spiritual self-help book If life is a game—these are the rules. *Discourse Society* **15**, 5-31 (2004).

154. Russell, J. A. & Lemay, G. Emotion concepts, in *Handbook of emotions.* (eds. Lewis, M. & Haviland-Jones, J. M.) (The Guilford Press, London, 2000).

155. Berghmans, R. L. P. & Widdershoven, G. A. M. Ethical perspectives on decision-making capacity and consent for treatment and research. *Med Law* **22**, 391-400 (2003).

156. Frank, G. et al. A discourse of relationships in bioethics: patient autonomy and end-of-life decision making among elderly Korean Americans. *Med Anthrop Q* **12**, 403-23 (1998).

157. Silverman, H. The role of emotions in decisional competence. *J Clin Ethics* **8**, 171-5 (1992).

158. Pritchard, R. S. et al. Influence of patient preferences and local health system characteristics on the place of death. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Risks and Outcomes of Treatment. *J Am Geriatr Soc* **46**, 1242-59 (1998).

159. Evans, D. A., Block, M. R., Steinberg, E. R. & Penrose, A. M. Frames and heuristics in doctor-patient discourse. *Soc Sci Med* **22**, 1027-34 (1986).

160. Kleinman, A. *The illness narrative: suffering, healing, and the human condition.* (Basic Books, New York, 1988).

161. Kleinman, A. *Patients and healers in the context of culture: an exploration of the borderland between anthropology, medicine, and psychiatry*. (University of California Press, Berkeley, 1980).

162. Allen-Burge, R. & Haley, W. E. Individual differences and surrogate medical decisions: differing preferences for life-sustaining treatments. *Aging Ment Health* **1**, 121-31 (1997).

163. Gillon, E. Editorial: resuscitation policies—action required. *J Med Ethics* **18**, 115-6 (1992).

164. Jorden, C., Little, M., Kerridge, I. & McPhee, J. From advance directives to advance care planning: current legal status, ethical rationales and a new research agenda. *Intern Med J* **35**, 563-6 (2005).

165. Dresser, R. S. Life, death, and incompetent patients: conceptual infirmities and hidden values in the law. *Ariz Law Rev* **28**, 373-405 (1986).

166. Dresser, R. S. Relitigating life and death. *Ohio State Law J* **51**, 426-37 (1990).

167. Forrow, L. The Green Eggs and Ham phenomena. *Hastings Center Rep* **24**, S29-32 (1994).

168. Moreno, J. D. Who's to choose? Surrogate decisionmaking in New York State. *Hastings Centre Rep* **23**, 5-11 (1993).

169. Finlay, I. Ethical decision-making in palliative care: the clinical reality, in *Facing death: an interdisciplinary approach.* (eds. Badham, P. & Ballard, P.) (University of Wales Press, Cardiff, 1996).

170. Teno, J. et al. Advance directives for seriously ill hospitalized patients: effectiveness with the patient self-determination act and the SUPPORT intervention. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. *J Am Geriat Soc* **45**, 500-7 (1997).

171. Teres, D. Trends from the United States with end-of-life decisions in the intensive care unit. *Intensive Care Med* **19**, 316-22 (1993).

172. Tulsky, J. A., Chesney, M. A. & Lo, B. How do medical residents discuss resuscitation with patients? *J Gen Intern Med* **10**, 436-42 (1995).

173. Braddock, C. H., Edwards, K. A., Hasenberg, N. M., Laidley, T. L. & Levinson, W. Informed decision making in outpatient practice: time to get back to basics. *JAMA* **282**, 2313-20 (1999).

174. Christakis, N. A. *Death foretold: prophecy and prognosis in medical care.* (University of Chicago Press, Chicago, 1999).

175. Christakis, N. A. The ellipsis of prognosis in modern medical thought. *Soc Sci Med* **44**, 301-15 (1997).

176. Gordon, E. J. & Daugherty, C. K. 'Hitting you over the head': oncologists' disclosure of prognosis to advanced cancer patients. *Bioethics* **17**, 142-68 (2003).

177. Kodish, E. & Post, S. G. Oncology and hope. *J Clin Oncol* **13**, 1817-22 (1995).

178. Ryan, C. J. Matters of life and death: the challenge of CPR decision making: How can we improve patient involvement in this complex process? *Med J Aust* **169**, 124-5 (1998).

179. The, A. M., Hak, T., Koeter, G. & van Der Wal, G. Collusion in doctor-patient communication about imminent death: an ethnographic study. *BMJ* **321**, 1376-81 (2000).

180. Imbus, S. & Zawacki, B. Autonomy for burned patients when survival is unprecedented. *N Engl J Med* **297**, 308-11 (1977).

181. Buckman, R. Breaking bad news: Why is it still so difficult? *BMJ* **288**, 1597-9 (1984).

182. Calam, B., Far, S. & Andrew, R. Discussions of "code status" on a family practice teaching ward: What barriers do family physicians face? *CMAJ* **163**, 1255-9 (2000).

183. Bedell, S., Pelle, D., Maher, P. & Cleary, P. Do-not-resuscitate orders for critically ill patients in the hospital: How are they used and what is their impact? *JAMA* **256**, 233-7 (1986).

184. Kerridge, I., Myser, C., Mitchell, K. R. & Hamblin, J. Guidelines for no-CPR orders. *Med J Aust* **161**, 270-2 (1994).

185. Misbin, R. I., O'Hare, D., Ledgerbeg, M. S. & Holland, J. C. Compliance with New York State's law at Memorial Sloan-Kettering Cancer Center: a review of patient deaths. *NY State J Med* **93**, 165-8 (1993).

186. Hardin, S. B. & Yusufaly, Y. A. Difficult end-of-life treatment decisions: Do other factors trump advance directives? *Arch Intern Med* **164**, 1531-3 (2004).

187. SUPPORT Principal Investigators. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). The SUPPORT Principal Investigators. *JAMA* **274**, 1591-8 (1995).

188. Vincent, J. L. Information in the ICU: Are we being honest with our patients? The results of a European questionnaire. *Intensive Care Med* **24**, 1251-6 (1998).

189. Seckler, A. B., Meier, D. E., Mulvihill, M. & Paris, B. E. Substituted judgment: How accurate are proxy predictions? *Ann Intern Med* **115**, 92-8 (1991).

190. Uhlmann, R. R., Pearlman, R. A. & Cain, K. C. Physicians' and spouses' predictions of elderly patients' resuscitation preferences. *J Gerontol* **43**, 115-21 (1988).

191. Wenger, N. S. et al. Physician understanding of patient resuscitation preferences: insights and clinical implications. *J Am Geriatric Soc* **48**, S44-51 (2000).

192. Hackim, R. B. et al. Factors associated with do-not-resuscitate orders: patients' preferences, prognoses, and physicians' judgments. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. *Ann Intern Med* **125**, 284-93 (1996).

193. Hofman, J. C. et al. Patient preferences for communication with physicians about end-of-life decisions. *Ann Intern Med* **127**, 1-12 (1997).

194. Moskowitz, E. H. & Nelson, J. L. Dying well in hospital: the lessons of SUPPORT. *Hasting Cent Rep* **SS25**, S3-6 (1995).

195. Phillips, R. S. et al. Choices of seriously ill patients about cardiopulmonary resuscitation: correlates and outcomes. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. *Am J Med* **100**, 128-37 (1996).

196. Pfeifer, M. P., Mitchell, C. K. & Chamberlain, L. The value of disease severity in predicting patient readiness to address end-of-life issues. *Arch Intern Med* **163**, 609-12 (2003).

197. Sayers, G. M., Schofield, I. & Aziz, M. An analysis of CPR decision-making by elderly patients. *J Med Ethics* **23**, 207-12 (1997).

198. Clemency, M. V. & Thompson, N. J. Do not resuscitate orders in the perioperative period: patient perspectives. *Anesth Analg* **84**, 859-64 (1997).

199. Schade, S. G. & Muslin, H. Do not resuscitate decisions: discussions with patients. *J Med Ethics* **15**, 186-90 (1989).

200. Blackhall, L. J. et al. Ethnicity and attitudes towards life sustaining technology. *Soc Sci Med* **48**, 1779-89 (1999).

201. Fallowfield, L. J. Editorial: participation of patients in decisions about treatment for cancer. *BMJ* **323**, 1144 (2001).

202. Fried, T. R. & Bradley, E. H. What matters to seriously ill older persons making end-of-life treatment decisions? A qualitative study. *J Pall Med* **6**, 237-44 (2003).

203. Hiltunen, E. F., Medich, C., Chase, S., Peterson, L. & Forrow, L. Family decision making for end-of-life treatment: the SUPPORT nurse narratives. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. *J Clin Ethics* **10**, 126-34 (1999).

204. Potter, J. M., Stewart, D. & Duncan, G. Living wills: Would sick people change their mind? *Postgrad Med J* **70**, 818-20 (1994).

205. Schonwetter, R. S., Teasdale, T. A., Taffet, G., Robinson, B. E. & Luchi, R. J. Educating the elderly: cardiopulmonary resuscitation decisions before and after intervention. *J Am Geriatr Soc* **39**, 372-7 (1991).

206. Schonwetter, R. S., Walker, R. M., Kramer, D. R. & Robinson, B. E. Resuscitation decision-making in the elderly: the value of outcome data. *J Gen Intern Med* **8**, 295-300 (1993).

207. Gattelari, M., Butow, P., Tattersall, M. H., Dunn, S. M. & MacLeod, C. A. Misunderstanding in cancer patients: Why shoot the messenger? *Ann Oncol* **10**, 39-46 (1999).

208. Stephens, R. Do not resuscitate orders: ensuring the patient's participation. *JAMA* **255**, 240-1 (1986).

209. Ley, P., Bradshaw, P. W., Kincey, J. & Atherton, S. T. A method for increasing patients' recall of information presented to them. *Psychol Med* **3**, 217-20 (1973).

210. McNamara, B. A good enough death? in *Health matters: a sociology of illness, prevention and care.* (eds. Petersen, A. & Waddell, C.) (Allen & Unwin, St. Leonards, 1998).

211. Strull, W. M., Lo, B. & Charles, G. Do patients want to participate in medical decision making? *JAMA* **252**, 2990-4 (1984).

212. Ende, J., Kazis, L., Ash, A. & Moskowitz, M. A. Measuring patients' desire for autonomy: decision making and information-seeking preferences among medical patients. *J Gen Intern Med* **4**, 23-30 (1989).

213. Stiggelbout, A. M. & Kiebert, G. M. A role for the sick role. patient preferences regarding information and participation in clinical decision-making. *CMAJ* **157**, 383-9 (1997).

214. Beaver, K., Luker, K. A., Owens, R. G., Leinster, S. J. & Degner, L. F. Treatment decision making in women newly diagnosed with breast cancer. *Cancer Nurs* **19**, 8-19 (1996).

215. Blanchard, C. G., Labrecque, M. S., Ruckdeschel, J. C. & Blanchard, E. B. Information and decision-making preferences of hospitalized adult cancer patients. *Soc Sci Med* **27**, 1139-45 (1988).

216. Butow, P. N., Maclean, M., Dunn, S. M., Tattersall, M. H. N. & Boyer, M. J. The dynamics of change: cancer patients' preferences for information, involvement and support. *Ann Oncol* **8**, 857-63 (1997).

217. Cassileth, B. R., Zupkis, R. V., Sutton-Smith, K. & March, V. Information and participation preferences among cancer patients. *Ann Intern Med* **92**, 832-6 (1980).

218. Degner, L. F. & Sloan, J. A. Decision making during serious illness: What role do patients really want to play. *J Clin Epidemiol* **45**, 941-50 (1992).

219. Puchalski, C. M. et al. Patients who want their family and physician to make resuscitation decisions for them: observations from SUPPORT and HELP. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. Hospitalized Elderly Longitudinal Project. *J Am Geriatr Soc* **48**, S84-90 (2000).

220. Hare, J., Pratt, C. & Nelson, C. Agreement between patients and their self-selected surrogates on difficult medical decisions. *Arch Intern Med* **152**, 1049-54 (1992).

221. Sehgal, A. et al. How strictly do dialysis patients want their advance directives followed? *JAMA* **267**, 59-63 (1992).

222. Terry, P. B. et al. End-of-life decision making: when patients and surrogates disagree. *J Clin Ethics* **10**, 286-93 (1999).

223. Blackhall, L. J., Murphy, S. T., Frank, G., Michel, V. & Azen, S. Ethnicity and attitudes towards patient autonomy. *JAMA* **274**, 820-5 (1995).

224. Goldstein, D., Thewes, B. & Butow, P. Communicating in a multicultural society. II: Greek community attitudes towards cancer in Australia. *Intern Med J* **32**, 289-96 (2002).

225. Hoshino, K. Bioethics in the light of Japanese sentiments, in *Japanese and Western bioethics* (ed. Hoshino, K.) (Kluwer Academic, Dordrecht, 1996).

226. Huang, X., Butow, P., Meiser, B. & Goldstein, D. Attitudes and information needs of Chinese migrant cancer patients and their relatives. *Aust N Z J Med* **29**, 207-13 (1999).

227. Lapine, A. et al. When cultures clash: physician, patient, and family wishes in truth disclosure for dying patients. *J Pall Med* **4**, 475-80 (2001).

228. Matsumara, S. et al. Acculturation of attitudes toward end-of-life care: a cross-cultural survey of Japanese Americans and Japanese. *J Gen Intern Med* **17**, 531-9 (2002).

229. Saillant, F. Discourse, knowledge and experience of cancer: a life story. *Cult Med Psychiatry* **14**, 81-104 (1990).

230. Mead, G. E. et al. What factors influence patient preferences regarding cardiopulmonary resuscitation? *J R Coll Physicians Lond* **29**, 295-8 (1995).

231. Singer, P. A., Martin, D. K. & Kelner, M. Quality end-of-life care: patients' perspectives. *JAMA* **281**, 163-8 (1999).

232. Steinhauser, K. E. et al. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA* **284**, 2476-92 (2000).

233. Teno, J. M. et al. Do advance directives provide instructions that direct care? SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. *J Am Geriatr Soc* **45**, 508-12 (1997).

234. Emanuel, E. J. & Emanuel, L. L. Proxy decision making for incompetent patients: an ethical and empirical analysis. *JAMA* **267**, 2067-71 (1992).

235. Alpers, A. & Lo, B. Avoiding family feuds: responding to surrogate demands for life-sustaining interventions. *J Law Med Ethics* **27**, 74-80 (1999).

236. Winzelberg, G. S., Hanson, L. C. & Tulsky, J. A. Beyond autonomy: diversifying end-of-life decision-making approaches to sere patients and families. *J Am Geriatr Soc* **53**, 1046-50 (2005).

237. Thomasma, D. C. & Pellegrino, E. D. The role of the family and physicians in decisions for incompetent patients. *Theor Med* **8**, 283-92 (1987).

238. Allen, F. S. & Shuster, J. L. The role of proxies in treatment decisions: evaluating functional capacity to consent to end-of-life treatments within a family context. *Behave Sci Law* **20**, 235-52 (2002).

239. Gubrium, J. F. & Holstein, J. A. *What is family?* (Mayfield, Mountain View, CA, 1990).

240. Bramstedt, K. A. Ethics in medicine: questioning the decision-making capacity of surrogates. *Intern Med J* **33**, 257-9 (2003).

241. Moore, C. D., Sparr, J., Sherman, S. & Avery, L. Surrogate decision-making: judgment standard preferences of older adults. *Soc Work Health Care* **37**, 1-16 (2003).

242. Lo, B. End-of-life care after termination of SUPPORT. *Hastings Center Rep* **25**, S6-8 (1995).

243. Buchanan, A. & Brock, D. W. *Deciding for others: the ethics of surrogate decision making*. (Cambridge University Press, Cambridge, 1989).

244. Blatt, L. Working with families in reaching end of life discussions. *Clin Nurse Spec* **13**, 219-23 (1999).

245. Welie, J. V. Living wills and substituted judgments: a critical analysis [Abstract]. *Med Health Care Philos* **4**, 169-83 (2001).

246. Ditto, P. H. et al. Advance directives as acts of communication: a randomized controlled trial. *Arch Intern Med* **161**, 421-30 (2001).

247. Marbella AM, Desbiens NA, Mueller-Rizner N & PM., L. Surrogates' agreement with patients' resuscitation preferences: effect of age, relationship, and SUPPORT

intervention. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. *J Crit Care* **13**, 140-5 (1998).

248. Sulmasy, D. P. et al. The accuracy of substituted judgments in patients with terminal diagnoses. *Ann Intern Med* **128**, 621-9 (1998).

249. Layde, P. M. et al. Surrogates' predictions of seriously ill patients' resuscitation preferences. *Arch Fam Med* **4**, 518-23 (1995).

250. Nelson, H. L. & Nelson, J. L. Preferences and other moral sources. *Hastings Center Rep* **25**, S19-21 (1994).

251. Harris, J. Consent and end of life decisions. *J Med Ethics* **29**, 10-5 (2003).

252. Lowe, J. & Kerridge, I. Implementation of guidelines for No-CPR orders by a general medicine unit in a teaching hospital. *Aust N Z J Med* **27**, 379-83 (1997).

253. Stoffell, B. & Lewis, S. Advance directives in South Australian law. *Aust Health Law Bull* **8**, 129-37 (2000).

254. Eburn, M. Withdrawing, withholding and refusing emergency resuscitation. *J Med Law* **2**, 131-46 (1994).

255. Kerridge, I., Lowe, M. & McPhee, J. *Ethics and the law for the health professions*. (The Federation Press, Sydney, 2005).

256. Clifford, C. A., Jolley, D. J. & Giles, G. G. Where people die in Victoria. *Med J Aust* **155**, 446-51, 456 (1991).

257. Hunt, R., Bond, M. J., Groth, R. K. & King, P. M. Place of death in South Australia. Patterns from 1910 to 1987. *Med J Aust* **155**, 549-53 (1991).

258. Hunt, R., Bonett, A. & Roder, D. Trends in the terminal care of cancer patients: South Australia 1981-1990. *Aust N Z J Med* **23**, 245-51 (1993).

259. Hunt, R. W., Fazekas, B. S., Luke, C. G. & Roder, D. M. Where patients with cancer die in South Australia, 1990-1999: a population based review. *Med J Aust* **175**, 526-9 (2001).

260. Maddocks, I. 'Good Palliative Care' Orders. *Palliat Med* **7**, 35-7 (1993).

261. Alemayehu, E. et al. Variability in physicians' decisions on caring for chronically ill elderly patients: an international study. *Can Med Assoc J* **144**, 133-8 (1991).

262. Taylor, D. M., Ugoni, A. M., Cameron, P. A. & NcNeil, J. J. Advance directives and emergency department patients: ownership rates and perceptions of use. *Intern Med J* **33**, 586-92 (2003).

263. Ashby, M. A., Kellehear, A. & Stoffell, B. Resolving conflict in end-of-life care: We need to acknowledge the inevitability of death to have some choice in the manner of our dying. *Med J Aust* **183**, 230-1 (2005).

264. Consent to Medical Treatment and Palliative Care Act 1995. South Australian Parliament, No. 26 of 1995 (Adelaide, South Australia, 1995).

265. Guardian and Administration Act 1993. South Australian Parliament, No. 61 of 1993 (Adelaide, South Australia, 1993).

266. Stratford, D. Letter. Opinion: in re: the Consent to Medical Treatment and Palliative Care Act 1995. Dated 13 July 2000 (Jeffcott Chambers, Adelaide, 2000).

267. Deegan, V. Report on Sentinel Event Panel showing audit of documentation of 'not for resuscitation' orders. Internal memorandum: Advance Care Plan. Dated 12 September 2005 (Central Northern Adelaide Health Service, Adelaide, SA, 2005).

268. Misbin, R. I. Do-not-resuscitate orders. *J Fla Med Assoc* **77**, 901-3 (1990).

269. Brown, M. The law and practice associated with advance directives in Canada and Australia: similarities, differences and debate. *J Law Med* **11**, 59-76 (2003).

270. Eliott, J. & Olver, I. Perceptions of 'Good palliative care' orders: a discursive study of cancer patients' comments. *J Pall Med* **19**, 100-6 (2003).

271. Owen, C., Tennant, C., Levi, J. & Jones, M. Resuscitation: patient and staff attitudes in the context of cancer. *Gen Hosp Psychiatry* **14**, 327-33 (1992).

272. Henman, M. J., Butow, P. N., Brown, R. F., Boyle, F. & Tattersall, M. H. Lay constructions of decision-making in cancer. *Psychooncology* **11**, 295-306 (2002).

273. Hagerty, R. G. et al. Communicating with realism and hope: incurable cancer patients' views on the disclosure of prognosis. *J Clin Oncol* **23**, 1278-88 (2005).

274. Davey, H. M., Lim, J., Butow, P. N., Barratt, A. L. & Redman, S. Women's preferences for and views on decision-making for diagnostic tests. *Soc Sci Med* **58**, 1699-707 (2004).

275. Clayton, J. M., Butow, P. N. & Tattersall, M. H. N. The needs of terminally ill cancer patients versus those of caregivers for information regarding prognosis and end-of-life issues. *Cancer* **103**, 1957-64 (2005).

276. Clayton, J. M., Butow, P. N. & Tattersall, M. H. When and how to initiate discussions about prognosis and end-of-life issues with terminally ill patients. *J Pain Symptom Manage* **30**, 132-44 (2005).

277. Clayton, J. M., Butow, P. N., Arnold, R. M. & Tattersall, M. H. N. Fostering coping and nurturing hope when discussing the future with terminally ill cancer patients and their caregivers. *Cancer* **103**, 1965-75 (2005).

278. Butow, P. N., Dowsett, S., Hagerty, R. G. & Tattersall, M. H. Communicating prognosis to patients with metastatic disease: What do they really want to know? *Support Care Cancer* **19**, 161-8 (2002).

279. Brown, R. F., Butow, P. N., Ellis, P., Boyle, F. & Tattersall, M. H. Seeking informed consent to cancer clinical trials: describing current practices. *Soc Sci Med* **58**, 2445-57 (2004).

280. Olver, I. N., Turrell, S. J., Olszewski, N. A. & Willson, K. J. Impact of an information and consent form on patients having chemotherapy. *Med J Aust* **162**, 82-3 (1995).

281. Vincent, J. L. Cultural differences in end-of-life care. *Crit Care Med* **29**, N52-5 (2001).

282. Leichtentritt, R. D. & Rettig, K. D. Values underlying end-of-life decisions: a qualitative approach. *Health Soc Work* **26**, 150-9 (2001).

283. Kellehear, A. *Dying of cancer: the final year of life.* (Harwood Academic Publishers, New York, 1990).

284. Callahan, K., Maldonado, N., & Efinger, J. (2003, March). Bridge over troubled waters: end-of-life (EOL) decisions, a qualitative case study. *The Qualitative Report* **8**(1). Retrieved 10 February 2005, from http://www.nova.edu/ssss/QR/QR8-1/callahan.html

285. Miyaji, N. T. The power of compassion: truth-telling among American doctors in the care of dying patients. *Soc Sci Med* **36**, 249-64 (1993).

286. Beach, D. L. Caregiver discourse: perceptions of illness-related dialogue. *Hosp J* **10**, 13-25 (1995).

287. Silverman, D. *Doing qualitative research: a practical handbook.* (Sage, London, 2000).

288. Qualitative Solutions & Research. QSR NUD*IST (Version 4) [Windows]. (Qualitative Solutions & Research, Melbourne, 1997).

289. Borreani, C., Miccinesi, G., Brunelli, C. & Lina, M. An increasing number of qualitative research papers in oncology and palliative care: Does it mean a thorough development of the methodology of research? *Health Qual Life Outcomes* **2**, 7 (2004).

290. Pope, C. & Mays, N. Reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research. *BMJ* **311**, 42-5 (1995).

291. Smith, J. A. Qualitative methodology: analysing participants' perspectives. *Curr Opin Psychiatry* **9**, 417-21 (1996).

292. Willig, C. Introduction: making a difference, in *Applied discourse analysis: social and psychological interventions.* (ed. Willig, C.) (Open University Press, Buckingham, 1999).

293. Burman, E. & Parker, I. Introduction—discourse analysis: the turn to the text, in *Discourse analytic research: repertoires and readings of texts in action.* (eds. Parker, I. & Burman, E.) (Routledge, London, 1993).

294. Potter, J. *Representing reality: discourse, rhetoric and social construction.* (Sage, London, 1996).

295. Potter, J. Discourse analysis and constructionist approaches: theoretical background, in *Handbook of qualitative research methods for psychology and the social sciences.* (ed. Richardson, J. T. E.) (PBS Books, Leicester, 1996).

296. Potter, J. & Wetherell, M. *Discourse and social psychology: beyond attitudes and behaviour.* (Sage, London, 1987).

297. Gergen, K. J. *Realities and relationships: soundings in social construction.* (Harvard University Press, Cambridge, Mass., 1994).

298. Lupton, D. *Medicine as culture: illness, disease and the body in western societies.* (Sage, London, 1994).

299. Parker, I. *Discourse dynamics: critical analysis for social and individual psychology.* (Routledge, London; New York, 1992).

300. Taylor, S. Locating and conducting discourse analytic research, in *Discourse as data: a guide for analysis.* (eds. Wetherell, M., Taylor, S. & Yates, S. J.) (Sage in association with The Open University, London, 2001).

301. Edley, N. Analysing masculinity: interpretative repertoires, ideological dilemmas and subject positions, in *Discourse as data: a guide for analysis.* (eds. Wetherell, M., Taylor, S. & Yates, S. J.) (Sage in association with The Open University, London, 2001).

302. Potter, J. & Wetherell, M. Discourse analysis, in *Rethinking methods in psychology.* (eds. Smith, J. A., Harre, R. & van Langenhove, R.) (Sage, London, 1995).

303. Wetherell, M. Debates in discourse research, in *Discourse theory and practice: a reader.* (eds. Wetherell, M., Taylor, S. & Yates, S. J.) (Sage in association with The Open University, London, 2001).

304. Antaki, C., Billig, M., Edwards, D. & Potter, J. (DAOL, 2003). Discourse analysis means doing analysis: a critique of six analytic shortcomings. *Discourse Analysis Online* **1**. Retrieved 24 July 2004, from http://www.shu.ac.uk/daol/articles/open/2002/002/antaki2002002-paper.html

305. Wetherell, M. Positioning and interpretative repertoires: Conversation Analysis and Post-structuralism in dialogue. *Discourse Soc* **9**, 387-412 (1998).

306. Willig, C. Beyond appearances: a critical realist approach to social constructionist work, in *Social constructionist psychology: a critical analysis of theory and*

practice. (eds. Nightingale, D. J. & Cromby, J.) (Open University Press, Buckingham, UK, 1999).

307. Foucault, M. *The archaeology of knowledge and the discourse on language.* (Pantheon Books, New York, 1972).

308. Prior, L. *The social organisation of death: social medical discourse and social practice in Belfast.* (Macmillan, Basingstoke, 1989).

309. Harré, R. & Davies, B. Positioning: the discursive production of selves. *J Theory Soc Behav* **20**, 43-63 (1990).

310. Willig, C. *Introducing qualitative research in psychology: adventures in theory and method.* (Open University Press, Buckingham, 2001).

311. Schegloff, E. A. 'Whose text? Whose context?' *Discourse Society* **8**, 165-87 (1997).

312. Billig, M. Discursive, rhetorical, and ideological messages, in *Disourse theory and practice: a reader.* (eds. Wetherell, M., Taylor, S. & Yates, S. J.) (Sage in association with The Open University Reader, London, 2001).

313. Riley, S. C. E. Constructions of equality and discrimination in professional men's talk. *Brit J Soc Psych* **41**, 443-61 (2002).

314. Billig, M. et al. *Ideological dilemmas: social psychology of everyday thinking.* (Sage, London, 1988).

315. Stenner, P. Discoursing jealousy, in *Discourse analytic research: repertoires and readings of texts in action.* (eds. Burman, E. & Parker, I.) (Routledge, London, 1993).

316. Lynch, M. From naturally occurring data to naturally organized ordinary activities: comment on Speer. *Discourse Studies* **4**, 531-7 (2002).

317. Potter, J. Two kinds of natural. *Discourse Studies* **4**, 539-42 (2002).

318. Speer, S. A. Transcending the 'natural'/'contrived' distinction: a rejoinder to ten Have, Lynch and Potter. *Discourse Studies* **4**, 538-48 (2002).

319. Potter, J. Discourse analysis and discursive psychology, in *Qualitative research in psychology: expanding perspectives in methodology and design.* (eds. Camic, P. M., Rhodes, J. E. & Yardley, L.) (American Psychological Association, Washington, 2003).

320. Potter, J. Discourse analysis, in *Handbook of data analysis.* (eds. Hardy, M. & Bryman, A.) (Sage, London, 2004).

321. Fontana, A. & Frey, J. H. The interview: from structured questions to negotiated text, in *Handbook of qualitative research.* (eds. Denzin, N. K. & Lincoln, Y. S.) (Sage, Thousand Oaks, CA, 2000).

322. Mishler, E. G. *Research interviewing: context and narrative.* (Harvard University Press, Cambridge, MA, 1986).

323. Gillham, B. *The research interview.* (Continuum, London, 2000).

324. Rice, P. L. & Ezzy, D. *Qualitative research methods: a health focus.* (Oxford University Press, South Melbourne, Victoria, 1999).

325. Grbich, C. *Qualitative research in health: an introduction.* (Allen & Unwin, St Leonards, NSW, 1999).

326. Bernard, H. R. *Research methods in cultural anthropology: Chapts 9 & 10.* (Sage, Newbury Park, CA, 1988).

327. McCracken, G. D. *The long interview.* (Sage, Newbury Park CA, 1988).

328. Bradburn, N. M. Response effects, in *Handbook of survey research.* (eds. Rossi, P. H., Wright, J. D. & Anderson, A. B.) (Academic Press, New York, 1983).

329. Kellehear, A. Ethics and social research, in *Doing fieldwork: eight personal accounts of social research.* (ed. Perry, J.) (Deakin University Press, Geelong, 1989).

330. Crabtree, B. F. & Miller, W. L. A qualitative approach to primary care research: the long interview. *Fam Med* **23**, 145-51 (1991).

331. Seidman, I. E. *Interviewing as qualitative research: a guide for researchers in education and the social sciences.* (Teachers College Press, New York, 1991).

332. Tagg, S. K. Life story interviews and their interpretation, in *The research interview: uses and approaches.* (eds. Brenner, M., Brown, J. & Canter, D.) (Academic Press, New York, 1985).

333. Kellehear, A. Rethinking the survey, in *Health research in practice: political, ethical and methodological issues.* (eds. Colquhoun, D. & Kellehear, A.) (Chapman & Hall, London, 1993).

334. Eliott, J. A. & Olver, I. N. Cancer patients' speech on 'do not resuscitate' decision making: a discourse analytic study. Paper presented at Issues of Rigour in Qualitative Research [Abstract A99] (Association for Qualitative Research, Melbourne, 1999).

335. Eliott, J. A. & Olver, I. N. The discursive properties of 'hope": a qualitative analysis of cancer patients' speech. *Qual Health Res* **12**, 173-93 (2002).

336. Eliott, J. A. & Olver, I. N. End-of-life decision making is more than rational. *Communication in Medicine* **2**, 21-34 (2005).

337. Eliott, J. A. & Olver, I. N. Legitimating do-not-resuscitate orders: a discursive study of cancer patients' speech. *J Pall Care* **6**, 59-68 (2003).

338. Olver, I. N. & Eliott, J. A. Autonomy and end-of-life decision-making. Paper presented at Fifth World Congress of Psycho-Oncology (Wiley, Melbourne, Australia, 1999).

339. Olver, I. N., Eliott, J. A. & Blake-Mortimer, J. Cancer patients' perceptions of do not resuscitate orders. *Psychooncology* **11**, 181-7 (2002).

340. Patton, M. *Qualitative evaluation and research methods*. (Sage, Newbury Park, CA, 1990).

341. Strauss, A. C. J. *Basics of qualitative research: techniques and procedures for developing grounded theory*. (Sage, Thousand Oaks, CA, 1998).

342. Lincoln, Y. S. & Guba, E. G. *Naturalistic inquiry*. (Sage, Newbury Park, CA, 1985).

343. Silverman, D. Analyzing talk and text, in *Handbook of qualitative research.* (eds. Denzin, N. K. & Lincoln, Y. S.) (2000).

344. Kitzinger, C. How to resist an idiom. *Res Lang Soc Interac* **33**, 121-54 (2000).

345. Moir, J. Occupational career choice: accounts and contradictions, in *Discourse analytic research: repertoires and readings of texts in action.* (eds. Burman, E. & Parker, I.) (Routledge, London, 1993).

346. Willig, C. The limitations of trust in intimate relationships: constructions of trust and risk taking. *Brit J Soc Psych* **36**, 211-21 (1997).

347. Charmaz, K. *The social reality of death: death in contemporary America*. (Addison Wesley, Reading, Massachusetts, 1980).

348. Seale, C. Using computers to analyse qualitative data, in *Doing qualitative research: a practical handbook.* (ed. Silverman, D.) (Sage, London, 2000).

349. Qualitative Solutions & Research. QSR N6 (Version 6) [Windows]. (Qualitative Solutions & Research, Melbourne, 2002).

350. Richards, L. *Using N6 in qualitative research*. (QSR International, Doncaster, 2002).

351. QSR International. *N6 Reference Guide*. (QSR International, Doncaster, 2002).

352. Seidel, J. Method and madness in the application of computer technology to qualitative data analysis, in *Using computers in qualitative research.* (eds. Fielding, N. & Lee, R.) (Sage, London, 1991).

353. Wooffitt, R. Researching psychic practitioners: Conversation Analysis, in *Discourse as data: a guide for analysis.* (eds. Wetherell, M., Taylor, S. & Yates, S. J.) (Sage in association with The Open University Press, London, 2001).

354. Burr, V. *Introduction to social constructionism*. (Routledge, London, 1995).

355. Hollway, W. *Subjectivity and method in psychology: gender, meaning, and science.* (Sage Publications, London, 1989).

356. Lincoln, Y. S. & Denzin, N. K. The seventh moment: Out of the past, in *Handbook of qualitative research.* (eds. Denzin, N. K. & Lincoln, Y. S.) (Sage, Thousand Oaks, 2000).

357. Guba, E. G. & Lincoln, Y. S. Competing paradigms in qualitative research, in *Handbook of qualitative research.* (eds. Denzin, N. K. & Lincoln, Y. S.) (Sage, Thousand Oaks, CA, 1994).

358. Parker, I. Qualitative research in psychology: criteria (2003). Retrieved 31 October 2005, from http://www.uel.ac.uk/cnr/documents/Parker.doc

359. Taylor, S. Evaluating and applying analytic research, in *Discourse as data.* (eds. Wetherell, M., Yates, S. J. & Taylor, S.) (Sage in association with The Open University, London, 2001).

360. Lincoln, Y. S. & Guba, E. G. Paradigmatic controversies, contradictions, and emerging confluences, in *Handbook of qualitative research.* (eds. Denzin, N. K. & Lincoln, Y. S.) (Sage, Thousand Oaks, 2000).

361. Seale, C. *The quality of qualitative research.* (Sage, London, 1999).

362. Stiles, W. Evaluating qualitative research. *Evid Based Ment Health* **22**, 99-101 (1999).

363. Seale, C. Changing patterns of death and dying. *Soc Sci Med* **51**, 917-30 (2000).

364. Ratner, C. Solidifying qualitative methodology. *J Soc Distress Homel* **5**, 319-26 (1996).

365. Speer, S. A. & Potter, J. From performatives to practices: Judith Butler, discursive psychology and the management of heterosexist talk, in *Talking gender and sexuality.* (ed. McIlvenny, P.) (John Benjamins, Amsterdam, 2002).

366. Nocera, T. Letters to the editor. *Med J Aust* **170**, 45 (1999).

367. Cassileth, B. R., Zupkis, R. V., Sutton-Smith, K. & March, V. Informed consent—why are its goals imperfectly realized? *N Engl J Med* **302**, 896-900 (1980).

368. Tomlinson, T. & Brody, H. Futility and the ethics of resuscitation. *JAMA* **264**, 1276-80 (1990).

369. Stoffell, B. & Ashby, M. On natural death and palliative care, in *Health care law and ethics.* (ed. Shotton, L.) (Social Sciences Press, Katoomba, NSW, 1997).

370. Ariés, P. *The hour of our death.* (Allen Lane, London, 1981).

371. Davis, S. Towards a conclusion, in *Uncommon ground: toward reinventing nature.* (ed. Cronon, W.) (W.W. Norton, London, 1995).

372. Metcalf, P. & Huntington, R. *Celebrations of death: the anthropology of mortuary ritual.* (Cambridge University Press, Cambridge, 1991).

373. Illich, I. The political uses of natural death, in *Death inside out.* (eds. Steinfel, P. & Veatch, R. M.) (Harper & Row, New York, 1974).

374. Nanda, S. Death from a cross-cultural perspective, in *Death and dying: understanding and care.* (eds. Backer, B. A., Hannon, N. R. & Russell, N. A.) (Delmar Publishing, New York, 1994).

375. Pugh, J. F. The semantics of pain in Indian culture and medicine. *Cult Med Psychiatry* **15**, 19-43 (1992).

376. Bleich, J. D. The obligation to heal in the Judaic tradition, in *Jewish bioethics* (eds. Rosner, F. & Bleich, J. D.) (Hebrew Publishing Company, New York, 1979).

377. Williams, R. *Problems of materialism and culture: selected essays by Raymond Williams.* (Verso, London, 1980).

378. Daston, L. The naturalized female intellect, in *Historical dimensions of psychological discourse.* (eds. Graumann, C. F. & Gergen, K. J.) (Cambridge University Press, Melbourne, 1996).

379. Billig, M. *Arguing and thinking: a rhetorical approach to social psychology.* (Cambridge University Press, Cambridge, 1996).

380. Coward, R. *The whole truth: the myth of alternative health.* (Faber & Faber, London, 1989).

381. Foucault, M. *The birth of the clinic: an archaeology of medical perception.* (Tavistock, London, 1975).

382. Cook, D. J. Transdisciplinary research to understand the rate of bias and heuristics in end of life decision making, in *Death and dying in the ICU.* (eds. Curtis, J. R. & Rubenfeld, G.) (Oxford University Press, New York, 2000).

383. Cordingley, L. & Webb, C. Independence and aging. *Rev Clin Gerontol* **7**, 137-46 (1997).

384. Devine, P. *The ethics of homicide.* (University of Notre Dame, Notre Dame, 1990).

385. Powner, D. J., Ackerman, B. M. & Grenvik, A. Medical diagnosis of death in adults: historical contributions to current controversies. *Lancet* **348**, 1219-23 (1996).

386. Lizza, J. P. Persons and death: What's metaphysically wrong with our current statutory definition of death? *J Med Philos* **18**, 351-74 (1993).

387. Veatch, R. M. Whole-brain, neocortical, and higher brain related concepts, in *Death: beyond whole-brain criteria.* (ed. Azner, R. M.) (Kluwer, Dordrecht, 1988).

388. Brummell, S. Resuscitation in the A & E department: Can concepts of death aid decision making? *Accid Emerg Nurs* **6**, 75-81 (1998).

389. Evans, A. Against brain stem death, in *Principles of health care ethics.* (ed. Gillon, R.) (John Wiley & Sons, Chichester, 1994).

390. Callahan, D. Necessity, futility and the good society. *J Am Geriatr Soc* **42**, 866-7 (1994).

391. Pearlman, R. A. Medical futility: Where do we go from here? *J Am Geriat Soc* **42**, 904-5 (1994).

392. Gillon, R. *Principles of health care ethics*. (John Wiley & Sons, Chichester, 1994).

393. Pearlman, R. A., Patrick, D. L., Uhlmann, R. F. & Cain, K. C. Validity of treatment preferences. *Gerontologist* **32**, 58 (1988).

394. Varma, V. K. Culture, personality and psychotherapy. *Int J Soc Psychiatry* **43**, 142-9 (1988).

395. Kakar, S. *The inner world: a psycho-analytic study of childhood and society in India*. (Oxford University Press, New Delhi, 1978).

396. Gergen, K. J. The social constructionist movement in modern psychology. *Am Psychol* **40**, 266-75 (1985).

397. Miller, B. L. Autonomy and the refusal of life-saving treatment. *Hastings Cent Rep* **11**, 22-9 (1981).

398. Billig, M. Methodology and scholarship in understanding ideological explanation, in *Analysing lay explanation: a case book.* (ed. Antaki, C.) (Sage, London, 1988).

399. Sampson, E. E. Psychology and the American ideal. *J Pers Soc Psychol* **35**, 767-82 (1977).

400. Luttrell, S. Decisions relating to cardiopulmonary resuscitation: commentary 2: some concerns. *J Med Ethics* **27**, 319-20 (2001).

401. Smedira, N. G., Fink, C. & Luce, J. M. Letter to editor. *N Engl J Med* **322**, 1892 (1990).

402. Watt, H. Decisions relating to cardiopulmonary resuscitation: commentary 3: degrading lives? *J Med Ethics* **27**, 321-3 (2001).

403. Cella, D. Quality of life, in *Psycho-oncology* (ed. Holland, J. C.) (Oxford University Press, Oxford, 1998).

404. Olver, I. N. A "highest vale on life" ethic for life or death decision making. PhD thesis submitted to the Philosophy Department, Faculty of Arts (Monash University, Melbourne, 1996).

405. Olver, I. N. *Is death ever preferable to life?* (Kluwer, Dordrecht, the Netherlands, 2002).

406. Sampson, E. E. Deconstructing psychology's subject. *J Mind Behav* **4**, 135-64 (1983).

407. Derrida, J. *Of grammatology.* (John Hopkins University Press, Baltimore, MD, 1976).

408. Taylor, C. The person, in *The category of the person.* (eds. Carrithers, M., Collins, S. & Lukes, S.) (Cambridge University Press, New York, 1985).

409. Hallam, E., Hockey, J. & Howarth, G. *Beyond the body: death and social identity.* (Routledge, London, 1999).

410. Gert, B. *Morality: its nature and justification.* (Oxford University Press, New York, 1998).

411. Grisso, T. & Appelbaum, P. S. Comparison of standards for assessing patients' capacities to make treatment decisions. *Am J Psychiatry* **152**, 1033-7 (1995).

412. Macklin, R. Philosophical conceptions of rationality and psychiatric notions of competency. *Synthese* **57**, 205-224 (1983).

413. The American Heritage® Dictionary of the English Language, 4th ed [Electronic version]. "Rational." (Houghton Mifflin, Boston, 2000). Retrieved 14 August 2003, from http://dictionary.reference.com/search?q=rational

414. Dubler, N. N. & Post, L. F. Truth telling and informed consent, in *Psycho-oncology.* (ed. Holland, J. C.) (Oxford University Press, New York, 1998).

415. Appelbaum, P. S. & Grisso, T. Assessing patients' capacities to consent to treatment. *N Engl J Med* **319**, 1635-8 (1988).

416. Stauch, M. Rationality and the refusal of medical treatment: A critique of the recent approach of the English courts. *J Med Ethics* **21**, 162-5 (1995).

417. Edwards, D. Emotion discourse. *Cult Psychol* **5**, 271-91 (1999).

418. Callahan, S. The role of emotion in ethical decision making, in *Life choices: A Hastings Center introduction to bioethics.* (eds. Howell, J. H. & Sale, W. F.) (Georgetown University Press, Washington, DC, 2000).

419. Roy, R. Beyond ego's domain: emotion, rationality and prajnana. *Psychology and Developing Societies* **11**, 1-24 (1999).

420. Solomon, R. C. The philosophy of emotions, in *Handbook of emotions.* (eds. Lewis, M. & Haviland-Jones, J. M.) (The Guilford Press, London, 2000).

421. Haviland-Jones, J. M. & Kahlbaugh, P. Emotion and identity, in *Handbook of emotions.* (eds. Lewis, M. & Haviland-Jones, J. M.) (The Guilford Press, London, 2000).

422. Johnson-Laird, P. N. & Oatley, K. Cognitive and social construction in emotions, in *Handbook of emotions.* (eds. Lewis, M. & Haviland-Jones, J. M.) (The Guilford Press, London, 2000).

423. Fallowfield, L. J., Jenkins, V. A. & Beveridge, H. A. Truth may hurt but deceit hurts more: communication in palliative care. *Palliat Med* **16**, 297-303 (2002).

424. Schofield, P. E. et al. Psychological responses of patients receiving a diagnosis of cancer. *Ann Oncol* **14**, 48-56 (2003).

425. Good, M. G. D., Good, B. J., Schaffer, C. & Lind, S. E. American oncology and the discourse on hope. *Cult Med Psychiatry* **14**, 59-79 (1990).

426. Brock, D. W. Good decision making for incompetent patients. *Hastings Cent Rep*, S8-11 (1994).

427. High, D. N. Families' roles in advance directives. *Hastings Cent Rep* **24**, S16-8 (1994).

428. Hines, S. C. et al. Improving advance care planning by accommodating family preferences. *J Pall Med* **4**, 481-9 (2001).

429. Costain Schou, K. Awareness contexts and the construction of dying in the cancer treatment settings: 'micro' and 'macro' levels in narrative analysis, in *The sociology of death: theory, culture, practice.* (ed. Clark, D.) (Blackwell, Oxford, 1993).

430. Cotler, M. P. The "do not resuscitate" order; clinical and ethical rationale and implications. *Med Law* **19**, 623-33 (2000).

431. Goldberg, R. J. Disclosure of information to adult cancer patients: issues and updates. *J Clin Oncol* **2**, 948-55 (1984).

432. Pinell, P. How do cancer patients express their points of view? *Sociol Health Illn* **9**, 25-44 (1987).

433. McNamara, B. Dying of cancer, in *Death and dying in Australia.* (ed. Kellehear, A.) (Oxford University Press, Melbourne, 2000).

434. Ballard, P. Intimations of mortality: some sociological considerations, in *Facing death: an interdisciplinary approach.* (eds. Badham, P. & Ballard, P.) (University of Wales Press, Cardiff, 1996).

435. Clark, D. Between hope and acceptance: the medicalisation of dying. *BMJ* **324**, 905-7 (2002).

436. Kellehear, A. & Fook, J. Sociological factors in death denial by the terminally ill. *Adv Behav Med* **34**, 527-37 (1989).

437. Little, M. & Sayers, E. J. While there's life. Hope and the experience of cancer. *Soc Sci Med* **59**, 1329-37 (2004).

438. Russ, A. J. & Kaufman, S. R. Family perceptions of prognosis, silence, and the "suddenness" of death. *Cult Med Psychiatry* **29**, 103-23 (2005).

439. Haraway, D. The biopolitics of postmodern bodies: determinations of self in immune system discourse. *Differences* **1**, 3-43 (1989).

440. Sontag, S. *Illness as metaphor and AIDS and its metaphors*. (Picador USA, New York, 1990).

441. Lemon, J., Edelman, S. & Kidman, A. D. Perceptions of the "mind-cancer" relationship among the public, cancer patients, and oncologists. *J Psychosoc Oncol* **21**, 43-58 (2003).

442. Crawford, R. The boundaries of the self and the unhealthy other: reflections on health, culture and AIDS. *Soc Sci Med* **38**, 1347-65 (1994).

443. McGrath, P. The burden of the 'RA RA' positive: survivors and hospice patients' reflections on maintaining a positive attitude to serious illness. *Support Care Cancer* **12**, 25-33 (2004).

444. Wilkinson, S. & Kitzinger, C. Thinking differently about thinking positive: a discursive approach to cancer patients' talk. *Soc Sci Med* **50**, 797-811 (2000).

445. Irving, L. M., Snyder, C. R. & Crowson, J. J. J. Hope and coping with cancer by college women. *J Pers* **66**, 195-214 (1998).

446. Beste, J. Instilling hope and respecting patient autonomy: reconciling apparently conflicting duties. *Bioethics* **19**, 215-31 (2005).

447. Sullivan, M. D. Hope and hopelessness at the end of life. *Am J Geriatr Psychiatry* **11**, 393-405 (2003).

448. Leydon, G. M. et al. Cancer patients' information needs and information seeking behaviour: in depth interview study. *BMJ* **320**, 909-13 (2000).

449. Sonnenberg, A. Exploring how to tell the truth and preserve hope: Can a balance between communication and empathy be calculated? *Clin Gastroenterol Hepatol* **2**, 518-22 (2004).

450. Begley, A. & Blackwood, B. Truth-telling versus hope: a dilemma in practice. *Int J Nurs Pract* **6**, 26-31 (2000).

451. Billig, M. *Ideology and opinions: studies in rhetorical psychology*. (Sage, London, 1991).

452. Good, G. J. & Good, M. J. D. "Learning medicine": the constructing of medical knowledge at Harvard Medical School, in *Knowledge, power, and practice: the anthropology of medicine and everyday life.* (eds. Lindenbaum, S. & Lock, M.) (University of California Press, Berkeley, CA, 1993).

453. Becker, E. *The denial of death*. (Free Press, New York, 1973).

454. Arena, F. P., Treanor, S. & Killackey, D. The aftermath of the do not resuscitate (DNR) decision: the surrogates' dilemma. Paper presented at the Annual Meeting of the American Society of Clinical Oncology [Abstract] (1991).

455. Jeffers, B. R. The surrogate's experience during treatment decision-making. *Medsurg Nurs* **7**, 357-63 (1998).

456. Farran, C. J., Herth, K. A. & Popovich, J. M. *Hope and hopelessness: critical clinical constructs*. (Sage, London, 1995).

457. Snyder, C. R. et al. The will and the ways: development and validation of an individual-differences measure of hope. *J Pers Soc Psychol* **60**, 570-85 (1991).

458. Snyder, C. R. et al. The development and validation of the Children's Hope Scale. *J Pediatr Psychol* **22**, 399-421 (1997).

459. Snyder, C. R. et al. Development and validation of the State Hope Scale. *J Pers Soc Psychol* **70**, 321-55 (1996).

460. Nunn, K. P., Lewin, T. J., Walton, J. M. & Carr, V. J. The construction and characteristics of an instrument to measure personal hopefulness. *Psychol Med* **26**, 531-45 (1996).

461. Farran, C. J., Wilken, C. & Popovich, J. M. Clinical assessment of hope. *Issues Ment Health Nurs* **13**, 129-38 (1992).

462. Poncar, P. J. Inspiring hope in the oncology patient. *J Psychosoc Nurs Ment Health Serv* **32**, 33-8 (1994).

463. Dufault, K. & Martocchio, B. C. Hope: its spheres and dimensions. Symposium on compassionate care and the dying experience. *Nurs Clin North Am* **20**, 379-91 (1985).

464. Cutcliffe, J. R. How do nurses inspire and instill hope in terminally ill HIV patients? *J Adv Nurs* **22**, 888-95 (1995).

465. Hall, B. A. The struggle of the diagnosed terminally ill person to maintain hope. *Nurs Sci Q* **3**, 177-84 (1990).

466. Yates, P. Towards a reconceptualisation of hope for patients with a diagnosis of cancer. *J Adv Nurs* **18**, 701-6 (1993).

467. Menninger, K. Hope. *Bull Meninger Clin* **51**, 447-62 (1987).

468. Perakyla, A. Hope work in the care of seriously ill patients. *Qual Health Res* **1**, 407-33 (1991).

469. Wilkinson, H. A. Hope, false hope, and self-fulfilling prophecy. *Surg Neurol* **63**, 84-6 (2005).

470. Eliott, J. A. What have we done with hope? A brief history, in *Interdisciplinary perspectives on hope.* (ed. Eliott, J. A.) (Nova Science, Hauppauge, NY, 2005).

471. Owen, D. C. Nurses' perspectives on the meaning of hope in patients with cancer: A qualitative study. *Oncol Nurs Forum* **16**, 75-9 (1989).
472. Herth, K. Fostering hope in terminally-ill people. *J Adv Nurs* **15**, 1250-9 (1990).
473. Stephenson, C. The concept of hope revisited for Nursing. *J Adv Nurs* **16**, 1456-61 (1991).
474. Snyder, C. R. Conceptualizing, measuring, and nurturing hope. *J Couns Dev* **73**, 355-60 (1995).
475. Simpson, C. When hope makes us vulnerable: a discusson of patient-healthcare provider interactions in the context of hope. *Bioethics* **18**, 428-47 (2004).
476. Ballard, A., Green, T., McCaa, A. & Logsdon, M. C. A comparison of the level of hope in patients with newly diagnosed and recurrent cancer. *Oncol Nurs Forum* **24**, 899-904 (1997).
477. Kylma, J. & Vehvilainen-Julkunen, K. Hope in nursing research: a meta-analysis of the ontological and epistemological foundations of research on hope. *J Adv Nurs* **25**, 364-71 (1997).
478. Lohne, V. Hope in patients with spinal cord injury. *J Neurosci Nurs* **33**, 317-25 (2001).
479. Nekolaichuk, C. L., Jevne, R. F. & Maguire, T. O. Structuring the meaning of hope in health and illness. *Soc Sci Med* **48**, 591-605 (1999).
480. Klenow, D. J. Emotion and life-threatening illness: a typology of hope sources. *Omega* **24**, 149-60 (1991).
481. Salander, P., Bergenheim, T. & Henriksson, R. The creation and protection of hope in patients with malignant brain tumours. *Soc Sci Med* **42**, 985-6 (1996).
482. Erikson, E. *Identity: youth and crisis*. (Norton, New York, 1968).
483. Godfrey, J. J. *A philosophy of human hope*. (Kluwer Academic Publishers, Dordrecht, 1987).
484. Herth, K. Development and refinement of an instrument to measure hope. *Sch Inq Nurs Pract* **5**, 39-51 (1991).
485. Herth, K. Abbreviated instrument to measure hope: development and psychometric evaluation. *J Adv Nurs* **17**, 1251-9 (1992).
486. Jakobsson, A., Segesten, K., Nordholm, L. & Oresland, S. Establishing a Swedish instrument measuring hope. *Scand J Caring Sci* **7**, 135-9 (1993).
487. Cutcliffe, J. R. Critically ill patients' perspectives of hope. *Brit J Nurs* **5**, 687-90 (1996).
488. Benzein, E. & Saveman, B. I. Nurses' perception of hope in patients with cancer: a palliative care perspective. *Cancer Nurs* **21**, 10-6 (1998).

489. Nowotny, M. L. Assessment of hope in patients with cancer: development of an instrument. *Oncol Nurs Forum* **16**, 57-61 (1989).

490. Morse, J. M. & Doberneck, B. Delineating the concept of hope. *Image J Nurs Sch* **27**, 277-85 (1995).

491. Danforth, S. On what basis hope? Modern progress and postmodern possibilities. *Ment Retard* **35**, 93-106 (1997).

492. Nekolaichuk, C. L. & Bruera, E. On the nature of hope in palliative care. *J Pall Care* **14**, 36-42 (1998).

493. Brown, N. Ordering hope: representations of xenotransplantation--an actor/actant network theory account. PhD thesis submitted to the School of Independent Studies 229 (Lancaster University, Lancaster, UK, 1998). Retrieved 28 April 2004, from http://www.york.ac.uk/org/satsu/OnLinePapers/Brown%20-%20Ordering%20Hope.pdf

494. Mulkay, M. Rhetorics of hope and fear in the Great Embryo Debate. *Soc Sci Med* **23**, 721-42 (1993).

495. Averill, J. R., Catlin, G. & Chon, K. K. *Rules of hope.* (Springer-Verlag, New York, 1990).

496. Healy, B. P. Editorial: Shouting 'cure' or whispering 'hope' in a crowded cancer ward. *J Womens Health* **7**, 489-90 (1998).

497. Nuland, S. B. *How we die: reflections of life's final chapter.* (Knopf, New York, 1994).

498. Lynch, W. *Images of hope.* (Notre Dame University Press, Notre Dame, IN, 1965).

499. Snyder, C. R. The past and possible futures of hope. *J Soc Clin Psychcol* **19**, 11-28 (2000).

500. Buckley, J. & Herth, K. Fostering hope in terminally ill patients. *Nurs Stand* **19**, 33-41 (2004).

501. Hickey, S. S. Enabling hope. *Cancer Nurs* **9**, 133-7 (1986).

502. Ersek, M. Examining the process and dilemmas of reality negotiation. *Image J Nurs Sch* **24**, 19-25 (1992).

503. Snyder, C. R., Rand, K. L., King, E. A., Feldman, D. B. & Woodward, J. T. "False" Hope. *J Clin Psychol* **58**, 1003-22 (2002).

504. Tobias, J. S. & Houghton, J. Comments and critique: Is informed consent essential for all chemotherapy studies? *Eur J Cancer* **30**, 897-9 (1994).

505. Hockley, J. The concept of hope and the will to live. *Palliat Med* **7**, 181-6 (1993).

506. Gordon, D. R. Embodying illness, embodying cancer. *Cult Med Psychiatry* **14**, 275-97 (1990).

507. Westburg, N. G. & Guindon, M. H. Hope, attitudes, emotions, and expectations in healthcare providers of services to patients infected with HIV. *AIDS Behav* **8**, 1-8 (2004).

508. Lantos, J. D. Futility assessments and the doctor-patient relationship. *J Am Geriat Soc* **42**, 868-70 (1994).

509. Gottschalk, L. A., Kunkel, R., Wohl, T. H., Saenger, E. L. & Winget, C. N. Total and half-body irradiation: effect on cognitive and emotional processes. *Arch Gen Psychiatry* **21**, 574-80 (1969).

510. Greer, S., Morris, T. & Pettingale, K. Psychological response to breast cancer: effect on outcome. *Lancet* **2**, 785-7 (1979).

511. Gottschalk, L. A., Fronczek, J. & Buchsbaum, M. S. The cerebral neurobiology of hope and hopelessness. *Psychiatry* **56**, 270-81 (1993).

512. Jenkins, C. D. Editorial comment. "While there's hope, there's life." *Psychosom Med* **58**, 122-4 (1996).

513. Snyder, C. R., Michael, S. T. & Cheavens, J. S. Hope as a psychotherapeutic foundation of common factors, placebos and expectancies, in *The heart and soul of change: what works in therapy.* (eds. Hubble, M. A. & Duncan, B. L.) (American Psychological Association, Washington, DC, 1999).

514. Ebell, M. H., Bergus, G. R., Warbasse, L. & Bloomer, R. The inability of physicians to predict the outcome of in-house resuscitation. *J Gen Intern Med* **11**, 16-22 (1996).

515. Bartley, B. Euthanasia and withdrawal of treatment: legal perspectives, in *An easeful death? Perspectives on death, dying and euthanasia.* (ed. Morgan, J.) (Federation Press, Leichhardt, NSW, 1996).

516. Emanuel, E. J. Ethics of treatment: Palliative and terminal care, in *Psycho-oncology.* (ed. Holland, J. C.) (Oxford University Press, New York, 1998).

517. Fieser, J. & Dowden, B. (2004).

518. Foot, P. Euthanasia, in *Ethical issues relating to life and death.* (ed. Ladd, J.) (Oxford University Press, Oxford, 1979).

519. McInerney, F. "Requested death": a new social movement. *Soc Sci Med* **50**, 137-54 (2000).

520. Seale, C. & Addington-Hall, J. Dying at the best time. *Soc Sci Med* **40**, 589-95 (1995).

521. Seale, C. & Addington-Hall, J. Euthanasia: the role of good care. *Soc Sci Med* **40**, 581-7 (1995).

522. Seale, C. & Addington-Hall, J. Euthanasia: why people want to die earlier. *Soc Sci Med* **39**, 647-54 (1994).

523. Seale, C., Addington-Hall, J. & McCarthy, M. Awareness of dying: prevalences, causes and consequences. *Soc Sci Med* **45**, 477-84 (1997).

524. Cassell, E. J. The nature of suffering and the goals of medicine. *N Engl J Med* **306**, 639-45 (1982).

525. Murphy, D. J. et al. The influence of the probability of survival on patients' preferences regarding cardiopulmonary resuscitation. *N Engl J Med* **330**, 545-9 (1994).

526. Woodhouse, S. P. Implementation of guidelines for no-CPR orders. *Aust N Z J Med* **28**, 67 (1998).

527. Wilkinson, T. J., Watson, D. R., Sainsbury, R. & Kidd, J. E. Implementation of guidelines for no-CPR orders. *Aust N Z J Med* **28**, 67-8 (1998).

528. British Medical Association. Decisions relating to cardiopulmonary resuscitation. A joint statement from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing. *J Med Ethics* **27**, 310-6 (2001).

529. American Heart Association in collaboration with the International Liaison Committee on Resuscitation. Guidelines 2000 for cardiopulmonary resuscitation and emergency cardiovascular care: an international consensus on science, Part 2: ethical aspects of CPR and ECC. *Circulation* **102**, I12-21 (2000).

530. American Heart Association. *Advanced Cardiac Life Support*. (American Heart Association, Dallas, 1994).

531. Baumrucker, S. J. AND versus DNR. *Am J Hosp Palliat Care* **18**, 370-1 (2001).

532. Meyers, C. Allow Natural Death—an alternative to DNR? (2000).Retrieved 5 May 2003, from http://www.lastacts.org/statsite/5274la_eln_newsletter.html

533. Parr, M. J., Hadfield, J. H., Flabouris, A., Bishop, G. & Hillman, K. The Medical Emergency Team: 12 month analysis of reasons for activation, immediate outcome and not-for-resuscitation orders. *Resuscitation* **50**, 39-44 (2001).

534. Herbert, C. L. 'To be or not to be'—an ethical debate on the not-for-resuscitation (NFR) status of a stroke patient. *J Clin Nurs* **6**, 99-105 (1997).

535. Maddocks, I. Letters to the Editor: Change "DNR" to "GPC." *Med J Aust* **156**, 888 (1992).

536. Clarke, C. W. Letters to the Editor: Change "DNR" to "GPC." *Med J Aust* **157**, 287 (1992).

537. Chessa, F. (2004). A rose by any other name: changing terminology to influence choices about end-of-life medical care (2004). Retrieved 28 February 2006, from http://abacus.bates.edu/acad/depts/phil/Faculty/chessa/Rose.pdf

538. O'Brien, M. E. Relief of suffering: where the art and science of medicine meet. *Postgrad Med* **99**, 197-200, 206-208 (1996).

539. Woodruff, R. *Palliative medicine: symptomatic and supportive care for patients with advanced cancer and AIDS.* (Asperula, Melbourne, 1993).

540. Ardelt, M. Physician-assisted death, in *Handbook of death and dying* (ed. Bryant, C. D.) (Sage, London, 2003).

541. Huang, F. Y. & Emanuel, L. L. Physician aid in dying and the relief of patients' suffering: physicians' attitudes regarding patients' suffering and end-of-life decisions. *J Clin Ethics* **6**, 62-7 (1995).

542. Frank, A. W. *The wounded storyteller: body, illness, and ethics.* (University of Chicago Press, Chigaco, 1995).

543. Brescia, F. J. Killing the known dying: notes of a death watcher. *J Pain Symptom Manage* **6**, 337-9 (1991).

544. Boelderl, A. R. & Mayr, D. F. The undead and the living dead: images of vampires and zombies in contemporary culture. *J Psychohist* **23**, 51-65 (1995).

545. Jacobson, J. A. et al. Patients' understanding and use of advance directives. *West J Med* **160**, 232-6 (1994).

546. Averill, J. R. & Sundararajan, L. Hope as rhetoric: cultural narratives of wishing and coping, in *Interdisciplinary perspectives on hope.* (ed. Eliott, J. A.) (Nova Science, Hauppage, NY, 2005).

547. Edgley, C. Dying as deviance: an update on the relationship between terminal patients and medical settings, in *Handbook of death and dying.* (ed. Bryant, C. D.) (Sage, London, 2003).

548. Chapple, H. S. Changing the game in the Intensive Care Unit: letting nature take its course. *Crit Care Nurse* **19**, 25-34 (1999).

549. Misbin, R. Sounding board: Physicians' aid in dying. *N Engl J Med* **325**, 1307-11 (1991).

550. Jalland, P. *Death in the Victorian family.* (Oxford University Press, Oxford, 1999).

551. Callahan, D. *Setting limits.* (Simon & Schuster, New York, 1987).

552. Cohn, F. & Lynn, J. Vulnerable people: Practical rejoinders to claims in favor of assisted suicide, in *The case against assisted suicide: for the right to end-of-life care.* (eds. Foley, K. M. & Hendin, H.) (John Hopkins University Press, Baltimore, 2002).

553. Taylor, E. M., Parker, S. & Ramsay, M. P. A patient's receipt and understanding of written information about a resuscitation policy. *Bioethics* **12**, 64-76 (1998).

554. Downie, R. S. Research on dead infants. *Theor Med Bioeth* **24**, 161-75 (2003).

555. Lithwick, D. Habeas corpses: What are the rights of dead people? (MSN, 2002). Retrieved 1 November 2004, from http://www.slate.com/?id=2063222

556. von Gunten, C. F. Discussing do-not-resuscitate status. *J Clin Oncol* **21**, S20-5 (2003).

557. Coppola, K. M. et al. Elderly adults' preferences for life-sustaining treatments: the role of impairment, prognosis, and pain. *Death Stud* **23**, 617-34 (1999).

558. Lantos, J. D. Bethann's death. *Hastings Center Rep* **25**, 22-3 (1995).

559. Jaffe, A. S. & Landau, W. M. Death after death: the presumption of informed consent for cardiopulmonary resuscitation—ethical paradox and clinical conundrum. *Neurology* **43**, 2173-8 (1993).

560. Hall, M. A. & Schneider, C. E. How should physicians involve patients in medical decisions? *JAMA* **283**, 2391-2 (2000).

561. Armstrong, D. Silence and truth in death and dying. *Soc Sci Med* **24**, 651-7 (1987).

562. Morris, D. B. *Illness and culture in the postmodern age.* (University of California Press, Berkeley, CA, 1998).

563. The American Heritage® Dictionary of the English Language, 4th ed [Electronic version]. "Jonah." (Houghton Mifflin, Boston, 2000). Retrieved 22 September 2004, from http://dictionary.reference.com/search?q=Jonah

564. Dresser, R. S. & Robertson, J. A. Quality of life and non-treatment decisions for incompetent patients: A critique of the orthodox approach. *Law Med Health Care* **17**, 234-44 (1989).

565. Stacey, J. *Teratologies: a cultural study of cancer.* (Routledge, London, 1997).

566. Deber, R. B. & Baumann, A. O. Clinical reasoning in medicine and nursing: decision making versus problem solving. *Teach Learn Med* **4**, 140-6 (1992).

567. Marshall, P. A. The SUPPORT Study. Who's talking? *Hastings Center Rep* **25**, S9-11 (1995).

568. Lee, M. & Cassel, C. K. The ethical and legal framework for the decision not to resuscitate. *West J Med* **140**, 117-21 (1984).

569. Baker, R., Dersch, V. & Fein, I. A. A comparative study of the effects of the New York DNR law and the JCAHO DNR policies, in *Legislating medical ethics: a study of the New York DNR law.* (eds. Baker, R. & Strosberg, M. A.) (Kluwer Academic Press, Dordrecht, 1995).

570. Levin, P. D. & Sprung, C. L. End of life decisions in intensive care. *Intensive Care Med* **25**, 893-5 (1999).

571. Kitzinger, C. & Frith, H. Just say no? The use of Conversation Analysis in developing a feminist perspective on sexual refusal, in *Discourse theory and practice: a reader* (eds. Wetherell, M., Taylor, S. & Yates, S. J.) (Sage, London, 2001).

572. Daniel, A. Trust and medical authority, in *Health matters: a sociology of illness, prevention and care.* (eds. Petersen, A. & Waddell, C.) (Allen & Unwin, St. Leonards, Australia, 1998).

573. Mappes, E. J. K. Ethical dilemmas for nurses: physicians' orders versus patients' rights, in *Bioethics: an anthology.* (eds. Kuhse, H. & Singer, P.) (Blackwell, Oxford, 1999).

574. Starr, P. *The social transformation of American medicine.* (Basic Books, New York, 1982).

575. Barber, B. *The logic and limits of trust.* (Longman, London, 1983).

576. Annas, G. J. How we lie. *Hastings Center Rep* **25**, S12-4 (1995).

577. Uhlmann, R. & Pearlman, R. Perceived quality of life and preferences for life sustaining treatment in adults. *Arch Intern Med* **151**, 495-7 (1991).

578. Mallary, S. D., Gert, B. & Culver, C. M. Family coercion and valid consent. *Theor Med* **7**, 123-6 (1986).

579. Edwards, A. P. Catch 22: manipulative family members. *Nurs Manage* **24**, 33-8 (1994).

580. Legal Services Commission of South Australia. The Law handbook: next of kin (Legal Services Commission of South Australia, 2004). Retrieved 15 August 2005, from http://www.lawhandbook.sa.gov.au/index_article.asp?id=2366

581. Latour, B. & Woolgar, S. *Laboratory life: the construction of scientific facts.* (Princeton University Press, Princeton, NJ, 1986).

582. Bruner, J. *Acts of meaning.* (Harvard University Press, Cambridge, MA, 1990).

583. Olver, I. N. Bioethical implications of hope, in *Interdisciplinary perspectives on hope.* (ed. Eliott, J. A.) (Nova Science, Hauppauge, NY, 2005).

584. Watson, M. et al. Relationships between emotional control, adjustment to cancer and depression and anxiety in breast cancer patients. *Psychol Med* **21**, 51-7 (1991).

585. Frankl, V. E. *Man's search for meaning: an introduction to logotherapy.* (Beacon Press, Boston, 1942/1962).

586. Parse, R. *Hope: An international human becoming perspective.* (Jones & Bartlett, Sudbury, MA, 1999).

587. Nunn, B. V. Getting clear what hope is, in *Interdisciplinary perspectives on hope.* (ed. Eliott, J. A.) (Nova Science, Hauppauge, NY, 2005).

588. Snyder, C. R., Cheavens, J. S. & Michael, S. T. Hope theory: history and elaborated model, in *Interdisciplinary perspectives on hope.* (ed. Eliott, J. A.) (Nova Science, Hauppauge, NY, 2005).

589. Duggleby, W. & Wright, K. Elderly palliative care cancer patients' descriptions of hope-fostering strategies. *Int J Palliat Nurs* **10**, 352-9 (2004).

590. Fairclough, N. The discourse of New Labour: Critical Discourse Analysis, in *Discourse as data: a guide for analysis* (eds. Wetherell, M., Taylor, S. & Yates, S. J.) (Sage, London, 2001).

591. Veatch, R. M. Why physicians cannot determine if care is futile. *J Am Geriat Soc* **42**, 871-4 (1994).

592. Schneiderman, L. J. The futility debate: effective versus beneficial intervention. *J Am Geriat Soc* **42**, 883-6 (1994).

593. Loprinzi, C. L., Johnson, M. E. & Steer, G. The art of oncology: when the tumor is not the target: Doc, how much time do I have left? *J Clin Oncol* **18**, 699-700 (2000).

594. Gottschalk, L. A. A hope scale applicable to verbal samples. *Arch Gen Psychiatry* **30**, 779-85 (1974).

595. Penrod, J. & Morse, J. M. Strategies for assessing and fostering hope: the Hope Assessment Guide. *Oncol Nurs Forum* **24**, 1055-63 (1997).

596. Stotland, E. *The psychology of hope.* (Jossey-Bass, San Francisco, 1969).

597. Eisenbruch, M. Cross-cultural aspects of bereavement II: ethnic and cultural variations in the development of bereavement practices. *Cult Med Psychiatry* **8**, 315-47 (1984).

598. Pickett, M. Cultural awareness in the context of terminal illness. *Can Nurs* **16**, 102-6 (1993).