End of Life Decisions and Practices: The Experiences of Doctors in Australia

Steven A Trankle

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Dedication

This thesis was written in loving memory of Victoria May Miller, 18 May 1927 – 30 January 2011, my beloved mother in-law, who lost her protracted battle with cancer, and with gratitude for the dedicated and compassionate palliative staff of Calvary who helped care for her.
Acknowledgements

I wish to express a heartfelt thank you to my participants who so enthusiastically engaged with my research and so generously referred their colleagues to me. Their contribution lies at the heart of this thesis.

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Through all its ups and downs, the support shown to me in this journey has been a humbling experience, but also a sustaining experience that bolstered my confidence when I felt it waning. I look forward to the journey yet to come.
Statement of Authentication

The work presented in this thesis is, to the best of my knowledge and belief, original except as acknowledged in the text. I hereby declare that I have not submitted this material, either in full or in part, for a degree at this or any other institution.

Steven A Trankle
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Abstract

This research investigates how physicians understand, practice and experience end-of-life care in the context of Australian palliative and critical and acute settings. Particular attention is given to how they negotiate decisions and practices that are also situation specific and multitudinally influenced. By adopting a critical realist framework that draws on complexity theory, an interpretive account is provided through thematic analysis to give an understanding of the ambiguity and inconsistency of end-of-life care practices and experiences reported in the available literature. New knowledge is bolstered by focusing specifically on Australian end-of-life settings and by also considering the physicians’ positive experiences and the coping strategies they utilise to counter aversive experiences. A total of thirteen physicians that included seven palliative specialists, three intensive care specialists, a respiratory-thoracic specialist, and two GPs identified how negotiating multiple macro, meso and micro influences affected the way they understood, practiced and experienced end-of-life care. Religious, political and professional doctrines, and personal beliefs and attitudes played out at the bedside in non-predictive and inconsistent ways. Physicians were not necessarily constrained by legal and professional imperatives, especially when death was regarded as hastened, but were guided by an internalised moral and ethical structure developed from multiple influences across the lifespan. The physicians’ capacity for agency within individual contexts and the efficacy with which they negotiated practices shaped their subsequent experiences. In addition to fostering a professional and empathic relationship with dying patients and patient loved ones, multifaceted requirements for end-of-life care saw physicians adopt multiple roles, some of which included research, patient advocacy, and navigating institutional and administrative barriers. Although the physician’s emotional self-efficacy and the positive experiences they drew from end-of-life care strongly mediated many of the aversive experiences they encountered, it was not always so. Implicating governance, resourcing, and training and support, physicians also experienced many negative aspects of care which exposed opportunities for research that targets interventions at macro, meso and micro levels.
Preface

In the world of end-of-life care, Australia holds a position of political and cultural importance ever since legalising the world’s first medicalised euthanasia program in 1996 - The Rights of the Terminally Ill Act (ROTI). It was at about the time of that legislation and the ensuing debate which ultimately ended in its demise, when this and associated issues surrounding personal control over the timing and manner of death, and management of the dying process, were topics that held my interest with an increasing passion. Since then, professional end-of-life care has become a formalised specialty and continues to develop in Australia and elsewhere.

Prior to embarking on the present research, I considered myself fortunate that, like many other people in this country, I had very little experience with death and dying. I am a mature aged researcher, and my family and I all enjoy good health. I am also fortunate to have a large extended family, but it is here that over that last four years I have had considerable exposure to terminal illness and death within my family. I have lost a grandmother whose dementia advanced quite rapidly, and a number of aunts and uncles who have succumbed to various cancers, neurological and cardio-vascular conditions. These experiences forced me to come to terms with grief and bereavement, but none more so than the recent death of my elderly mother-in-law from metastatic cancer. She is someone with whom I had a significant emotional attachment, developed over the last 20-25 years, and indeed she was a much-loved member of my family. The bonds my wife shared with her mother were even tighter.

But it should be emphasised that well before the actual death of a loved one, the impending threat of death and the prior suffering and incremental physical and mental deterioration that goes with this for the person affected, is not necessarily a localised event. It has broad reaching ramifications for many others who are in any way connected with that person or with each other. For me, and much of my family, grieving for my mother-in-law began with the terminal prognosis, yet we all made efforts to enjoy life as much as we could together and we continue to commemorate her life. However, I also believe that with
age, and experiences with the deaths of others, comes an increased awareness (and acceptance perhaps) of one’s own mortality.

Yet, no matter how much control we might think we have in relation to our own deaths, we willingly place ourselves in the care (sometimes at the mercy) of physicians who hold an extraordinary power over suffering and death. As we approach the end of our lives, many of us will place the responsibility of empathic and compassionate care into their skilled hands. We obligate them with our trust, to respect our dignity, alleviate our suffering and treat us as valued fellow human beings. At least this is what I would like when that time comes for me. I know I would certainly like to maintain as much personal control over the timing and manner of my death and have my wishes respected and carried out as closely as possible. Accordingly, many of us, including myself, may make requests to physicians, perhaps pleadingly, to hasten that process of dying in order to end the burden of suffering.

If I were a physician charged with dispensing end-of-life care, I am not sure how I would respond to individual suffering or indeed such requests, simply because I could expect to find conflict between being a law abiding medical scientist and also a feeling and compassionate human being with my own beliefs and values. I could struggle to maintain consistency in my decisions and practices across diverse situations with individual patients, particularly in a domain where inconsistency and specificity dominate. Hence, I could experience my interactions with dying patients and their loved ones in a range of ways, sometimes rewardingly and sometimes aversively. It might also be difficult to pre-empt how I would need to cope in particular situations and how effective my strategies for this might be.

It is for these reasons, as much as being a recent consumer, that I am intrigued with how physicians negotiate their decision-making and practices in Australian end-of-life care and how they subsequently experience the provision of that care. To this point, specific research that may have satisfied my curiosity or answered that intrigue is considerably limited. This has been a major factor motivating me to embark on this course of research
and the journey thus far has certainly been a privileged one in terms of the encouragement provided by many eminent physicians who have willingly contributed and taken me into their trust, but especially enlightening in terms of the information, often very personal, which they have generously given me.

I believe it is important to point out that my level of interest and involvement in end-of-life care means that I hold particular positions and views on death and dying and the practices that physicians may engage in when providing end-of-life care. Without doubt, this has influenced my choice of research topic and the process of investigation I have adopted. Being conscious of this has allowed me to acknowledge (and value) my reflexivity and also maintain scientific rigour throughout my investigation.

This thesis begins with a brief overview, the current state of play in how death and dying is understood and managed in Australia and other Western nations. In Chapter 2, I reflect my world view and discuss the corresponding epistemological and theoretical considerations that position this research. Chapters 3 – 5 contain a review of the literature structured to reflect those considerations. In Chapter 6, I provide the methodological rationale and the procedures adopted for investigation, while Chapters 7, 8, and 9 constitute the analyses, each with individual discussions. I conclude the thesis at Chapter 10 by drawing together and reflecting on the research findings. Here I offer suggestions that may enhance the provision of end-of-life care in Australia and correspondingly point to future research directions.
Chapter 1

End-of-Life Care: The State of Play

End-of-life care is a growing area for the provision of health services in Western cultures such as Australia’s (National Institute on Aging, 2009; The Victorian State Government, 2004). Western populations are aging and advances in pharmacology and medical technology, as well as behavioural changes, are facilitating an increase in both longevity and quality of life (Rechel, Doyle, Grundy, & McKee, 2009). Indeed, the Australian Government predicts that by the year 2056, one in four Australians will be over the age of 65 and that the population will increase from its current 21 million to between 31 and 43 million and, furthermore, that the proportion of the population over 85 years of age will increase from its current 1.6% to between 5% and 7% (Australian Bureau of Statistics, 2008).

In addition, a significant increase in expenditure directed toward end-of-life care will be required to maintain the health of Australia’s population (Australian Bureau of Statistics, 2006a). For example, current trends indicate that, without policy change, health-care spending will increase from 9.3 per cent of GDP in 2002-03 to 12.4 per cent in 2032-33, a 33 per cent real increase. Commonwealth expenditure on health and residential aged care is scheduled to rise from $85 billion to $246 billion a year (Goss, 2008). Of further interest, around 30 per cent of the health expenditure for people aged 65 years and over, occurs in the last year of life (Kardamanidis, Lim, Da Cunha, Taylor, & Jorm, 2007; Lorenz et al., 2008; Nitschke & Stewart, 2005). This means that the last six
to twelve months of life are an expensive affair, especially when around half of all deaths occur in hospitals with a further 24 per cent in hospices (Nitschke & Stewart, 2005). However, other practitioners in the field believe the real figure is even higher, with up to 70% of Australians dying in critical/acute hospital settings (Hillman, 2009b). Patients in emergency situations are often resuscitated and brought to intensive care by ambulance as a matter of procedure because not enough is known about patient wishes or if advance care directives have been established (Hillman, 2009b, 2011). Yet, if those that are dying or seriously ill are being kept alive against their will or receiving inappropriate treatment, particularly in acute or critical settings, rather than being palliated or even facilitated in ending their lives in a way that is also at a time and place of their choosing, then this proportion of health expenditure can only increase.

Indeed, current funding is skewed towards maintaining and expanding critical or intensive care facilities (Australian Productivity Commission, 2009, pp. 23, 31, 40, 104) and consequently terminal patients with a poor prognosis are sometimes subjected to aggressive forms of treatment when it might often be more appropriate to palliate (Hillman, 2009a). For example, Hillman, an intensive care practitioner, identified that an intensive care unit (ICU) he manages in a major Sydney hospital had six beds 20 years ago, but recently this has been expanded to 60 beds due to “demand”. However, he questions whether this is real demand or a reluctance of some physicians to refer patients appropriately. Although acknowledging that oncologists frequently refer patients to palliative care, he states many other patients with equally limited prognoses such as those suffering from liver failure, cardiovascular disease or respiratory conditions are kept in intensive care. He further points out that many patients arrive at the ICU due to an acute episode of a chronic condition, often from general wards, and these patients who subsequently die in the ICU frequently do so in a way that would not be considered “a good death” (Hillman, 2009b). Yet, an Australian intensive care bed costs between $3000 to $4000 per day but, by comparison, as little as $600 to $1600 per day for a specialist
palliative care bed depending on the complexity of illness (Education and Health Standing Committee, 2010, p. 431).

Dying peacefully in hospitals is a major challenge for the health system. Although most people want to die at home (Abel, Bowra, & Walter, 2011; Foreman, Hunt, Luke, & Roder, 2006), most will die in acute hospitals and other institutions (Hillman, 2011). Almost one quarter of those will spend their last days on a ventilator and almost 40% will die in pain (Angus et al., 2004). In the USA, approximately 20% of all deaths occur in intensive care units and at least 90% of these deaths are as a result of withdrawing or withholding treatment (Angus, et al., 2004; Keenan et al., 1997; Prendergast & Luce, 1997). Caring for end-of-life patients in acute hospitals is often inappropriate (Curtis & Rubenfeld, 2001) and presents physicians (and society) with considerable challenges. Yet even though there is evidence that formal involvement of end-of-life palliative care improves patient and carer outcomes (Lorenz, et al., 2008; McKeown, Booth, Strachan, Calder, & Keeley, 2011), palliative care physicians in acute hospitals usually have to be formally consulted by the practitioner under whose care the patient was initially admitted (Chen, Flabouris, Bellomo, Hillman, & Finfer, 2008; Hillman, 2011). There are protocols and procedures that apply.

Furthermore, terminal patients are often unclear of their situation when they are brought to intensive care, being particularly unaware that they are dying (Angus, et al., 2004; Hillman, 2011). Intensive care physicians are obliged to practice from within a cure rather than comfort model of care and patients and loved ones may grasp at false hope as a consequence (Curtis & Rubenfeld, 2001; Miles, 2001; Seymour, 2003). Communication between the physician and the patient and their loved ones is thus, from within such a paradigm and may provide difficulties in end of life decision-making which needs to be in the best interests of the patient. However, one could expect that the patient’s best interests can only be served if as many relevant factors as possible can be considered in that decisional process.
Yet, maintaining the current allocation of health expenditure directed towards curative and expensive models of care, particularly at end-of-life, may seriously deplete provision of other health resources, further straining the ability of doctors to deliver the care to patients as they deem necessary and appropriate. As an example, an increasingly ageing population also suffers illnesses and diseases that are not characteristic of younger populations. Specifically, dementias such as Alzheimer’s, or osteoarthritic conditions, as well as the accelerated breakdown in organic functioning are generally irreversible but nonetheless common qualities of the aging process, and provide further challenges to the already greater symptomatic complexity at end-of-life (Palliative Care Australia, 2011a). Furthermore, with half a million Australians expected to develop dementia by 2031 (Australian Institute of Health and Welfare, 2007) health provision geared towards end-of-life will most likely need to become increasingly specialised and multidisciplinary, and require strategically targeted funding (Rechel, et al., 2009). However at the same time, difficult issues like euthanasia and physician-assisted suicide, which are intimately related to end-of-life decision making and practice (Lickiss, 2003), need to be openly and honestly discussed, especially when Australia’s aging and multicultural population with its diverse views on end-of-life care will become increasingly exposed to these topics, and that includes the physicians providing that care.

Euthanasia and physician-assisted suicide are emotive and contentious issues, which are continually placed under the spotlight in many countries including Australia. Although the majority of Australians support these practices with transparency and open debate (Allen, 1998; Ashby, 2003; Sikora & Lewins, 2007), legislators, religious doctrines, legal and professional directives silence them (Magnusson, 2002). Those opposed commonly cite the “slippery slope” as justification, arguing that any legalisation of these practices would open the system to abuse (Pereira, 2011), yet research in the Netherlands since legalisation has shown an actual decline in patient requests for euthanasia (Norwood, Kimsma, & Battin, 2009; Rietjens, van der Maas, Onwuteaka-Philipsen, van Delden, & van der Heide, 2009). Most Australians also support individual
autonomy and freedom in decision-making yet some also fear the legitimisation of these practices would blur the boundaries between when a practice is voluntary and when it is non-voluntary (Sanson et al., 1998). Some fear a transformation of “ethical sensibility” where, through subtle and indirect coercion, the dying, sick, vulnerable and unproductive would be pushed towards death (Magnusson, 2004a). Arguments also abound over who should control such practices if legalised (Idol & Kaye, 1999), specifically, whether decisional control should be left to the discretion of physicians, something physicians are divided over (Sikora & Lewins, 2007), the legal fraternity, who have deliberated over individual cases often to the detriment of the patients and families concerned (Brice, 2009; Faunce, 2009; Faunce & Stewart, 2005; Gostin, 1997; Stewart, Peisah, & Draper, 2011; Williams, 2009) or somehow seek a collaborative approach that better involves patients and their loved ones, something that legislatures in Australia are generally reluctant to consider (Idol & Kaye, 1999). However, the debate over whether to legalise such practices in end-of-life care continues unabated both here in Australia and in other countries across the globe (Biggs & Ost, 2010; Haigh, 2012; Jotkowitz & Glick, 2009; Oduncu & Sahm, 2010; Robinson & Scott, 2012; Volmar, 2009), and although there is some acknowledgement that these practices are occurring clandestinely and will continue to do so, some countries have taken steps to regulate them.

In particular, euthanasia and physician-assisted suicide became legal in the Netherlands and Belgium in 2002 (Quill & Battin, 2004) while Luxembourg legalised these practices in 2008 (Simon, 2009). However, Switzerland prohibits euthanasia but has allowed physician-assisted suicide for “altruistic” motives by both physicians and non-physicians since 1941 and also currently extends this service to non-nationals (Battin, 2005; Quill & Battin, 2004). Elsewhere, the US also prohibits euthanasia but has allowed physician-assisted suicide in the State of Oregon since 1997 (Brock, 2004) while, more recently in 2008, the US State of Washington passed similar legislation allowing this practice (United States Government Secretary of State, 2008). Still further reflecting what appears to be a growing trend in the USA; physicians in the State of Montana have also
been cleared to provide assistance with suicide when in late 2009 its Supreme Court ruled that the practice does not contravene State law (Bostrom, 2010; Purvis, 2012). However, the world’s first legalised euthanasia program occurred in Australia, where for a brief period between 1996 and 1997, Australia’s Northern Territory enacted euthanasia legislation known as the Rights of the Terminally Ill Act (ROTI) (McInerney, 2006; Perron, 1995).

Although euthanasia and physician-assisted suicide remain illegal in Australia, they are widespread, albeit, covert practices in the Australian community performed by doctors, nurses and other health workers (Magnusson, 2002). Such practices sometimes occur without patient consent (up to half the cases) and sometimes with nurses and others acting autonomously without instruction from doctors (Idol & Kaye, 1999; Kuhse & Singer, 1993). Indeed, over one third (36.5%) of all Australian deaths are caused or hastened by medical end-of-life decisions but over two thirds are subject to them (Kuhse & Singer, 1988; Kuhse, Singer, Baume, Clark, & Rickard, 1997). That death rate is nearly twice that of the Netherlands (19.5%) where all euthanasia cases must be reported, but this may remain inexplicable without Australian legislation, especially when there is also little consensus about what constitutes euthanasia (Allen, 1998; Douglas, 2009; White, Willmott, & Ashby, 2011). Further, over half of all Australian doctors, and considerably more nurses, support euthanasia for some patients; and not only for physical suffering (Kuhse & Singer, 1993; Neil, Coady, Thompson, & Kuhse, 2007). Although somewhat counterintuitive, this support has remained relatively consistent for 20 years despite considerable improvements in medical technology and analgesia (Neil, et al., 2007).

The illegality of such death hastening practices fosters attempts to end life that are sometimes unsuccessful, particularly when some are forced to contemplate suicide on their own in an effort to protect their family from prosecution (Chapple, Ziebland, McPherson, & Herxheimer, 2006). Not only patients and their families, but also the health professionals who are sometimes called upon to rectify unsuccessful suicides, report such instances as particularly harrowing and difficult to deal with emotionally and
psychologically (Magnusson, 2002, 2004b). However, for those with connections, a euthanasia underground supported by medical professionals is available and quietly condoned in Australia but, with similarities to the illicit euthanasia practices in the USA (Quill & Battin, 2004), cannot always provide the most favourable or expected outcomes (Magnusson, 2002).

To illustrate further, end-of-life practices were investigated in the Australian and US HIV/AIDS community through narrative interviews with 49 participants that included doctors, nurses, psychologists, community workers and a funeral director (Magnusson, 2002). This research revealed that health care workers were largely motivated by compassion for their dying and suffering patients as well as anger for the failings of current end-of-life procedures and lack of legislative support when actively assisting to hasten patient deaths. Frustrated patients, loved ones and, indeed, health care workers often resorted to mixing pharmacological cocktails with inexact dosages to achieve their goals. Not surprisingly attempts were frequently unsuccessful, even when under the supervision of experienced medical personnel, and such experiences were particularly distressing, especially when some patients then needed to be suffocated. Sometimes medical staff also had to “finish off” amateur attempts by sufferers forced to commit suicide by agonising and unsuccessful means such as jumping from bridges and buildings. Due to the illegal and clandestine nature of euthanatic practices, support and debriefing may be difficult to obtain, especially for those involved outside the closed HIV/AIDS community which may tend to look after its own.

Indeed, interviews with family members of 23 deceased patients revealed similar complications arose for some US physicians in palliative and critical care who were unsuccessful at assisting a hastened death. Similar drastic measures were then required but interviewees reported physicians were reluctant to discuss such experiences further and this sometimes strained the relationship between these family members and their physician at a particularly sensitive time (Back, 2004).
Some physicians working with critical or terminal patients find themselves with a difficult conflict between their ethical and professional duty to relieve suffering and their understanding of their ethical and professional duty not to use means which deliberately hasten death (Brock, 2004). If physicians accede to a patient’s request for hastened death due to intractable suffering, they are caught between a caregiver duty toward their patient and their duty as a law-abiding citizen. Furthermore, physicians providing end-of-life care often confront the dilemma of a “devil’s choice” where they empathise with the suffering of their dying patients and at the same time recognise the extraordinary power they hold over the lives of those patients (Magnusson, 2006). Understandably, some physicians may be uncomfortable even discussing these issues with their patients.

Recent structured interviews with 228 Australian cancer outpatients at different stages of their disease, found the majority supported euthanasia and physician-assisted suicide generally, as well as for themselves, but relatively few reported actually discussing this with their doctor (Carter et al., 2007). This finding might be suggestive of ineffective doctor-patient communication due to any number of personal or organisational factors. Indeed, Back (2004) suggested that doctors often “block” such communication and patients are then reluctant to broach the topic. However, patient requests to hasten death may therefore be underestimated because statistical data in the extant literature identifies the “actual” numbers of requests reported, yet if doctors “block” such communication (for whatever reason) then many patients who want to ask don’t. Unfortunately, there is no significant research, particularly investigating relevant qualitative aspects, which might help explain why many doctors avoid discussion of end-of-life topics and requests to hasten death.

Attitudes toward euthanasia vary greatly between individuals and populations through the many factors that mediate them and, although doctors are often more reluctant to embrace death hastening practices than the general public, there is also significant variance in attitudes among doctors themselves. Research with first and fifth year Swedish medical students found younger doctors favoured euthanasia more than
older doctors and although one third were favourable, half opposed euthanasia (Karlsson, Strang, & Milberg, 2007). Furthermore, those medical students varied widely on whether they would consider euthanasia for themselves in a future situation with 18% ruling it out, 45% perhaps considering it and 36% undetermined. Yet, in other research with doctors (Wenger & Carmel, 2004), the majority supported possible euthanasia for themselves at a later date even if not supporting it as strongly for patients, but that attitude also appeared strongly mediated by religiosity. Specifically, those with stronger religiosity maintained a traditional medical ethic of life preservation as well as consistency in the treatments they would provide to themselves and others. Discrepancies in attitude between self and other appear common among doctors and suggest that the positions doctors hold are inconsistent and not rigidly applied. However, such ambivalent attitudes on euthanasia may foster internal conflict for physicians, with adverse psychological and emotional implications, especially if their practices are also inconsistent.

In other recent research, an exhaustive cross-cultural study with 16,486 physicians from multiple specialties in six European countries and Australia investigated their experience with end-of-life decision-making (Löfmark et al., 2008). Of 1,478 Australian physicians, 7% reported complying with patient requests for euthanasia with 28% willing to comply under certain conditions and 66% stating they would never comply. However, 77% reported withholding or withdrawing treatment while 83% intensified the alleviation of pain through analgesia with the probability or certainty of hastening death. It appears that most Australian physicians in this study performed both passive and active forms of euthanasia at least once, yet on the request of patients very few complied (7%). This discrepancy suggests physicians are also performing these practices without patient consent. However, it highlights an inconsistency between practices and beliefs and the importance of investigating how physicians negotiate these practices and understand their meanings.

Moreover, there is also an assertion by those opposing euthanasia that good palliative care renders it unnecessary (Palliative Care Australia, 2011c). However,
research with 1,100 GPs in New Zealand working in end-of-life contexts, reported 693 (63%) had made medical decisions in the previous 12 months that could actually hasten death (Mitchell & Owens, 2003). Thirty-nine (5.6%) deaths were consistent with physician-assisted suicide or euthanasia. In 17 of these deaths doctors did not discuss their actions with the patient. In other words, non-voluntary euthanasia occurred, and in 34 (87%) of the 39 deaths palliative services were available. Mitchell and Owens suggest that doctors did not consider palliative care adequate in meeting patient needs and that supports findings using the same questionnaire in Australia, Belgium and the Netherlands (Deliens et al., 2000; Kuhse, et al., 1997; van der Maas, van Delden, & Pijnenborg, 1992). However, physician-assisted death rates in New Zealand, without prior consultation with the patient, paralleled those of Belgium and Australia but were higher than those of the Netherlands. Ninety-four (13.6%) New Zealand doctors reported actions that were “partly” intended to hasten death and 50 (53%) of these did not discuss with the patient beforehand. Furthermore, 132 (19%) withdrew or withheld treatment or increased medications to alleviate symptoms knowing it would probably hasten death. Doctors uniquely negotiate and experience end-of-life practices and meanings. However, their understandings of end-of-life care, and their subsequent decisions and interventions based on these, appear inconsistent both within the profession and across settings.

Due to the uniqueness of context, it is understandable that end-of-life medical decisions are rarely clear-cut or without ambiguity, however one could also ask if Australian medical personnel also need to be legal practitioners and bioethicists in this area of health care. Definitional ambiguities around terms like euthanasia persist (Flegel & Hébert, 2010; Goldney, 2012; McCormack, Clifford, & Conroy, 2011) even though this has long been problematic to end-of-life decision-making (Davis et al., 1993; Kelleher et al., 1995; Wilkes & White, 1995). Euthanasia is generally defined as providing an easy and painless death or the means for bringing this about. Euthanasia stems from the Greek “eu” (good or well) + “thanatos” (death). However, according to public policy and legal statutes, euthanasia in any form, whether active (e.g.
administering lethal doses of drugs) or passive (e.g. withdrawing treatment or life support), voluntary or involuntary (with or without patient consent), and physician-assisted suicide (providing the means) is prohibited in Australia. Yet, these acts are often obscured behind accepted protective legal positions such as the Principle of Double Effect which centres on the “intent” of a physician when performing a death hastening intervention, specifically; an intent to kill a patient versus an intent to address suffering with an unintended, albeit foreseeable, consequence of death (Douglas, 2009; Quill, 1998; White, et al., 2011); as well as divisive practices like palliative sedation (also known as terminal sedation, deep or continuous sedation, or pharmacological oblivion) which are closely related to that principle (Douglas, Kerridge, & Ankeny, 2008; Hahn, 2012; Seale, 2010; Tännsjö, 2004).

Although palliative sedation is particularly controversial, Löfmark et al. (2008) identified 28% of Australian physicians administering terminal sedation when making end-of-life decisions. When two thirds of all Australian deaths are subject to medical decisions that could be considered death hastening (Neil, et al., 2007), this represents a significant proportion. Sedation also occurs frequently in countries where euthanasia is legal, for example, palliative sedation in the Netherlands accounted for 8.2% of all deaths in 2005, and within palliative care settings generally, the incidence of using sedatives prior to death was between 15% and 60% of all patients (Rietjens et al., 2008).

However, even when medical practitioners have openly admitted intent for hastening their patients’ deaths, Australian law has been reluctant to respond. In March 1995, seven Victorian doctors, known as the Melbourne 7, went public on the front page of the Age newspaper and, in an open letter to the Victorian Premier, declared their active participation in euthanasia. Both the Victorian police and the Medical Practitioner’s Board of Victoria abandoned their investigations through lack of evidence (Magnusson, 2002). Similarly, no physician participating in assisted suicide, other than the late Dr Jack Kevorkian (a case surrounded by controversy), has ever been successfully prosecuted in the USA either (Brock, 2004). Legal imperatives may be difficult to enforce when
definitional consensus remains elusive and easily challenged. However, the lack of any prosecutions also perhaps tends to reinforce current practices and the autonomy of physicians in providing end-of-life care when there is so much flexibility and ambiguity in practice guidelines as they currently stand. For example, it is unlikely that physicians would risk their professional credibility and livelihood; rather, if it came to prosecution, they could easily manipulate their interpretation of current practice imperatives, or reposition themselves in relation to the intent of their intervention by claiming it was aimed at alleviating suffering.

Even so, physicians providing end-of-life care are further positioned within a system where they are compelled to engage in discriminatory practices. For example, patients on life support can request an assistance to die by declining further life sustaining interventions; however those that are not on life support, yet with an equally terminal condition and prognosis, cannot make such a request (Kuhse, 2004). Respecting a competent patient’s request for treatment withdrawal is enshrined in law and accepted medical ethics, and doctors are legally obliged to comply. However, some might further regard such compliance as physician-assisted suicide because the physician is actually assisting (also with intent) a patient intending to terminate their life. On the other hand, when patients are no longer competent to make an informed request, the decision rests with doctors and other medical staff (unless collaborated with next of kin) but the intention remains the same and might be considered euthanasia especially when the patient had given no advance directive.

Decisions regarding provision of euthanasia or assistance to die become even more complex when medical opinions about the “terminal” nature of disease and “futility” of treatments differs (Field & Addington-Hall, 1999; Gedge, Giacomini, & Cook, 2007; Johnson, 2011; Kissane, Street, & Nitschke, 1998; Pattison, 2006). For example, there have been significant improvements in prognoses for HIV/AIDS sufferers with the availability of new drugs, while mapping the trajectory of a dementia patient’s illness, such as one deteriorating with Alzheimer’s but whose physical functioning
remains largely unimpaired, is still difficult to achieve. Not surprisingly, differences of opinion regarding futility among individual physicians, but especially between the medical system and patient families, have sometimes been extremely acrimonious and only decided by courts after protracted legal battles (Chapple, et al., 2006; Faunce & Stewart, 2005).

Yet, even landmark court rulings cannot be applied generally across different contexts. For example, although Vacco v Quill was a precedent case in New York City outlawing physician-assisted suicide (Gostin, 1997), other US states legalise assisted suicide. Thus, physicians that have cross-jurisdictional involvement in end-of-life care may need to conceptualise practices differently according to individual contexts, and may experience their involvement in a variety of ways. The Chief Justice in this case also conceded that withdrawing, or accepting refusal of treatment (both legal), had the same outcome as assisted death or euthanasia and that “intent” was the determining difference. However, as identified above with the Principle of Double Effect, there can be great difficulty in establishing intent.

End-of-life care is much more than hastening death, but both are intimately connected. Physicians will have some impact on the timing of death, the suffering endured by patients and others involved with that patient, and how that death and the process leading to it is conceptualised. At the same time, the ability of physicians to provide end-of-life care is contingent upon the control and autonomy they have in decision-making (Rumbold, 1998) and how they might be influenced by social, legal, professional, and personal (e.g. intrapsychic) factors, and the different settings from which they practice (Shapiro, Astin, Shapiro, Robitshek, & Shapiro, 2011).

1.1. Summary

There are considerable differences and inconsistencies in individual end-of-life practices with some physicians favouring a hastened death for some patients in some situations. There appears to be great flexibility in how care is determined and
administered when illegal practices are performed as frequently as they are and with relative impunity. Seemingly there is ambiguity in the definitions and meanings around specific medical end-of-life practices and the way they are understood by physicians (McLachlan, 2008). As much as there are legal and professional guidelines in place, they are generalised and seldom appropriate or binding in a domain where individuality and context specificity appear crucially influential in determining how end-of-life care is provided. With literature predominantly focused internationally, it is further difficult to understand differences in end-of-life care within Australian contexts.

Moreover, the extant literature, offers little by way of detailed explanations for the current lack of consistency in medical end-of-life care or its inherent ambiguity. This is particularly surprising when it is also reported that physicians experience their end-of-life decision-making and subsequent interventions in many different ways, sometimes rewardingly but, sometimes quite aversively (Meier, Back, & Morrison, 2001). There is little empirical research documenting this principal aspect of end-of-life care which impacts on outcomes. Such an understanding is important because positive or rewarding experiences may enhance the motivation, enthusiasm and engagement, as well as the physical and psycho-emotional wellbeing of physicians (Rumbold, 1998; Vachon, 2003), while more negative experiences may foster burnout and affect physician health adversely, and prompt them to disengage from patients (Blomberg & Sahlberg-Blom, 2007; Keidel, 2002; Meier, et al., 2001; Shapiro, et al., 2011). Furthermore, these experiences may also be a product of how physicians negotiate care provision within very specific contexts.
Chapter 2

A Critical Window into the Complex World of End-of-Life Care

Physicians are subject to a number of influences when deciding on treatments and practicing end-of-life care that is unique to each individual, situation and setting. They must consider legal, professional and institutional imperatives and what constitutes best practice (Shapiro, et al., 2011). They also bring their own individuality in terms of personal beliefs, values and ethics to every encounter they participate in (Adler, 2007). Physicians frequently empathise with their patients and patient families, and experience emotional and psychological influences to care provision (Meier, et al., 2001; Seymour, 2003, pp. 331-335). No two patients are the same nor are any two situations the same.

Physicians assess, collaborate, diagnose, prognosticate and decide actions that need to be taken. End-of-life care and how it is understood and practiced is reflective of such complexity. It reflects the culture and laws of the land, and those expectations, but also needs to acknowledge diversity such as that which can be found in a multicultural Australia.

Such a diversity of influences may be considered inseparable from the social world we live in, where expectations, attitudes and beliefs, and laws are shaped through discourses and ways of thinking that also regulate practices (Davies & Harré, 1990; Foucault, 1972). However, discourses and ways of thinking evolve through ongoing social interaction and influence differentially in specific situations (Foucault, 1972; Harré
& van Langenhove, 1999; Mills, 2004). Definitions and meanings around end-of-life care, as physicians regard them, may be ambiguous because they are socially influenced and do not always represent a commonly accepted reality or worldview that is equal to all. This may be reflected through the practices physicians engage in that often appear inconsistent across settings and situations when providing end-of-life care.

Our social world may therefore be understood in many different ways. Any philosophy that provides a particular worldview colours how we perceive reality and who we are, and underpins the expectations we place on ourselves and others through influencing how daily life is conducted (Bhaskar, 2011). It guides and legitimates our cultural/social practices, and shapes attitudes and beliefs. Certain ways of thinking and behaviour become mainstream in society. However, a philosophy that defines a particular reality and becomes a culturally accepted lens on the world also strongly influences what constitutes knowledge and the ways of obtaining it (Bhaskar, 2011). Unless challenged, a particular philosophical standpoint may become self-perpetuating but, in so doing, risks excluding, or at the very least constrains alternate (and perhaps equally valid) explanations of reality in our complex social world. It may be very helpful therefore, if a philosophy that represents a less constraining view on reality, may accommodate (if not integrate) two ubiquitous but contrary and often adversarial ontological and epistemological positions; specifically, those of Positivism and Postmodernism.

2.1. A Critical Realist View

Critical realism has been regarded a “broad church” because of its both positivist and relativist/social constructionist aspects (Potter & Lopez, 2001a, p. 15). Certainly, the biological nature of humans places them in the natural world; however their inherently social nature also places them in a linguistically-oriented and “constructed” one. Critical realism, an epistemological “midwife” as Bhaskar describes it (Bhaskar, 2011, p. 24), fits between a positivist world which emphasises that what is knowable is directly observable, empirically measurable and quantifiable; and a constructionist world which emphasises that what is known is only in and via the mind (Harvey, 2002; Murray & Poland, 2006;
Williams, 2003). Critical realism emphasises that reality is not only ascertainable through empirical methods, or discursive practices, but also shaped by power structures. Consequently, this perspective is concerned with exploring the connections between human action and social and material conditions (Bhaskar, 2011; Murray & Poland, 2006).

By acknowledging the existence of a real biophysical world beyond immediate awareness and one that is socially constructed and dependent on human action, a position of epistemological scepticism and ontological realism allows for explanations of changes, and differences in practices and understandings that are less partial. Investigating the interaction of biophysical and social worlds provides another potentially revealing layer of explanation (Forsyth, 2001, p. 148).

However in advocating a more inclusive and integrative approach to science is not to dismiss research conducted within more restrictive paradigms. For example, positivism and its quantitative methods have helpfully identified “real” aspects of practices and events in Australian end-of-life care. Statistical evidence has provided the incidence and prevalence of those aspects, and also epidemiological data that, through the World Health Organisation and Australian Bureau of Statistics, have subsequently informed government policy and professional practice. Without such data, governments and hospital administrations could not effectively control and allocate health funding and resources. Yet, exclusive quantitative approaches and epidemiological data cannot explain the inconsistency and ambiguity, and diversity in outcomes and experiences also identified in Australian end-of-life care. There are other forces at work that also contribute to a more “complex” reality (Bhaskar, 2011, p.199).

Critical realism emerged as a hybrid between “transcendental realism” (Bhaskar’s general philosophy of science) and “critical naturalism” (a general philosophy of human sciences) (Bhaskar, 2011, p.190). It anchors its argument on a more complex understanding of reality, but gives a much richer and fuller description of that complexity (Potter & Lopez, 2001a, p. 11). The critical realism of Roy Bhaskar insists on a
structured, differentiated and changing/emerging world. In doing so, critical realism recognises “truth” as not only on the surface but also residing in underlying structures, and therefore embraces a coherent account of the nature of nature, society, science, human agency and philosophy (including itself) (Bhaskar, 2011, pp. 190-191).

2.1.1. The reality of a “structured” social world. Reality for those with a positivist world view is fixed, predictable and subject to universal laws (Williams, 2003). For those holding a more constructionist view, reality is non-determined and fluid, a “product” of human action from negotiating discourse (Harré, 2002; Harré & Varela, 1996). Indeed, some social constructionists suggest that nothing exists outside of discourse (Frosh, 1999).

In a Bhaskarian world that is structured, differentiating and changing, critical realists do not deny the reality of events and discourses, in fact they insist upon them (Bhaskar, 2011, p. 2). But, very importantly, the social world can only be understood or changed if the structures at work in generating those events and discourses are identified. Although ever-present and highly influential, these structures are often only implicit in observable patterns of events, and only identified through the practical and theoretical work of the social sciences.

Accepting a critical realist perspective is to acknowledge a multidimensional world. Traditionally such a world is regarded as objective - one of physical entities; subjective - one of understanding, meaning and truth; and cultural - the product of human mind, rules and norms (Hodgkiss, 2001, pp. 47-50). However, Scott (2001, p. 84) argued that the term “social structure” is elusive and ill defined. Although it is regarded as “institutional” where individuals act in terms of normative expectations, it is also regarded as “relational” because people often act outside of institutionally expected patterns.

Common social structures, for example, the State, religion, family, language and so on depend upon presupposed social relations (Bhaskar, 2011, p. 4). These may include
parent/child, husband/wife, doctor/patient or State/church, or many other combinations. However, the relations entered into pre-exist those individuals entering into them, but it is their activity that reproduces and transforms them. As relational and therefore not directly observable, social structures exist only in virtue of the activities they govern and cannot be empirically identified independently of them (Bhaskar, 2011, pp. 78-79; Scott, 2001). It is to these structures that critical realism directs its attention, both as an explanatory means of understanding social events and trends and focussed to the negotiated aspect of social activity that allows structural transformation and social change; in other words, agency.

Moreover, structures that are reproduced or transformed by agentic activity are also structures of power that might involve alienation, domination and marginalisation (Bhaskar, 2011, p. 6). For example, physicians holding non-normative views on end-of-life care might be professionally alienated, while biomedical science often marginalises patients, and physicians dominate medical decisions. Yet they may all be subordinated by institutional power that regulates resources. According to Potter and Lopez (2001a, p. 8), social action is best regarded as “meaningful” and does not occur in a vacuum. There are interests and goals (Giddens, 1979, p. 55; Harvey, 2002; Patomaki, 1991), and antecedents and consequences (Potter & Lopez, 2001a, p. 15). There is structural causality (structural efficacy) and effect (Potter & Lopez, 2001a, p. 6; Murray & Poland, 2006).

Although structures are also considered context dependent, being socially and historically situated (Mingers, 2004), the traditional dichotomy between social and natural worlds is unsustainable because there are multidirectional causes and effects between them. For example, dying is a biomedical process but may be strongly influenced and mediated psychosocially to affect both timing and manner of death.

Furthermore, social structures are concept-dependent (language-borne) and also “material” (Bhaskar, 2011, p. 4), as the world of personal experience attests to. They have real and tangible effects from many levels. People do experience homelessness and
hunger through, for example, socioeconomic and other related factors, and suffer pain through inadequate end-of-life care or cultural norms on the “expression” of pain and discomfort. Physicians who are caught up in the definitional ambiguity of particular medical practices or professional constraints when confronted by intractable patient suffering and requests to hasten death, will uniquely experience the way they are able to negotiate outcomes.

Social phenomena are the product of a complex plurality of structures (i.e. multilevel influences) (Bhaskar, 2011, p. 3). But depending on context, such structures are often hierarchically ranked in terms of their explanatory importance, and they influence differentially. For example, a physician with strong religious world views may be influenced in adhering to politically and legally prescribed ways of practice (that preserve life) and rely on these even in the face of intractable patient suffering that might prompt others to hasten death. Hierarchically, cultural or religious imperatives might direct professional conduct, which subsequently affects personal experience.

Yet, at the same time past experience also strongly influences values and decision-making (Kelly et al., 2003; Wilkes, 1993) and thus future practices. Some physicians may avoid dying patients after a previously aversive experience with them, but particularly rewarding experiences may also motivate continued engagement in end-of-life care. Such experiences may be the product of how physicians were able to negotiate complex multilevel influences, but experiential outcomes (aversive or rewarding) may also be coping resources for particular physicians who draw on them in similar and subsequent situations. A consideration of personal experience and its relation to other (non-linear) structural influences is important for understanding the reportedly inconsistent practices in end-of-life care.

Even so, intrapersonal influences like experience demonstrate still further complexity when an “embodied” structure is also included. Scott (2001, p. 84) regards habits and skills inscribed in human bodies and minds as capable of reproducing or transforming institutional and relational structures. In some ways this perhaps relates to
an existential aspect, the uniquely personal of the physician which is brought to bear “in the moment” when negotiating multilevel influences.

However, regardless of which structures are involved in any particular event, or point in time, they will differentially influence according to the level of agentic practice that is “possible” within them (Giddens, 1979, p. 55). According to Bhaskar (Harre & Bhaskar, 2001, pp. 36-37), structure forms the conditions for possibility, so any effort to explore these conditions relative to specific events (e.g. why and how deaths are sometimes hastened) may be helpful in understanding the diversity in practices and experiences of physicians reported in the literature. All the same, a perceived dualism of structure as causal yet subject to human action has been somewhat problematic for critical realism (Lewis, 2000; Patomaki, 1991).

2.1.1.1. The dualism problem: Structure/action (causality vs. agency). Generally speaking, critical realists contend social structure exerts a causal influence over people’s choice of action, and although social structure is unobservable, it can nevertheless be considered real because it makes a difference to observable human behaviour (Lewis, 2000). But critical realists also hold that social structure and human agency are recursively related, where they are both a condition for and consequence of the other (Giddens, 1984, p. 171). People constantly draw on social structures in order to act, and in acting they either reproduce or transform those structures.

Furthermore, critical realists also recognise a temporal dimension and contend that the interaction between social structure and human action must be understood as an inherently historical and “tensed” process in which at any given moment, people stand in temporal relations of priority and posteriority towards one another (Archer, 1995, pp. 65-92, 137-158). With critical realism, structures pre-exist and people confront these pre-existing structures in their context and act within the boundaries of possibility. To illustrate this, Lewis (2000) offers that every human agent is born into a world of social structures where they learn a particular language and face a culture and mode of economic (as well as legal and moral) expression which is not of their making. In effect,
these structures which consist of positions, practices, rules and resources, establish the conditions of “possibility” for social action (Giddens, 1984, p. 25; Mingers, 2004).

A critical realist view emphasises the interdependence of social structures and human agency because this makes structures social (Mingers, 2004). But this also avoids reifying them and therefore diffuses some of the “ontological critique” sometimes levelled at critical realism (Archer, 1995, p. 196; Bhaskar, 1989, p. 37; Harré & Bhaskar, 2001, p. 30; Harré & Varela, 1996; Patomaki, 1991; Varela, 2001, pp. 63-64). Humans are agentic and determined, yet the apparent dualism can be reconciled under critical realism (Bhaskar, 2011 p. 129). Certainly, physicians that provide end-of-life care must act within a pre-existing medical (and legal) system and have different possibilities for negotiating specific care or “good deaths”. However, given that physicians may act (compelled or not) in any number of ways within combinations of structures, the reality of a very “complex” social world, as emphasised by critical realists, becomes highly apparent but also amenable to richer descriptions and more inclusive (and non-reductionist) explanations.

2.1.2. A critical realist ontology. The notion of who we are and our place in the world, as we understand it (our nature of being), is described and explained by the philosophy of a particular world view. However, Bhaskar (2011, p. 181) refutes ontology as reducible to knowledge, of “being” in terms of epistemology (the “epistemic fallacy”), or reducible in terms of language/discourse (the “linguistic fallacy”). Rather, he also acknowledges the experiential of “being” in a structured yet changing and differentiated social world. We influence and are influenced by a world that is not always in cognitive awareness. We are not purely determined by outside forces (as behaviourists might argue in a positivist natural world), but possess agency. Our past experiences, thoughts, imaginations, hopes and aspirations are part of us, where our individuality uniquely and dynamically interacts with a complex structured social world that also exists independently of immediate discourse. We live in both a natural world and one of our

In such a philosophical worldview that regards both nature and the sciences as stratified and differentiated, the possibility arises, therefore, that the behaviours (nature) of higher order biological entities such as human beings might be both explanatorily irreducible to (or emergent from) and yet completely consistent with lower order physical laws (Bhaskar 2011, p. 24). Ontology from a critical realist perspective is irreducible partly because different (for example cognitively oriented) practices presuppose different and incompatible accounts of the world (Bhaskar, 2011, p. 153). It is not sufficient to explain rationality and epistemic authority by reference to what society “lets” us say (Rorty, 1980, p. 174), thereby rendering our “being” as contingent upon that. Societal or any other doctrines can always be reasoned according to one logic or another, to justify or criticise what one says and does (Rorty, 1980, p. 182). If ontology is irreducible, then what society or one’s peers or contemporaries “ought” to let one say or do is also legitimate and important to consider, especially in the case of conflicts between different discourses or ideological viewpoints (Bhaskar, 2011 p. 153). Certainly, such conflict is ever-present in end-of-life care, particularly as this is where the “nature of being” (or not) is grappled with. It is not necessarily irrational therefore to ask for death (Kissane, 2001; Kissane, Clark, & Street, 2001).

A critical realist ontology emphasises a potential to understand ourselves and the world we occupy, in a multitude of ways and without constraint, however, Bhaskar regards discourses as crucial for existentially differentiating between empirical (natural) selves and as moral agents (Bhaskar, 2011, p. 166). Without discourse we would be determined. There could be no true or false without discourse, and there would be no “choice”. He reiterates that materially we are determined but free as speaking and writing subjects. But he also stresses that there are no objective “factual” constraints in society because discourse is “distinctive” of human beings, and norms and values are irreducible to facts and descriptions (Bhaskar, 2011, p. 169). All things can be redescribed and facts
are not necessarily consistent across discourses. Ontologically, one is free to choose new descriptions (for all things including oneself) (Rorty, 1980, pp. 361-362). This is an important recognition by critical realists and assists in understanding the ambiguity in end-of-life meanings and inconsistency with practices.

Nonetheless, such ontological freedom also allows humans to engage in “abnormal” discourses (e.g. those that hasten death) and by redescribing these (e.g. in terms of intentionality or only foreseeability), assists coping with other discourses (e.g. religious or legal) that hold more constraining positions (Rorty, 1986, p. 14). However, in the act of redescribing, one also redescribes oneself and thus “identity and subjectivity” are also reinvented, both for self and others (Bhaskar, 2011, p. 171). Further, abnormal discourses can become normalised with constant exposure and if repeated often enough become habitual and influential; discourses are “historically” situated (Mills, 2004, p. 23). For example, with a powerful media and supportive people in authority and positions of power, “abnormality” can rapidly become accepted and enshrined in law (e.g. Australia’s Rights of the Terminally Ill act-ROTI, Oregon’s “Death with Dignity” act, and subsequent others that allow medically hastened death).

2.1.2.1. Identity and coping. Identity reflects a person’s sense of being but, as discussed above, the potential for redescription and reinvention means that identity does not necessarily need to be fixed or enduring. Possibilities exist when negotiating manifold influences and the multiple roles available, to assume multiple context specific identities. This is consistent with a structured yet differentiated and changing world. In end-of-life settings, physicians in their professional role may be an astute scientist, a compassionate guide and friend, a researcher and an administrator (to name a few). Although there is a contextual limit on possibilities, there are possibilities nonetheless.

Indeed, Harvey (2002) identified the production of identity where a Bhaskarian “dispositional self” (or self as a process) interacts with the world, transforming it, and, in turn, having its own possible paths of future self-realisation irreversibly set by a running string of reproductive successes and failures. This is how the Self builds a biography and
a social identity over time. The dispositional self is, thus, not so much a constellation of stable personality traits as it is an open-ended assemblage of time-dependent feedback loops capable of being monitored, of being recursively redefined and strategically redirected.

Identity may be further regarded as an important experiential aspect of being (Kelly & Field, 1996) and, thus, implies strategies for coping. For example, a physician who is law abiding but rejects legal and professional prescriptions in a particular situation and hastens death, intentionally or otherwise, may have acted as both scientist and as a compassionate and empathic friend. The latter identity may provide justification to some physicians for their actions, and cognitively mediate any sanctionable measures they may risk professionally or legally. Reframing a practice consistent with a particular identity, and its role, may be a coping strategy for any aversion physicians may experience in hastening death or any disciplinary measures they might expect.

Nonetheless, coping with social reality entails more than only coping with “other people”. It also involves other social entities including institutions, traditions, networks of relations and the like, which are irreducible to people and differentially constraining or enabling (Bhaskar, 2011, p. 175). This recognition provides some understanding as to why the experiences of physicians providing end-of-life care are so diverse.

Bhaskar’s social world is made up of “both” discursive and non-discursive structures within which narratives co-exist (Potter & Lopez, 2001b, p. 20). Discursive practices are important and certainly not ex nihilo as critics of constructionism might assert, but rather quite explanatory if considered in conjunction with pre-existing structures (Bhaskar, 2011, p. 29; Lewis, 2000). Narratives are highly influential, especially in terms of constructing particular meanings and identities (see McInerney, 2006 and ROTI) but they are still produced within pre-existing social contexts (e.g. a national media taps into cultural attitudes on death and dying). Critical realism accommodates such a plurality of structures (Lewis, 2000) and therefore has significant implications for clinical practice and research, not least, in end-of-life care.
2.2. An Explanatory Lens

The assumptions underpinning a critical realist account of science, where a structured, differentiated and changing world also considers causal effects from specific structural sources and emancipatory transformation (i.e. the possibilities of agency), allows us to see how the interactive elements in the world “hang together” (Bhaskar, 2011, pp. 146-7). In such an interactive and complex world, critical realism has crucial cross-disciplinary importance (Parker, 1999), particularly in the area of health and illness, and end-of-life care.

Certainly, there are diverse experiences and outcomes in health that are linked to multiple factors such as socioeconomic barriers, public education, and personal and social attitudes, to name a few (Trankle & Haw, 2009; Wainwright & Forbes, 2000). Murray and Poland (2006) recognised this when, in the interests of greater health equality, they effectively linked health psychology with social action by considering the broader social, cultural, political and historical (multilevel) contexts in which health and illness (and power) are enmeshed, but also the important dialectical relationship of the personal/individual to these structures.

In a more clinical context, Pilgrim and Bentall (1999) explored depression from a critical realist perspective because mainstream either/or approaches inadequately accounted for the complexity of depression in terms of its almost limitless symptomatic diversity. They considered a “middle ground” approach to the reality of psychopathology; one that accounted for the biological and the social (and experiential), and their interaction. Similarly, biopsychosocial models of health (and illness) (Adler, 2007; Engel, 1977, 1980), as multileveled, consider illness and disease as more than either a biological phenomenon or social construct, and not simply reducible to these (Williams, 2003). Yet, multileveled explanations may be far more exhaustive if they also consider intrapsychic influences.
Indeed, some of the work within the sociology of chronic illness and disability has been more explanatorily comprehensive by also considering the “self” and “identity” as core aspects in the experience of illness (Kelly & Field, 1996). These are important considerations for physicians, where their self and identity influences the care they provide in terms of the roles and role-contingent practices they adopt. In related fields of inquiry such as the sociology of death and dying, Lawton (2000) also considered these intrapsychic aspects and provided a powerful “realist” account of the dying experience. Through a graphic (and multilevel) ethnographic study of the fleshy vicissitudes and ravages of terminal disease; she described complex multitudinal processes, which quite literally render bodies unbounded and uncontainable. Physicians need to engage with the experiential aspect of dying patients and provide appropriate care, but they are also experientially immersed in that interaction themselves.

A critical realist stance in end-of-life care is helpful in understanding the day-to-day experiences of physicians, but also on those occasions when they might have hastened death. It seeks to establish the criteria that make particular practices possible, a matter of choice (or necessity) and how they have actually occurred. A critical realist stance has important implications legally, professionally and socially and could operate within accepted judicial methods. In end-of-life care it is important to understand what factors (e.g. cultural, institutional, professional or personal) predispose or ultimately prompt a physician to hasten death in some cases. If causal relationships are considered important they must be afforded a legitimate, if not dominant, role in dialogues that seek to establish physician culpability in patient deaths.

A critical realist investigation may be explanatorily enhanced if implemented with a compatible theoretical perspective. Bhaskar contends that “rational” (scientists are fallible) theory choices need to exhibit “practical effectiveness” but explanation (not prediction) is of prime importance and therefore this should drive theory choice (Bhaskar, 2011, pp. 19-20, 69-73). Indeed, theory should be chosen on its ability to answer a particular question (Peacock, 2000).
2.2.1. A multilevel systemic approach. Acknowledging that much of the social world operates at various levels is helpful in organising and understanding often quite complex information; and theories that provide such a multilevel capacity of analysis may be particularly revealing. For example, researchers like Vygotsky (Sociocultural Theory) focused on how culture - the values and beliefs, customs and skills of a social group, is transmitted to the next generation (Vygotsky, 1978, 1987), while multiple levels of influence to a complex system of relationships in the social world were also recognised by Bronfenbrenner (1989) who developed Ecological Systems Theory to study lifespan development. These researchers, and others like Kohlberg (1969; 1983) who generated a Theory of Moral Development, all demonstrated the often hierarchically arranged and nonlinear relationships of a nested system of influential social structures.

Systemic thinking is a well-documented approach in research. For example, General Systems Theory (GST) was proposed by Bertalanffy (1968, 1975) in the 1940s. According to GST, a whole system was more than the sum of its parts and therefore the parts of a system are best understood in the context of the whole. GST attempted to explain how related components at different levels interacted with one another in forming a system, including the interaction of these various units at different levels and the interrelationships among the units (Bowler, 1981). In particular, GST attempted to develop useful generalizations across systems; it argued that all systems had some characteristics in common and that it was useful to understand different systems in terms of those common characteristics.

General systems theory had a long tradition in the natural, behavioural, and social sciences (Bertalanffy, 1968, 1975), where it added substantial insights to the understanding of a wide variety of complex phenomena (Bowler, 1981). In generalist medical practice, GST has increasing advocacy to counter the reductionist biomedical approaches (and patient marginalisation) driven by “productivity” based on the number of patients seen per hour, and “quality” based on disease-specific process measures of care (Stange, 2001; Stange, Miller, & McWhinney, 2001). Changing environments and
expectations challenge medical practice to adapt by embracing complexity and interrelatedness (Félix-Bortolotti, 2011; Stange et al., 1998).

Systems may be conceptualised as analogous to the “structures” of Bhaskar’s critical realist philosophy. For example, a system may include the family within which there are hierarchically structured interpersonal (and intrapersonally mediated) relationships that interact to influence the lives of its members. In medical and end-of-life settings there are similarly structured systems that involve physicians, their patients and families, medical colleagues and also include legal and professional (ethical/moral) layers. There is potential interaction within and between different systems. At the same time, systems that interact may influence differentially. For instance, a system of government that incorporates cultural and religious values writes laws that influence personal and professional behaviour and thinking. However, laws that prohibit killing can be manipulated or reconceptualised, and physicians may hasten a death yet maintain professional and legal credibility. The end-of-life care provided by physicians may be motivated by a mixture of personal, professional and cultural (or other) factors and thus illustrates great complexity.

Recognising the cross-disciplinary importance of a systemic multileveled approach for researching complex social phenomena, Pilgrim and Rogers (1999) developed an effective analytical framework to investigate mental health policy and its underlying politics. To further illustrate the interdisciplinary and transdisciplinary utility of this three-tiered framework for analysing complex issues, Pilgrim (2010) later applied it to his investigation of systemic abuse within the Catholic Church. He identified interactive macro, meso and micro level factors in complex causal relationships, which fostered the perpetuation of abuse. Pilgrim advocated a “holistic scope” and spoke of “complex modern systems” and “multifactorial complexity”, but his three-tiered framework provided ease of analysis. Pilgrim’s approach is consistent with other theorists who recognised that although generalist systemic approaches demonstrate cross-
disciplinary utility they have limitations in their analytical ability to explain complexity (Byrne, 1998; Urry, 2003).

2.2.1.1. Complexity theory. Byrne (1998, p. 161) states: “Every PhD student in everything should get to grips with the “complexity” programme, not for reasons of fashion or even legitimate career building, but because this is the way the world works and we need to understand that”. Urry (2003, p. 12) observes that complexity is “a potential new paradigm for the social sciences, having transformed much of the physical and biological sciences”. He sees it as a means of dissolving some of the binary divides (whether quantitative/qualitative, environmental/social, structure/agency, or medical/sociocultural).

In moving beyond GST, which assumes homeostasis or equilibrium is a desired state (Bertalanffy, 1968), complexity theory holds that the real world has little to do with equilibrium (Byrne, 1998, pp. 29-32). Equilibrium means death (Bertalanffy, 1968). Although that may certainly be the case for patients at end-of-life, it is not the case for physicians who provide care to them. For example, although homeostasis might be desirable, physicians who experience burnout or struggle with conflict could not be considered as achieving that state.

Similarly, rather than assuming that system boundaries are largely fixed (Richardson & Midgley, 2007), in complex systems, the boundaries are continually changing and always permeable, with critical exchanges between the inside and out (Manson, 2001). For example, the legal boundary where palliative care ends and euthanasia begins is ambiguous and dependent on context. Physicians practicing within legal and professional boundaries also practice within their own personal boundaries and therefore end-of-life care further embodies that complex exchange between structures or systems. A conceptualisation of boundary permeability fits with a critical realist epistemology in terms of emergence and nonlinearity (Bhaskar, 2011 pp. 114-117). But, because permeability can also account for the uniquely individual of the physician and
their equally unique (context specific) interactions when providing end-of-life care, it is particularly relevant to the current research investigating ambiguity and experience.

If we acknowledge a complex world of hierarchically structured social systems, we also cannot unreservedly consider hierarchies fixed in terms of power, age, size, and formal position. Although parents are at the top of the family hierarchy (Bertalanffy, 1975), complexity redefines what those with formal authority should do and who wields it (Urry, 2003). In end-of-life care a hierarchy of authority may be inconsistent, for example although physicians generally preside over medical decisions and take responsibility for them, patients and their families might also have some input, while institutional authority may also influence the care a physician can provide.

Complex systems are always considered in relation to the larger systems outside and the smaller (sub) systems inside (Byrne, 1998, pp. 30-31; Urry, 2003). They cannot be understood otherwise. As the system changes, it, in turn, changes the environment (Anderson, 1999). Primary characteristics of complexity theory emphasise relations and networks, non-linearity, and emergence (Gatrell, 2005). Rather than being fixed, complex systems are flexible and accommodate uncertainty and change (Haggis, 2010; Keshavarz, Nutbeam, Rowling, & Khavarpour, 2010). Further consistent with a non-reductionist realist epistemology and an emphasis on explanation, methodological diversity is also possible, and indeed encouraged by a complexity approach (Williams, 2003).

Accordingly, complexity theory has demonstrated broad cross-disciplinary applicability with researchers finding it explanatorily revealing. For example, Byrne (2005) in Sociology, Davis and Sumara (2006) in Education, and Valsiner (1998) and Fogel (1993) in Psychology all illustrated its utility, while Folke, Hahn, Olsson, and Norberg (2005), in management and organisational contexts, regarded complex multitudinal influences in turbulent times of change and crisis as potential opportunities for creativity and adaptive governance. Sawyer’s (2005) book “Social Emergence: Societies as complex systems”, gives a further overview of recent work in this area, while complexity research has been similarly useful in the natural sciences like meteorology.
(Palmer, 1992), evolutionary biology (Cohen & Stewart, 1994), and neuroscience (Mainzer, 1996), and is making important inroads into primary healthcare research (Griffiths & Byrne, 1998; Litaker, Tomolo, Liberatore, Stange, & Aron, 2006).

Primary care practice is complicated (Stange, 2002; Stange, et al., 1998), with previous work demonstrating the challenges associated with changing clinician behaviour to improve care (Berwick, 2003; Eisenberg, 1985). Because opportunities for change vary at each practice, complexity theory suggests that interventions successfully addressing problems or barriers in one setting may have limited utility elsewhere. Hence, the design of interventions must take existing conditions, practice configuration, and dynamics into consideration. The specificity of death and dying, and terminal care, equally demands such an understanding of complexity.

In specialised end-of-life settings, experienced palliative care practitioners are certainly aware of the complexity of issues within the discipline (Palliative Care Australia, 2011a). Physical, psychological, social and spiritual issues need to be considered to ensure the highest possible quality of life for patients and their families. Interactions of factors within and between these categories result in diverse patient needs and call for attention to detail when evaluating patients and developing individual management plans. Recognising emergent qualities in relationships of entities with the whole, Munday, Johnson, & Griffiths (2003) contend palliative care cannot only focus on singular aspects in a complex yet specific interactive system of patient, family and others.

As end-of-life care evolves, an ability to provide individualised and effective palliation across settings is becoming increasingly emphasised. For example, patients and families facing terminal illnesses are turning with greater frequency to home hospice (where available) as an alternative way to provide care for dying family members (Kirschling, 1990, pp. 109-115). Kirschling presented an elaborate conceptual framework that blended three primary components: the family as a system, family life cycle, and components of practice. Families were presented as open systems (therefore non-predictive) that always have the potential for change and growth. In caring for dying
loved ones, families inevitably face changes in family structure, shifts in role expectations, altered expectations of the future, as well as the sadness of a loved one’s death. Kirschling articulated and applied family systems concepts to home hospice care that recognised critical issues, specifically, sources of family stress, the impact on couples when a partner is dying at home, the necessity of support for family caregivers, and the inherent wisdom and value of a collaborative approach to palliative care. Although American research, there is strong relevance for Australian community outreach programs and resourcing especially when, given the choice, most Australians wish to die at home surrounded by loved ones (Foreman, et al., 2006).

Consistent with, but extending such biopsychosocial considerations to health, complexity theory views the patient-physician relationship as constituted by complex responsive processes of relating (Suchman, 2006). The interaction of physician and patient can be viewed as an emergent, self-organising process. It is established and maintained by reciprocal, iterative psychosocial responses through which each mutually influences and co-regulates the other’s interdependent behaviour and personal experience (Adler, 2007). Adler suggests this mutual influence may be subjectively experienced as empathy, and may be skilfully employed by the clinician to directly improve the patient’s psychobiology. That relationship thus, also reconceptualises the function of the physician-from a provider of treatment to a co-participant in treatment, with emergent consequences for both patient and physician. Complexity theory and biopsychosocial considerations carry importance across medical contexts but, may be particularly relevant in critical/acute settings (e.g. ICU) where patients are more likely to die under a biomedical model of care.

2.3. Summary

Theories of complex adaptive systems carry strong pedigree and arguably have the potential to examine and articulate many aspects of complex phenomena which have thus far defied articulation by more conventional means. There are good reasons, however, why aspects of social complexity have resisted clear articulation for so long. For example,
the embedded nature of social systems; the sheer number of components involved, and the even greater number of connections between them; the fact that they are dynamic, in constant formation, constantly adjusting themselves to movements and historical effects both within and external to themselves; the permeable nature of boundaries between systems; and the fact that human elements of larger systems have consciousness, and can thus act intentionally upon such systems, as well as unconsciously carrying out actions in response to biological and social rules of which they are quite unaware (Kandel & Squire, 2000); render any social understanding obtained through less inclusive means as inadequate (Haggis, 2010).

Critical realism provides a “re-invigorated” series of research agenda, and methodological eclecticism in health and beyond (Williams, Birke, & Bendelow, 2003). As such, it may indeed profitably serve as an “underlabouring” philosophy, in health contexts like end-of-life care as it may elsewhere (Bhaskar 2011, p. 174). Critical realism does not so much deny or do away with other perspectives and approaches, including some of the important insights of positivism and postmodern critiques (Sayer, 2000). Instead, it attempts to engage with yet “go beyond” them, thereby moving toward a more satisfactory approach to the natural and social world, themselves inextricably and irreducibly bound together in relational, emergent, open terms.

In recognising the structured complexity of end-of-life care, the current research is grounded in a critical realist epistemology. Drawing on cross-disciplinary research using systemic approaches, particularly with relevance to medical contexts; I adopt a deterministic framework informed by Complexity Theory that emphasises a multilevel analysis. The following literature review is organised using a three-tiered systems approach (Pilgrim, 2010; Pilgrim & Rogers, 1999) that provides the descriptive and explanatory lens through which my data is ultimately analysed and interpreted. Such a multilevel structure incorporates macro, meso and micro levels for understanding end-of-life care practices and meanings, and explores their current ambiguity and lack of consistency across contexts, and how physicians negotiate and experience this. The macro
level considers more global and overarching aspects, for example, cultural influences like politics, religion, media, and philosophical/ideological considerations, customs, values and beliefs, morals and ethics. Meso level considerations address professional and organisational influences that include legal as well as ethical and moral implications, and particular medical ideologies with different care practices. The micro level examines the personal experiences of physicians exposed to multiple influences in end-of-life care and considers issues like burnout, interpersonal relationships, and intrapsychic factors.
Chapter 3

Macro Level Considerations in End-of-Life Care

All societies have some form of structure that contains customs and beliefs, rules and regulations, and the power to enforce. Particular philosophies and ideologies to life (and death) are constructed and guide moral and ethical thinking, social attitudes and behaviour. Australia, while reflecting its own uniqueness in many ways, shares philosophical and ideological commonalities with many other countries and they influence how life is engaged in and experienced. This chapter will review such global influences as well as religion and politics, mass media, and philosophical and bioethical aspects to end-of-life care.

3.1. Religion

Although modern Australia is regarded as multicultural and secular, Christianity exerts a powerful influence in the Australian way of life and could be argued as the most fundamental and enduring influence, particularly in a social world that is emphasised as dynamic and undergoing continual change. The Australian system of government is a constitutional monarchy with the Queen of England as Monarch and head of the Church of England. Traditionally, when any new government or politician is sworn into office it is with a solemn oath swearing allegiance to the constitution and the laws of the land. Excluding the current Prime Minister Julia Gillard, allegiance is customarily sworn with a hand on the Christian Holy Bible. Similarly, all Australian courts dispensing justice in
accordance with the laws of the land require that the whole truth be given and sworn by “Almighty God”, and provide extreme sanction for anyone wishing to perjure themselves. Again, this oath is traditionally sworn on the Christian Holy Bible although, recognising multiculturalism, courts also accept other Holy books. Australians also observe Christian holidays of Christmas and Easter as well as their Monarch’s birthday. Christianity is the dominant religion in Australia (Department of Foreign Affairs and Trade, 2008).

Furthermore, many Australian charities are Christian based and provide essential support to the community that would otherwise be neglected. Indeed the word charity is derived from the Latin “Caritas” (the Christian concept of spiritual and brotherly love for all people), and is the name adopted by the Catholic Church for one of its major charities. Without charities our hospitals could struggle to fund the research they conduct, and adequate investment in medical technology or community outreach programs caring for the sick and their loved ones (e.g. respite) could also suffer. The elderly and other disadvantaged sections of our community might also struggle without assistance from Christian institutions. As unacknowledged as those providing this assistance sometimes are, they are supported by a hierarchical and well organised Christian structure.

Many Australian hospices and end-of-life institutions began as church funded facilities and, even though funding is now administered by Federal and State Governments, and end-of-life care is entrenched in mainstream medicine, the values and philosophies provided by such foundations remain embedded in today’s hospice and palliative facilities (Saunders & Baines, 1983). Although, end-of-life care has developed considerably from its church-based roots, it was only in the recent past that nurses were often referred to as “Sister” and “Matron” and dressed similarly to nuns who once occupied that caring and supportive role. Today, the Christian traditions of end-of-life care continue with specialised pastoral workers and religious and spiritual counsellors who are a regular and vital part of end-of-life care settings, providing spiritual comfort and guidance to many patients and their families.
Christianity influences how physicians provide end-of-life care by grounding professional practice in Christian values that are egalitarian, caring and compassionate, supportive, and reduce suffering without inflicting harm (Palliative Care Australia, 2011b). Death should be painless, blameless and peaceful (Engelhardt Jr & Smith Iltis, 2005), but Christianity prescribes an overarching axiom that death is not deliberately hastened (Ashby, 2003; Gielen, van den Branden, & Broeckaert, 2009; Stempsey, 2010). Yet, within Christian-based end-of-life care there are physicians who take a moderate, perhaps even non-religious position towards hastening death, while others are guided by a more fundamental one (Cocconi et al., 2010; McCormack, et al., 2011; Seale, 2009).

3.1.1. Sanctity of life. A central tenet to the Sanctity of Life position is that control over life and death rests, in its most fundamental sense, in the hands of the divine creator – God, and is not something given to mortal humans (including physicians) to decide (Gormally, 2004). Of course, there are ideological differences within Christianity where for example, the Catholic Church opposes birth control while other denominations do not. However, one thing that unites Christianity is the position that death must never be intentionally hastened (National Council of Churches Australia, 1996, pp. 25-26). Sanctity of life is also intrinsic for other religions like Judaism (Dorff, 2005), Islam (Abdulaziz, 2005), Hinduism (Firth, 2005), and Buddhism (Keown, 2005), which all share a fundamental belief that a God or a higher force controls life and death.

Likewise, the Sanctity of Life position is held by a number of Australian politicians who are influential in framing laws and professional practice. For example, in 1997, the Christian Federal Parliamentarian and current Opposition Leader, Tony Abbott, in collaboration with some of his parliamentary colleagues, overturned the world’s first legal euthanasia program in the Northern Territory, The Rights of the Terminally Ill (ROTI) Act (Nitschke & Stewart, 2005). This was at a time when Australia’s Prime Minister, John Howard, also positioned himself as an unwavering monarchist. In 1995, the Chief Minister of the Northern Territory, Marshall Perron, who was a principal architect of that legislation, resigned shortly after the successful passage of the ROTI Bill.
through parliament. However, he was replaced from Canberra with Shane Stone, a Christian anti-euthanasia campaigner and close friend of the Prime Minister, charged with the task of overseeing the full implementation of the ROTI Bill, but also complicit in its demise (Nitschke & Stewart, 2005, p. 38). History illustrates how those in key positions of political power exert a huge social influence (agency) that may reframe laws and medical practice. ROTI was contrary to their position and they were able to overturn legislation enacted through proper democratic process. However, political influence becomes all the more possible with support from powerful like-minded institutions within the Australian community such as the Church and medical profession (Magnusson & Ballis, 1999; Nitschke & Stewart, 2005).

Indeed, another highly effective way the new Act became undermined was ensuring that Northern Territory doctors shunned the legislation. This was achieved through the Territory's Department of Health taking an explicit anti-euthanasia position by joining forces with the Australian Medical Association (AMA) (Nitschke & Stewart, 2005). The AMA, the Royal College of Physicians, specialties including the Australasian Chapter of Palliative Medicine, the College of Intensive Care Medicine, the Australian New Zealand College of Anaesthetists, and the Australian Nursing Federation all take up the sanctity of life position. They officially denounce any notion of hastening death intentionally through medical intervention. Yet at the same time, while God might be the final arbiter of death, these medical professionals have much control over the processes of life and death through scientific medical technology.

However, an official sanctity of life position does not necessarily constrain the personal understanding, beliefs and values held by physicians toward end-of-life care and practices that might hasten death (Magnusson, 2009). Oppositional positions are also available. For example, most Australian States have “Right to Die” societies “Dignity in Death” societies and “Voluntary Euthanasia” societies which advocate politically, publicly and professionally and are served by many actively practicing physicians across a number of specialties.
Indeed, further challenges to the sanctity of life position in end-of-life practices have occurred since the abolition of ROTI in 1997. Although unsuccessful to date, all Australian State Parliaments have been presented, sometimes on a number of occasions, with pro-euthanasia and assisted suicide bills (Volmar, 2009). However, sometimes political change brings the potential for cultural change, for example, Tasmania has a pro-euthanasia Premier and many of the unsupportive members of the previous South Australian Parliament are no longer there (ABC News, 2011). At the Federal level, Prime Minister Julia Gillard is on the record as holding atheist views (ABC News, 2010) and the balance of political power currently rests with The Greens who are strongly pro-voluntary euthanasia (The Greens, 2006).

Ongoing public and political debate over euthanasia and assisted-suicide, fundamentally divided along religious lines, is of importance to end-of-life care because physicians who do hasten death intentionally do not have a political or legal/professional structure to guide and protect them. Yet policy at the macro political level, religiously inspired or otherwise, permeates multiple levels in end-of-life care, from the negotiated bedside practices to how they are experienced by physicians and others.

Sanctity of life remains powerfully influential but may also be challenged. There are different end-of-life care positions taken up by physicians both professionally and personally. However, the various social structures influencing those views and positions shape the particular meanings, definitions and understandings that physicians hold and how end-of-life care is provided.

3.2. Mass Media

Death and dying, and particularly issues of euthanasia and assisted suicide, are topical issues receiving generous coverage in the media (Hausmann, 2004; Scolding, 2011). At the same time, the mass media plays a crucial role in the emergence and development of public debates (Silverstone, 1999). It mediates between citizens and their government; it provides stages for the expression of professional and lay opinions; it
constitutes an important channel for the dissemination of ideas and the mediation of experience. Through its ability to select and organise information, the media is also central to the process of agenda setting, influencing what issues will be considered important and worthy of attention (McCombs & Shaw, 1993).

Although the press may not determine what readers think, it does shape what they think about and subsequently talk about, and influences social movements. For example, McInerney (2006) analysed discursive constructions around death and dying and medicine in selected Australian print media at the height of Australia’s requested death movement (1995-1997). Requesting death was seen as “heroic” and contrasted strongly against the horrors of natural death and decay. Further, “heroes” were supportive medical practitioners and politicians, and those unsupportive were cast as “villains”. Such constructions create public perceptions of who physicians are and expectations of how they should practice.

The media traditionally endorses a “voluntary euthanasia discourse”, creating the perception of “choice” and legitimates euthanasia along those lines, a view that is also widely shared by the public (Hausmann, 2004). However, Hausmann argues that the press also draws on a “terminal illness discourse” where terminal illness becomes the marker justifying euthanasia. Vivid descriptions of suffering are given that become the determinant of hastening death rather than any preference or choice to die. Doctors wishing to alleviate the suffering of terminal patients sometimes hasten death but, in the case of terminal illness, acts of euthanasia (voluntary or otherwise) attract the label of “tragic” rather than “criminal” or “negligent” as they might in cases where terminal illness is not a factor. Distinguishing euthanasia further, as either acts of “mercy” or “murder”, is similarly influential in shaping public views (Janz, 2009).

As a media tool, language exerts a powerful influence on social attitudes. For example, a consistently supportive media stance towards family assisted suicide was evidenced by depictions of dying persons and perpetrators as autonomous and conscientious individuals; by idyllic portrayals of family relations; and by praising judges
for their lenient verdicts (Birenbaum-Carmeli, Banerjee, & Taylor, 2006). Media reports proliferate where a loving spouse or friend acted with compassion and mercy to assist a suffering partner to die (Scolding, 2011). Language like “stricken by” and “afflicted with”, mediates the public perception of culpability (Janz, 2009). The media engenders sympathy for the surviving partner while arguing with a single voice in favour of change.

Other journalistic strategies include treating degenerative dying as an aberrant condition, smoothing over botched attempts and abbreviating the decision making process, while presenting the law as a dated and “heartless” State system, and marginalising opposing voices, further enhances the supportive media message (Banerjee & Birenbaum-Carmeli, 2007). Journalists with a liberal inclination, who favour individual autonomy and shun the State’s infringement on personal liberties, glorify euthanasia advocates like Dr Kevorkian as rebels fighting against a backward State or pitied as pawns in a larger judicial drama (Kalwinsky, 1998).

The media thus also applies political influence. For example, referring to Tracy Latimer, a girl with severe cerebral palsy who was euthanased by her father, Janz and Hayward (2009) found left-wing (progressive) portrayals of this case not only created a “preferred version and vision of social order” (Ericson, Baranek, & Chan, 1991, p. 4), but also affirmed a utilitarian ethical and a normative framework of reference that could be used in courts of law to argue for the voluntary and, more importantly, the non-voluntary euthanasia of “defective” and “deformed” individuals. Contrastingly, publications of the religious right, countered this normative framework of utilitarian ethics by consistently providing space for Tracy Latimer’s story to be told in a more non-secular way that emphasises sanctity of life.

Birenbaum-Carmelia, Banerjeeb, & Taylor (2006) also observed that a media commending the self-reliance of families engaging with assisted suicide, and the call for decreased State interference in personal affairs, aligns with the neo-liberal spirit that has gained prominence in some countries since the 1980s; where people are encouraged to take control and responsibility for their lives, and also their deaths. In non-linear fashion
the media thus also reflects social attitudes, while further entrenching the ideologies underlying them through advocacy.

The media is powerfully positioned to effect social change or maintain the status quo. Although most medicalised deaths are not deliberately hastened, physicians will experience media influence both directly and through their contextualised interactions with patients and their loved ones, and other professional colleagues, regardless of their personal views on end-of-life care practices.

3.3. Philosophical and Bioethical Aspects to End-of-Life Care

Culturally informed understandings of life and death also colour expectations as to how end-of-life care should be conducted (Fenigsen, 2011). The way we fundamentally conceptualise life and death, for example, if we consider it natural but under divine control, or if we consider it ruled by universal laws of science and therefore largely accessible to human control, will sometimes provide answers to questions like “can or should life be ended” and if it can then “how” or “when”? Such questions are integral to end-of-life care when considerations need to be given to how much suffering dying patients are required to endure. That also then raises further questions on what actually defines suffering (Dees, Vernoij-Dassen, Dekkers, & van Weel, 2010). However, regardless of fundamental beliefs, answers to these sorts of questions are seldom answered consistently.

3.3.1. Manipulating life and death. Current science and medical technology has never had a stronger ability to create or prolong life. Yet, that ability also raises huge ethical issues. For example, In Vitro Fertilisation programs create large numbers of embryos, with the surplus or unsuccessful implants later discarded (Gruen, Grabel, & Singer, 2007) and for some, particularly those holding a sanctity of life position, this may potentially outweigh the benefits (Damiano, 2011; Roberts, 2006). Moreover, in practices of preimplantation genetic diagnosis (PGD), new life is sometimes created specifically for the purpose of finding a genetically pure match for a sibling who might be suffering a life
threatening condition, for example, one who is perhaps in dire need of a bone marrow transplant (Damiano, 2011). On the face of it, this might seem an admirable cause and few parents would not pursue such a course if it promised a potentially normal life for their suffering or dying child. However, others, including the specifically created donor child, or “saviour siblings” as they are sometimes referred to (Australian Medical Association, 2004; Liu, 2007; Strong, 2009), might see their value and purpose in life as a source of spare parts and no doubt such genetic manipulation or selection further exposes a raft of other ethical and moral considerations, some of which are probably still to be evaluated. Similarly, with the advances of science and genetic technologies, the issue of stem cell and embryonic research deeply polarises opinion but also has the potential to enhance and prolong life. So in order to delay death, medical science and its physicians sometimes take on the role of “divine creator” (Roberts, 2006).

However, an advance in medical science and technology that has enhanced the ability to prolong life is also a double edged sword because it raises questions on just how far life should be prolonged. Ostensibly, the answer to this centres on “quality of life” but exactly what that is, specifically for each individual, is difficult to define (Johnson, 2011; Singer & Bowman, 2002). Indeed, the machines in the intensive care unit can take over most physiological functions reasonably well and prolong life far beyond the point of futility, and futility is another divisive concept (Faunce & Stewart, 2005; Seale, 2009). Physicians need to decide, according to individual situations, when to disconnect life support and withdraw life sustaining treatment. Although there are medical guidelines and parameters around such practices, for example “clinical care pathways”, (a meso level consideration addressed in the following chapter), decisions are also informed by broader considerations of what is culturally and legally acceptable to ending life but they are frequently ambiguous and not consistently agreed upon by physicians (Lindblad, Juth, Fürst, & Lynoe, 2010; Solarino, Bruno, Frati, Dell’Erba, & Frati, 2011). However, physicians must also have an understanding on what constitutes death.
3.3.2. Clinical definitions of death. For many, the way death is defined appears ambiguous and without consensus, and clouds end-of-life care and decision making (Singer, 1995). There is moral and professional disagreement on how to define death and it is an ongoing source of argument and debate in the highest legal forums (Faunce & Stewart, 2005). Cross-cultural definitions of death are also variable, for example, until very recently, Japan differed from most other developed countries such as the USA, Canada, UK, Australia and those in Europe, which adopted the criterion of “brain death” to inform professional and legal judgements on when to withdraw life sustaining treatment (Morioka, 2001; Yoshioka et al., 1986). Declaring clinical death in Japan had been at the discretion of physicians who could decide between their own interpretation of brain death or “traditional death” (cardiac death) (Aita, Miyata, Takahashi, & Kai, 2008; Mizuguchi, 2010), while individual Hospitals also had unique policies on withdrawing life sustaining treatment (Akabayashi, 2002). Now, consistent with other developed countries, standardised brain death criteria (if also agreed with by family) has become legally accepted in Japan since 2010, particularly when considering organ donation (Mizuguchi, 2010).

However, what constitutes “brain death” is particularly uncertain. For example, religion often defines brain (and physical) death as when the soul departs, or the loss of personality (Eberl, 2005). Some pro-life groups and Catholic philosophers, consider death to be the irreversible loss of “integrated organic functioning”, or total brain death, because they regard the brain as the organ that maintains the dynamic equilibrium of the entire system (Eberl, 2005; Singer, 1995). Others consider brain death as the permanent loss of consciousness or intellect, in other words cortical function, while the Harvard Brain Death Committee defined the commonly accepted medical criteria for brain death as “irreversible coma” where; for example, those in a “persistent vegetative state” cease to have any discernible brain stem and central nervous system activity (Beecher et al., 1968; Singer, 1995). Yet, even this definition was somewhat broadened by the United States Uniform Determination of Death Act by changing the Harvard Committee’s reference to
the absence of central nervous system “activity” to the absence of central nervous system “function”. In a sense, this made the definition more permissive because, as the United States President’s Commission recognised, electrical and metabolic activity may continue in brain cells or groups of cells after the organ has ceased to function (Singer, 1995). It might also be argued that a more permissive definition of brain death might facilitate earlier access to viable organs for transplanting while at the same time, in a neoliberal sense, taking some load off a medical system that is increasingly burdened by growing numbers of patients occupying life support systems and other medical resources.

Nevertheless, others, including many in Japan, believe death should be further defined as the cessation of organ function such as heart or lungs because the heart may still beat and a patient may still be warm, pink and breathing, and display reflexive movement when the brain is deemed to be dead (Morioka, 2001; Smith Iltis & Cherry, 2010; Yoshioka, et al., 1986). Furthermore, research has shown that when brain dead patients are cut open to remove organs for transplantation, their blood pressure may rise and their heartbeat quicken (Halevy & Brody, 1993). Such reactions indicate the brain is still carrying out some of its normal functions. Cortical function and other higher brain regions may be permanently damaged and non-responsive but lower brain areas such as the medulla may still have limited capacity. This potentially poses severe moral, ethical and legal dilemmas for physicians who, metaphorically, may be compelled to seal a patient’s coffin when some of these life signs are still intact.

3.3.2.1. Organ donation. The issue of organ donation is receiving increased prominence in aging Western cultures but in practice is contingent upon being able to declare actual death according to how it is conceptualised. For example, New South Wales has strict guidelines in place where, if using the criteria of “cardiac death”, death must occur within 30, 60 or 90 minutes (depending on the organ) after removal of life support; otherwise donation cannot proceed (NSW Government, 2011). Yet, such an arbitrary timeframe is sometimes seen as unrealistic and impractical; it denies the wishes of patients and families, and wastes viable organs. Indeed, one specialist ICU physician
described a case where physicians had removed life support and cardiac death occurred at 62 minutes; the physicians involved adhered to guidelines but were deeply divided about whether they should have proceeded.\(^1\)

Certainly, organ donation demands that organs are removed as soon as possible after death to ensure optimum success for transplantation. However, if “brain death” is the accepted criterion for actual and permanent death then, as described above, physicians are potentially harvesting organs from patients who still retain biological life-signs. Indeed, an American patient kept alive on life support after suffering a gunshot wound to the head, was only pronounced officially dead after the removal of his organs for transplantation (Tomlinson, 1990). Adding further complexity, another patient might have signed a valid advance care directive, which specifies that they must not be resuscitated or subjected to any life sustaining interventions, yet that same patient may have also consented to organ donation, but in many cases patients must be kept on life support until a recipient is ready for a donated organ. This can create another dilemma by placing two different types of legal directive in conflict with one another. Beside the strong potential for conflict between patient families and medico/legal fraternities, physicians may also struggle to reconcile personal conflicts between their own morals and values, and social and professional imperatives.

3.3.3. Terminating life. Despite the illegality of euthanasia and assisted suicide in Australia, physicians need to understand those meanings but reconcile them in particular situations where their decisions will have some impact on either shortening or prolonging life. There are culturally prescribed legal and professional guidelines that need to be applied regardless of a physician’s personal position on such issues. In some situations, physicians are legally allowed to terminate life yet in others, where some might see it equally or more justifiable, they are not.

For example, although Australia has numerous pro-life groups that oppose abortion, a majority of the population is supportive if it is performed due to acceptable

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\(^1\) Dr Anders Aneman, personal communication with the author, September 22, 2010, Liverpool.
needs and according to accepted medical practices (Betts, 2009). What exactly constitutes acceptable needs and practices was determined at a cultural/political level, enshrined in law, and then written into professional practice. Abortion is also partly covered through Medicare (Pratt, Biggs, & Buckmaster, 2005), somewhat reframing it's meaning as a medical procedure. The right to terminate life, if it is considered that way (abortion is often referred to as terminating pregnancy), is performed due to health and other personal reasons, sometimes regardless of viability, and contingent upon when a human life actually begins and that is arbitrarily decided. Normally most abortions are conducted by the end of the first trimester at 12 weeks but variances across Australian States allow abortions to be performed up to the end of the second trimester at 24 weeks and to a maximum of 28 weeks in South Australia (Pratt, et al., 2005). However, any abortions performed within the second trimester are usually at the discretion of individual physicians. Although abortion is culturally, legally and professionally accepted, when it comes to life and death physicians have their own understandings of whether they are actually ending a human life and if or when it is justified.

Nonetheless, the idea of what constitutes a human life is problematic for physicians in some situations because while they may legally terminate a healthy viable foetus, they may not terminate a pregnancy that progresses beyond a stipulated timeframe even if the foetus is suffering catastrophic deformity/impairment with little chance of a normal life. Only, a risk to the mother’s health would provide grounds for termination. For example, anencephalic babies (born without brain, having brain stem only) are allowed to just die naturally. Some may cry, cough or sneeze and express behaviours similar to healthy babies and although they will not generally live beyond a few hours, some live for up to three months (Singer, 1995). Yet those babies and others that are cortically dead, either through extreme prematurity or from a mishap during or shortly after birth (e.g. oxygen starvation), will never regain consciousness. Even though some babies may stay alive for some time, normal medical practice is to just allow them to die “naturally”, sometimes even prolonging the inevitable and keeping them alive indefinitely
through artificial means, particularly at the request of parents (Leenen & Ciesielski-Carlucci, 1993; Singer, 1995). However, because they were not aborted within the womb, their life can now no longer be legally terminated. Physicians must differentiate between killing and letting die.

It is no different in end-of-life care where patients endure suffering in different forms. Physicians need to carefully titrate to provide legally and professionally acceptable care (even if not always culturally/personally acceptable). However, it might be hard to understand how one can legally abort a healthy life not yet lived but not a dying one that has. Dementias like Alzheimer’s disease are often comorbid in elderly patients at end-of-life and many also suffer delirium at end stages of their disease due to psychoactive drugs, drug interaction, and the effects of their illness progression. Yet, for many patients so afflicted they bear no resemblance to the person they once were, and never will. This is not only undignifying for the patient but also very difficult for their families. How we as a culture conceptualise life and the value we place on it, is not always congruous but is directive in how it may be ended or prolonged.

3.3.4. Killing versus letting die. The distinction between killing and letting die is a prevalent consideration in end-of-life care and something physicians need to deal with every day regardless of where they stand on issues of euthanasia and assisted suicide (Douglas, 2009; Goodman, 2010; Ho & Penney, 1992). That distinction is a strongly philosophical and bioethical one but one with moral and legal implications for practices at the bedside.

There is, clearly enough, a common-sense view that some outcomes are made to happen (by some kind of positive involvement of an agent) and some outcomes are allowed to happen (by some kind of negative involvement of the agent) (Howard-Snyder, 2002). Certainly, administration of narcotics for symptom control is a positive act but generally provided with titration in an effort to reduce suffering while not at the same time hastening death. Withdrawing or limiting treatment is regarded as a negative or passive act that is aimed at reducing the futility of treatment, particularly those that are
more aggressive. In both cases there is an expected outcome that is balanced against the patient’s condition and needs. On the face of it this may seem quite straight forward but if death is actually hastened as a result, which often occurs at end stages, it could be deemed in either case as killing the patient or letting them die depending on particular circumstances (McLachlan, 2010; McMahon, 1994; Thompson, 1999).

The distinction between killing and letting die must, therefore, also be considered in terms of death being intended or only foreseen (MacIntyre, 2006). For example, even with titration, opiates can depress respiration especially in those patients where respiration is already compromised as part of their illness, but as patients become more tolerant increased doses are then required, sometimes in bolus quantities, to achieve sufficient analgesia (Douglas, et al., 2008; Fohr, 1998). If death then ensues, some may say the physician has only managed the patient’s suffering and allowed nature to take its course, but others might equally say that increasing analgesia and depressing respiration has a foreseeable outcome and is an agentic act of killing (Quinn, 2001). Similarly, withdrawing treatment such as a ventilator is regarded as letting nature take its course because life is only being preserved artificially anyway. But there is 100% certainty of the patient dying when the ventilator is removed and it is the physician who decides (intends) and physically removes it. Such an act cannot, therefore, be considered “passive”.

Australian law differentiates between killing and letting die only on the basis of whether an allegedly hastened death was intended or merely foreseen. And yet this is a difficult position for the law if it holds an absolute view that killing is not permissible because a death that is merely foreseen but with 100% certainty is a potential exception to that rule. Some “killings” may therefore be allowed. However, a conviction is contingent upon a physician confessing intent, although the case of The Melbourne 7 shows otherwise (Magnusson, 2002, 2009), or at least compelling evidence that a physician was derelict in his professional duty. Australian law regards culpability for killing as black and white, yet practices in end-of-life care may be anything but those colours.
3.3.4.1. The concept of force majeure. Australian corporate law considers the concept of “force majeure” as a mediator of professional and personal culpability; for example, “acts of God”. Unlike its use in countries such as the Netherlands and Belgium where euthanasia and assisted suicide are now legal, there is no scope in Australian medical end-of-life law to consider the concept of “force majeure”. This was a recognised defence (now no longer necessary) in the Netherlands and Belgium prior to legalisation of these practices (Pollard, 2008; Van Der Weyden, 1997). Force majeure, or “superior force”, was considered in the light of a multitude of pressures a physician may face when providing compassionate and professional end-of-life care (Leenen & Ciesielski-Carlucci, 1993; van der Wal & Dillmann, 1994). In particular, it was recognised that physicians are subject to not only cultural, professional and legal influences, but also significant psychological and emotional influences that direct them in patient care. By making that consideration, Dutch and Belgian law better recognised the important specificity of context when deliberating over individual cases of alleged hastened death. Another important factor is that with some avenue of defence it also encouraged greater honesty in physicians who did not need to reconceptualise their intent, before the law, in terms of only foreseeing death.

Rights of patients are central to end-of-life decisions, at least insofar as doctors generally have a duty to provide care to patients who want to be treated, an obligation to withhold treatment from patients who refuse it, and an obligation to consider what a non-competent patient might or might not have consented to, had he/she been competent (Douglas, 2009). Whether a physician is acting appropriately according to accepted medical and legal practice really is determined by the individual situation the physician is confronted with. However, a physician may fundamentally hold a position consistent with sanctity of life views and not intend to kill a patient under any circumstances, but there comes a point where prolonging life futilely and inflicting greater suffering cannot be tolerated ethically or in terms of patient rights, or for what we as a culture consider humane. Patients will die and physicians need to manage this with those considerations in
mind and apply them equally but specifically. Yet physicians need to be clear on whether they are killing or allowing a patient to die and, at the same time, carefully navigate generalised legal and professional imperatives that may frequently appear ambiguous and unhelpful.

3.3.5. Moral guidance. All cultures have a moral code with which to live by, a code that reflects the basic values and behaviour expected by that particular culture. Christianity, at the very least, provides values of compassion, altruism, peace and understanding (and hope) in most Western cultures. Core values permeate all aspects of everyday life influencing politicians and laws, they prescribe certain professional and personal behaviour, and because of their ubiquitous nature are internalised already from a young age through familial and other social influences (Bronfenbrenner, 1989, 1995; Kohlberg, 1969; Kohlberg, et al., 1983). Western cultures in particular, generally promote four principles of respect (for autonomy), justice, non-maleficence, and beneficence which form a commonly held set of pillars for moral life (Dawson & Garrard, 2006; Gillon, 1994).

Professionally, physicians swear to uphold such core cultural values and morals, and practice ethically to promote their patient’s welfare and the reputation of their profession (Antiel, Curlin, Hook, & Tilbert, 2011; Veatch & Macpherson, 2010). Two particularly fundamental principles that guide physicians are beneficence and non-maleficence. Broadly speaking, beneficence means to “always do well”, by providing benefits to persons and contributing to their welfare; non-maleficence represents an obligation not to inflict harm intentionally (Dawson & Garrard, 2006).

In medical ethics, the physician’s guiding maxim is “first, do no harm” (from the Latin - primum non nocere), a tradition in medicine even before Galen in ancient Rome (Smith, 2005). Non-maleficence, which derives from the maxim, is one of the principal precepts of medical ethics taught to all medical students and is a fundamental principle for emergency medical services around the world (Dawson & Garrard, 2006). In practice, it may be better not to do something, or even to do nothing, than to risk causing more
harm than good. It reminds the physician that they must consider the possible harm of any intervention, particularly one that carries an obvious risk of harm but a less certain chance of benefit. Certainly, physicians will create scars in order to repair a heart problem, and amputate a foot to save the whole leg, but such harm is a means to a higher end. However, practicing with non-maleficence is not always so straightforward because when a physician is confronted by the intractable suffering of a dying patient, something like the “judicious” use of medication may be open to interpretation if there is a foreseeable chance of death ensuing closely thereafter.

The principles of beneficence and non-maleficence are particularly pertinent for end-of-life care and at the forefront of considerations for physicians deciding treatment. However, such noble concepts can often only guide because of the unique individuality among patients and their situations that requires care to be administered very specifically. There may be vast differences as to what is beneficent or non-malefent in each particular case. Indeed, beneficence might well conflict with non-maleficence because “doing well” might be to perform euthanasia or an assisted suicide, but that could also be seen as doing the ultimate harm.

Debates over philosophical and bioethical implications of end-of-life care most likely will (and probably should) go on indefinitely. In the meantime, however, physicians need to decide “appropriate” end-of-life care on a daily basis that is specific and gives equal consideration to all of their patients. It may be a very simple philosophy, but reconsidering Jeremy Bentham’s (1748-1832) forceful opening statement of utilitarian hedonism in his *Introduction to the Principles of Morals and Legislation* (Bentham, 2001), might be helpful:

Nature has placed mankind under the governance of two sovereign masters, pain and pleasure. It is for them alone to point out what we ought to do, as well as determine what we shall do…they govern us in all we do, in all we say, in all we think. (p. 1).
In the end, these are the two principles that everyone is subject to, regardless of membership with a particular race or culture. These same principles are also embodied by the creed of the medical profession in Australia, specifically to enhance quality of life and therefore the intrinsic pleasure of that life, while at the same time eliminating pain and suffering. Yet, these two fundamental principles that could represent true equality in moral rights for all often clash with other philosophical viewpoints that provide contradictory ethical and moral directions. It is not surprising therefore when Australian physicians engaged with the suffering of the dying and terminally ill struggle to negotiate and then justify their decision-making and practices to patients and their families, and ultimately to themselves.

3.4. Egalitarian Expectations of End-of-Life Care in Australia

By world standards, Australia is fortunate to have the capacity to provide a health care system that is relatively accessible to all of its citizens. The expertise of its practitioners, the medical technology at their disposal and the cutting edge medical research conducted, places the Australian health care system in an enviable position by comparison to other developed countries.

The taxation funded Medicare system in Australia is a universal health insurance system which provides free access to public hospital services and up to 85% of the fee for some out-of-hospital services like radiology, physiotherapy and mental health (Australian Bureau of Statistics, 1996, 2006b). However, the Australian government also encourages and partly subsidises a private health insurance system and provides a conditional Pharmaceutical Benefits Scheme to cap the price of particular medications (Australian Government Department of Health and Aging, 2006). The Australian public health system does not exclude on the basis of an individual’s capacity to pay (Becker, 2001; Washington, 2001). This does not mean that services are not prioritised and waiting lists are not applied, however, ultimately everyone is treated.
Providing such health care is not possible without considerable expenditure however, and a significant driver in escalating health costs is the developing litigious mentality in Australia which now somewhat parallels the health system in the USA (Cunningham & Wilson, 2011; Kessler, 2011; Studdert et al., 2005). Rising professional indemnity insurance premiums are factored into health costs but forces physicians to practice “defensive medicine” (Studdert, et al., 2005). Physicians fearing malpractice suits want to be seen as doing everything possible for their patients and are often compelled to ordering unnecessary diagnostic tests and procedures (Cunningham & Dovey, 2006; Salem & Forster, 2009). Yet, even with new legislation designed to minimise “assurance” type (unnecessary additional testing) and “avoidance” type (avoid treating high risk patients) measures, the results of a qualitative survey completed by 90 physicians revealed that many medical practitioners in New South Wales remain unaware of the legal reforms and the consequent reduction in their legal liability and continue to practise defensive medicine (Salem & Forster, 2009). These reforms, while not the same across all states of Australia, have been in effect since 2002 and perhaps illustrate the limitations of law reform to effectively engender social change without the active use of educative and other implementation initiatives. For example, it is unclear whether defensive practice strategies are also further promoted by health management in an effort to protect their institutional “duty of care”.

The cost of technology, however, is another huge driver of medical expenditure; particularly the cost of imaging (Bodenheimer, 2005). Yet physicians must balance their perceived obligations to their patients with those placed on them by the government, through medical institutions and management, to more effectively utilise services and manage expenditure. Physicians therefore also become “gate keepers” of health services by determining who receives specific services and who does not (Davis & Slater, 1989).

Rising current and projected expenditure to meet Australia’s health care needs is becoming increasingly unsustainable, especially with an aging population and decreasing scope for taxation. There is a greater onus on individuals to take more responsibility for
their health through adaptive lifestyle choices and use professional services more sparingly. It makes good sense to discourage those with common colds or minor ailments from choking up hospital emergency rooms because of a reluctance to consult a private physician and pay for their own medication. Australia is unlikely to follow an almost exclusive “user pays” American health model, but utilitarian attitudes may begin to influence what we expect from health services and expect our taxation to cover.

Indeed, the burden of health care particularly for those at end-of-life is being increasingly met by families, and often with little funding support or adequate respite (Monterosso, Kristjanson, & Phillips, 2009). Clearly many terminal patients wish to die at home surrounded by their loved ones and many family members accommodate that willingly even if it poses difficulties (Hudson, 2004; Kübler-Ross, 1969; Palliative Care Australia, 2004). At the same time palliative care encourages dying patients to spend time at home for as long as possible, providing in-patient services to bring symptoms under control and then community outreach, as available, to assist home care. This is beneficial in terms of freeing up hospital beds and facilitating the wishes of dying patients, but reflects an ideological change to a more collaborative and shared approach in managing care.

Such an approach to care also has benefits in terms of promoting greater patient autonomy and control over decision making but dying patients sometimes also see themselves as a burden on their families. Quite importantly, greater respect for personal autonomy has underpinned growing support for a right-to-die (Gostin, 1997; Judd & Seale, 2011; Rosenfeld, 2004). Indeed, economic pressures faced by families supporting older members and those of society in providing universal or subsidised health care, are fostering duty-to-die attitudes in some elderly people and others who feel they are a burden (Konishi & Davis, 2001). These concepts, particularly the latter, remain relatively unexplored. However, acceptance of a duty-to-die may already be creeping into attitudes, particularly as Western populations’ age. Although Konishi and Davis found Japanese nurses strongly rejected the concept, other Western nurses gave it weak support. Some
patients feel abandoned by their families or a burden to them, and more pervasive neoliberal attitudes within Western health, that influence everyday practice, could be accused of regulating the treatment older patients can receive (e.g. chemotherapy or radical surgery may not be considered a cost effective allocation of resources) especially when strained public health expenditure emphasises greater “individual responsibility” rather than “community” or “public” obligation (Alston, 2007; Davies & Gannon, 2006; Rumbold, 2006). A duty-to-die attitude is perhaps another confronting issue health professionals might need to negotiate especially if it underpins increased requests to hasten death.

3.4.1. Neoliberalism. More utilitarian attitudes foster other ways of thinking that become influential and quite pervasive across society. Structural discourses like “neoliberalism” currently dominate many Western institutions such as education and academia (Davies & Gannon, 2006). Neoliberal regimes of thought remove the locus of power, particularly in educational and academic contexts, from practicing professionals and their knowledge and give that locus to economists and administrators to make policy with more fiscally important bottom lines. Neoliberalism is characterised as the “death of society” where modern individuals within society who once regulated and self-managed their own behaviour, are now in need of a new kind of management, surveillance and control (Davies & Gannon, 2006, p. 62).

Neoliberalism is also pervasive in other areas of Western society; for example economically responsible provision of medicine and health care, particularly for those at end-of-life is emphasised at government and institutional levels (Alston, 2007; Rumbold, 2006). Economics may prohibit certain interventions that prolong life (and perhaps also reduce suffering) and doctors who frequently become gatekeepers of health services, sometimes contrary to their own wishes and those of patients and their families, must negotiate a balance between economic imperatives and patient needs. The associated surveillance ensures that medicine is practiced from within these new ideological structures and penalises, in terms of financial (e.g. reduced funding) or professional
sanctions (e.g. redistribution of responsibility), those that resist (Heide, 2011). However, although neoliberal systems of thought may be a constraining influence, the structures that also define accepted legal and medical ideologies are sometimes challenged and reflect the variance within end-of-life care practices when doctors provide interventions that may be considered euthanasia or assisted suicide in an effort to reduce patient suffering. There may be other possibilities for action when beyond the reach of surveillance that, seemingly, appears ubiquitous within institutionalised structures.

Davies and Gannon (2006, pp. 16-17) suggested that in a process of “subjection” everyone is presented with and inserted into discursive positions by practices, which locate us in meaning and regimes of truth. Although it might seem contradictory, we learn to master these positions while also being submissive to them. For example, Butler (1997) states:

The more a practice is mastered, the more fully subjection is achieved.
Submission and mastery take place simultaneously, and it is this paradoxical simultaneity that constitutes the ambivalence of subjection. Where one might expect submission to occur in a yielding to an externally imposed dominant order, and to be marked by a loss of control and mastery, it is paradoxically marked by mastery itself… the lived simultaneity of submission as mastery, and mastery as submission, is the condition of possibility for the subject itself (p. 116.).

This means that, for example, doctors who might feel constrained and subjected by the currently dominant medical discourses are often not only the authors and architects of such discourses but also facilitate them through their mastery that further promotes them. But mastery may also provide possibility for change through the exercise of power and in a process of continual negotiation, influences that guide care, perhaps inappropriately sometimes, are mediated and may partly explain why practices are inconsistent across individual situations. Some people seem more adept than others in navigating a management system and can “make things happen”. For example, with the correct use of language, and professional respect, palliative specialists might be able to transfer terminal
patients out of futile and aggressive intensive care settings and into their care with more appropriate goals. Similarly, by talking the language of economists and administrators in terms of suitable modelling and outcome measures, care at the bedside may be optimised through effective resource appropriation.

Physicians who provide end-of-life care must do so in a way that is compatible with cultural expectations, prioritises their patient’s welfare and autonomy, but also upholds the values and reputation of their profession, and their own ideals and standards. Physicians who are intimately engaged with life and death are influenced in multitudinous ways that may vary considerably across different situations. For example, multicultural Australia embraces diversity which physicians need to reconcile when providing end-of-life care. Indeed, people from some cultural backgrounds require that “everything is done” despite overwhelming evidence of futility, particularly when encouraged by other physicians, while others will more readily allow a loved one to die (Hillman, 2011).

Furthermore, although other resources might be made available, utilitarian or neoliberal pressures may limit some aspects of care that a physician considers important for a dying patient. Similarly, institutionally prescribed “defensive” practices may not be in the patient’s best interests and conflict with the professional and personal values a physician holds.

3.5. Summary

Macro level influences are particularly powerful and enduring, and interact with influences at other levels. Indeed, religious and political/legal doctrines are often internalised early in life through family and other social structures. Corresponding moral and ethical attitudes, that are prescriptive of social order and behaviour, shape meanings and particular definitions, and guide medical practices. Physicians are subject to these influences in every end-of-life interaction they engage with, sometimes only implicitly, but frequently quite explicitly, and actively negotiate them in the best way they can. Their own experiences, but particularly those of the dying and their loved ones, are contingent upon this, and therefore important to identify.
Chapter 4

Meso Level Considerations for End-of-Life Care: The Bedside

Meso level influences may often be found at the bedside and affect the way end-of-life care is provided to individual patients. These influences shape the way care is understood in different settings and specialties, and directs focus toward particular outcomes. It includes professional education and training, and institutional and managerial imperatives. Meso level influences, often informed by higher level macro influences (and the personal views and values a physician might hold), guide the professional practices a physician may engage in and provides a framework for professional codes of moral and ethical conduct. It is at the bedside where differences in care provision are most noticeable and perhaps reflective of the negotiation (across levels) that must take place within particular settings and according to individual patient needs. This chapter will consider such professional and organisational influences that hold legal, ethical and moral implications, and review particular medical ideologies (e.g. palliative versus critical/acute) with different models for care practices.

The medical profession has a long history, with traditions that have remained relatively unchanged and a lasting influence to current day practices (Isaacs, 2011). Physicians continue to be guided by a fundamental motive that promotes the well-being of patients by enhancing their health and providing relief for their suffering. The Australian Medical Association has a code of ethics that embodies these basic and ancient principles, albeit in an expanded form that also attempts to maintain relevance with
current day practices, for example organ transplantation (Australian Medical Association, 2006a). These ethical codes reflect the professional standards that physicians are expected to uphold at the bedside, and promote the profession’s obligation to society. The ideals embodied within these codes of ethics are emphasised throughout medical training, being uniquely adapted and internalised by physicians as a guiding philosophy (Veatch & Macpherson, 2010).

4.1. The Hippocratic Oath

For over 2500 years physicians upon graduation (or attaining recognised status as a physician) have sworn allegiance to the Hippocratic Oath, endeavouring to embody the ethics and values laid down within it from Ancient Greece by the father of modern medicine, Hippocrates (Isaacs, 2011). The Oath has been philosophically and ethically enduring across Western civilisation (Helidonis & Prokopakis, 2001) and has only recently been modified by some universities with their students to somewhat reflect greater relevance in recent times, specifically the latter 20th century to now (Isaacs, 2011; McNeill & Dowton, 2002; Veatch & Macpherson, 2010).

Some of the original Hippocratic Oath is more controversial. There is an emphasis on the sanctity of life, which is no longer universally accepted; in the Oath, the physician swears not to give a lethal drug if asked and not to cause a woman to have an abortion. Physician-assisted suicide and therapeutic termination of pregnancy are now legal in many countries. Furthermore, the physician taking the Oath swore not to cut for (kidney or bladder) stones, because this was a menial task performed by the barber surgeons; literally barbers who also cut hair (Isaacs, 2011). These days however, urology is a stand-alone and respected specialty.

However, the importance of the Hippocratic Oath as a moral guide was reflected in a self-administered questionnaire by 2000 practicing physicians in the USA where 26% declared it exerted “a lot” of influence, 37% declaring it “somewhat” influential, 24% “a little” and 13% “not at all” influential to how they practice (Antiel, et al., 2011). Still,
when asked about other sources of moral guidance that had “significantly” influenced their professional practice, few physicians (16%) cited the American Medical Association Code of Ethics. Many more said their “personal sense of right and wrong” (92%), great moral teachers (35%), and specific traditions (28%) influenced their practice. This research strongly demonstrated the unique nature of medical ethics for individual physicians but, very importantly, how physicians draw on multiple influences to guide their practices, particularly their sense of right and wrong. However the moral compass that guides a physician can only be determined relative to context.

To illustrate, Veatch and Macpherson (2010) argued that physicians may sometimes disregard “prescribed” codes of medical ethics and instead practice true to personally held ethical and moral values, or at least an amalgam of these. Physicians are exposed to various ethical codes and standards where some are derived from within the medical profession, and some are associated with various religious and secular systems of belief and value but also incorporated into medical practice (Graham, 2000; Veatch & Macpherson, 2010). It may therefore be problematic in practice to expect physicians to conform to rigid and generalised ethical codes and, as Veatch and Macpherson allude to, medical school graduates should instead be encouraged to swear an oath or make a declaration, perhaps self-designed, that contains core fundamental human values but is flexible enough to account for the multiple influences a physician may be exposed to.

Physicians practicing ethical medicine do so across many different settings, yet each is unique and influences the way care may be provided. Each specialty has priorities suited to patient needs and thus positions the physician within an institutional context with certain expectations and parameters.

4.2. The Palliative Care Model

Palliative care is a holistically focused model of care based on providing comfort to dying patients and their loved ones (World Health Organization, 2008); with the terms “comfort care model” (Waldrop & Kirkendall, 2009) or “holistic care model” (Deebs,
Palliative care incorporates physical, psycho-emotional, social, and spiritual and existential aspects in end-of-life care (Palliative Care Australia, 2011a) and, unlike some curative models (e.g. intensive care), also has the capacity to be administered from within a number of settings (Glare et al., 2003; Palliative Care Australia, 2004).

While the majority of deaths in Australia take place in hospitals, the care of individuals who are recognised to be in a palliative phase of their illness increasingly takes place in patients’ homes (Palliative Care Australia, 2011a). It has long been acknowledged that home care is preferable over institutional care wherever possible, particularly as a way of promoting patient autonomy. For example, after conducting over 500 interviews with dying patients in the 1960’s, Kübler-Ross highlighted the emotional and psychological aspects of dying and the need to “listen to the dying patient” (Kübler-Ross, 1969). Although perhaps reflective of the institutional care available at that time, patients overwhelmingly expressed a desire to die at home and have greater control over decisions. However, as circumstances dictate, when home care can no longer provide the required care or medication, hospitalisation in mainstream general and palliative care wards, hospices or nursing homes becomes necessary.

The term “hospice” (from the same linguistic root as “hospitality”) can be traced back to medieval times when it referred to a place of shelter and rest for weary or ill travellers on a long journey and wounded soldiers returning from the crusades. Care was provided by monks and nuns in monasteries (Connor, 1998; Robbins, 1989). Although one of the first hospices was established in Sydney by the Sisters of Charity in the late nineteenth century (today’s Sacred Heart at St Vincent’s), the name was first applied to specialised care for dying patients in 1967 by physician Dame Cicely Saunders, who founded the first modern hospice, St. Christopher’s, in a suburb of London (Saunders & Baines, 1983). The hospice movement developed out of the recognition that traditional hospitals with their routines, curative emphasis and depersonalised atmosphere were inadequate for helping the dying.
Today, hospice is no longer simply a place, but rather an ideal and philosophy of care for the patient with a life-limiting illness and their loved ones facing a difficult journey. The purpose remains the same - for them to find rest, to be cared for and to gather courage to face the remaining days of their journey together (Connor, 1998). The notion of hospice has become mainstream through government rather than charity funding, establishing itself as dedicated palliative care in many major public and private hospitals, and specialising formally in Australia in 1999 (Australasian Chapter of Palliative Medicine, 2011).

Palliative care embodies the ideals of hospice and emphasises quality of life for those that are dying (Aranda & Milne, 2002; Parker & Aranda, 1998). It strives to promote expert pain and symptom management, patient dignity, personal autonomy and control, particularly in relation to decision making, and delivers holistic care that incorporates the patient’s family (Palliative Care Australia, 2004). It seeks to alleviate distress and maintain patient relationships with their family in a caring and compassionate environment (Parker & Aranda, 1998). In addition, palliative care also provides home support through community nursing, home modifications that aid showering, toileting and mobility (e.g. wheelchair ramps), installs hospital beds and promotes access to spiritual and psychological care. However, when institutional care becomes necessary, quality of life is also fostered through other practices that maintain patient dignity, autonomy and sense of purpose.

4.2.1. Dignity at the end-of-life. The tenets of palliative care may be summarized as the goal of helping patients die with dignity. The term “dignity” provides an overarching framework that may guide the physician, patient, and family in defining the objectives and therapeutic considerations fundamental to end-of-life care. Dignity-conserving care is care that may conserve or bolster the dignity of dying patients and maintain their sense of worth and value (Chochinov, 2002).

For some patients, a sense of dignity is indivisible from their core being or essence. The notion of “basic dignity” has been described as referring to a universal moral
quality that is internally held, and inherent in and inseparable from life itself (Pullman, 1996). “Personal dignity” is frequently invoked in reference to the potential indignities of death and dying, as a construct that is more individualistic, transient, and tied to personal goals and social circumstances (Kant, 1987; Pullman, 1996). Loss of dignity is also one of the most common responses given by physicians in studies examining why patients request euthanasia or assisted-suicide (Ganzini et al., 2000; Kant, 1987; Meier et al., 1998). It makes sense therefore that physicians deal with issues threatening dignity, not only for the sake of patients and their loved ones, but also for their own experiences that are intimately linked to that unique context (Adler, 2007).

The physician’s approach to the problem of dignity in end-of-life care should recognise that the end-of-life is a natural phase of life where a lack of meaning or dignity is not a psychiatric disorder but rather a natural life occurrence (Ferrell, 2005). Individuals have a need for life closure and enhanced communication with those whom they love and when this can be achieved, suffering and distress may be significantly diminished (Chochinov, 2007). Palliative care as a model which emphasises biomedical, psychological, psychosocial, existential, and spiritual considerations is a multilevel structure of care with significant therapeutic clinical implications and particularly well placed to enhance the quality of life for dying patients.

Dignity enhancing practices can be quite simple, for example, small acts of kindness can personalise care and often take little time to perform (Turner et al., 1996). Such behaviours convey a powerful message, indicating that the person is worthy of such attention (Chochinov, 2007) and is important when caring for patients with advanced disease “both because of the physical threats of dying and because of the challenge to sense of self-worth and self-coherence” (Chochinov, Hack, McClement, Harlos, & Kristjanson, 2002, p. 438). Diversional therapy (e.g. art classes) also assists keeping patients’ minds off their illness and focused on living. Patients’ hanging their artwork on bedside walls reinforces a sense of achievement, functionality, provides a sense of control and personalises the institutional environment.
For some patients, the preservation of dignity can be achieved by a connection to a spiritual or religious practice or community (finding spiritual comfort) and allowing expression of culturally held beliefs (Daaleman & VandeCreek, 2000). For others, ensuring that some aspect of life may transcend death (i.e. generativity/legacy) holds the key to a maintained sense of dignity (Fisher, 1995). For these patients, participating in a life project such as making an audiotape or videotape, writing letters, or keeping a journal can offer the comfort of knowing that something of their essence or personhood will survive beyond death (Chochinov, 2002).

Furthermore, patient autonomy and control are closely related to dignity and, when facilitated, may provide a means of empowerment at the end-of-life (Chochinov, 2002, 2007; Volker & Wu, 2011). Several studies have reported that the undermining of autonomy has the potential to undermine the value patients ascribe to life, with hopelessness and loss of control correlated with a heightened interest in death-hastening measures (Back, Wallace, Starks, & Pearlman, 1996; Block, 2001; Ganzini, Johnston, & Hoffman, 1999; Seale & Addington-Hall, 1994; Sikora & Lewins, 2007). Therefore, strategies that bolster autonomy and control are paramount to the conservation of dignity and central to palliation at end-of-life, but also in the physician’s interest when many experience requests for death aversively and discuss them with reluctance (Back et al., 2002; Back, 2004; Georges, The, Onwuteaka-Philipsen, & van der Wal, 2008).

However, the degree to which physicians may practice a dignity care approach could also be constrained by the setting, especially if it is dominated by a curative or biomedical ideology (Seymour, 2001), or simply if resources are not available (Curtis & Rubenfeld, 2001; Shipman et al., 2008). Inhibiting the care physicians may provide to patients and patient families subsequently influences their own experiences, especially when many report an emotional investment in their patients (Seymour, 2003, p. 333; Wilkes, 1998). Physicians working with dying patients in other non-palliative settings need to negotiate care within the constraints they have, yet even when palliative care is
available there are differences in the application of palliative goals, most noticeably for younger patients.

**4.2.2. Palliative care in paediatrics.** Palliative care is generally synonymous with “aged” end-of-life care, yet similar goals should apply when providing care to younger patients and children who are dying from terminal illness or trauma from injury (Brown & Sourkes, 2010). Approximately 25% of children with cancer die of their disease (Hurwitz, Duncan, & Wolfe, 2004), yet the growth in palliative care for adults has not been paralleled in paediatrics (Monterosso & De Graves, 2003; Monterosso, et al., 2009). For children with life threatening illnesses, the assumed goal of medical practitioners is to achieve a “cure” (De Graves & Aranda, 2005).

Most industrialised countries have a “death defying” culture in which the death of a child is a foreign and socially unacceptable event (Mills, 2004; Orloff & Huff, 2010). Advances in modern medicine and public health mean the death of a child is relatively rare, and that doctors are less prepared when they encounter a child who is dying (Orloff & Huff, 2010). The natural reaction of physicians is to fight for a child’s life because it seems “unnatural” for a child to die (Monterosso & De Graves, 2003) but, despite modern medicine and state-of-the-art technology aimed at prolonging life, children will still die.

Many physicians feel a sense of helplessness and lack confidence caring for dying patients, particularly children or young adults, and often claim their palliative skills are inadequate to meet the challenges presented by some terminal patients (Sheetz & Bowman, 2008). Monterosso and Kristjanson (2008) further report that the concept of palliative care is not well understood by physicians in Australia, much less in relation to paediatrics. But Australia also has an acute shortage of specialised palliative physicians (Palliative Care Australia, 2011b) and, thus, a lesser likelihood that an appropriate referral will take place or that a consulting palliative specialist could be found when required.

Physicians also face other barriers in providing optimum end-of-life care. For example, care goal transition is frequently problematic, particularly when early in the
course of a patient's illness such as cancer it is often impossible to determine whether the disease will be cured with cancer-directed treatment. When potentially curative therapy is no longer an option, the patient, family, and oncology team face enormous medical, psychological, and spiritual challenges (Brown & Sourkes, 2010; Hurwitz, et al., 2004). Shifting the focus of care from cure to palliation is not experienced as a discrete event but rather, as an awareness and acceptance that slowly develops (De Graves & Aranda, 2005). However, until that realisation occurs, the child may actually be subjected to further futile and perhaps aggressive forms of treatment (e.g. continued chemotherapy). The trajectory of childhood cancer is characterized by uncertainty, especially following relapse where there is reduced clarity surrounding the child’s outcome (Monterosso & Kristjanson, 2008).

Physicians also often feel out of their depth when communicating with young patients (and parents) (Hurwitz, et al., 2004). Doctors need to communicate to dying children in a clear and specific way and at a level familiar to the child, and include the fact that they are dying (Monterosso & De Graves, 2003). Excellent communication skills in end-of-life care are therefore crucial to develop trust, provide support and give information that keeps focus on the reality of the situation in an empathic and sensitive way but also to not provide false hope.

Yet, poor or ineffectual communication around crucial decisions is especially problematic and sometimes an aversive experience for physicians (St-Laurent-Gagnon, Carnevale, & Duval, 2008). Forbes, Goeman, Stark, Hynson, and Forrester (2008) identified numerous barriers in discussing withholding or withdrawing life-sustaining treatment which included clinician concerns about family readiness for the discussion, prognostic uncertainty, family disagreement with the treating team regarding the child’s prognosis/diagnosis and concerns about managing family requests for treatments that are not perceived to be in the child’s best interests. It also appeared that more senior physicians had slightly greater confidence discussing and negotiating these difficult issues than junior physicians, suggesting that communication proficiency was developed with
experience in the job, rather than any formal dedicated effort to educate physicians in these skills as part of basic Australian medical training. Yet strangely, although all physicians in this study eagerly supported ongoing professional skill development, it seems specific communication training is provided less today than it once was because 58% of junior physicians reported receiving no formal communications training but only 35.8% of senior physicians.

But physicians are also reluctant to be the bearers of bad news, finding this task particularly difficult in relation to dying children. Palliative Specialist Dr Richard Chye from Sacred Heart at St Vincent’s said it is not uncommon for physicians to avoid such discussion. They tend to talk around the topic and rather than saying “yes you are dying but we can help you”, they often only say “I’m sorry the treatment did not work as well as hoped for”, or “there is nothing more we can do”. Specialised palliative care can do much for the dying patient and their family but often there is a professional unawareness of what palliative care is and/or a reluctance to refer (Le & Watt, 2010), with some physicians being uncomfortable even using the term (Monterosso & Kristjanson, 2008; St-Laurent-Gagnon, et al., 2008). For some physicians death is conceptualised as medical failure and constitutes an admission of defeat (Weissman, 1999).

Australian end-of-life care must be contextually negotiated using the expertise and resources that are available. But how physicians might accomplish this in non-specialised settings (e.g. the home) or without specialised collaboration is unclear. The many influences affecting the way doctors negotiate and experience their interventions when treating dying children has not been explored. For example, it is unclear how physicians improvise when they often admit feeling out of their depth in providing appropriate holistically focused care. It might be additionally problematic if cure is always emphasised over comfort and palliation for dying children, especially by comparison with dying adults. Furthermore, doctors are also expected to be objective in their treatment of dying children yet many may also identify in some way with their young patients, but

how they personally manage or negotiate those situations, and what support they draw on, is also relatively unknown.

4.3. Care Goal Transition

The timely transition in treatment goals is also often regarded as problematic across medical settings (Le & Watt, 2010; Seymour, 2003). As discussed above, transition to a palliative model of care is frequently delayed for paediatric patients. It becomes just as problematic in mainstream critical and acute settings where the emphasis of treatment is curative and, due to the highly technical nature of the setting, decisions are exclusively in the hands of physicians and other medical staff (Curtis & Rubenfeld, 2001; Redpath, 1998). Unlike treatment from within a palliative model, decisions are not as collaborative between physicians and patients with their loved ones. Furthermore, the level of information that is provided to patients varies by setting. In a technical environment like intensive care, information is exchanged between physicians and other medical staff in a language that is often out of reach of the lay person (Miles, 2001). In such an environment, it is not the patient that is the focus for intervention but rather the patient’s condition. Accordingly, the patient becomes medicalised.

Dying patients are, therefore, often disempowered and unaware of their situation, especially where the particular medical facility or setting, and its physicians, determine the level of collaboration in decision-making that may occur with patients and their families; and also how much and what type of communication will take place (Clarke, 2010; Hancock et al., 2007). Setting characteristics that influence decisional control, and prescribe curative and aggressive clinical practices, may actually inhibit the appropriate care a physician can provide and literally increase patient suffering. For example, many cancer patients find that the context in which awareness of terminal illness begins is the treatment situation (Redpath, 1998). According to Schou (1993, pp. 246-247):

There is no facile boundary between the end of mainstream treatment and the beginning of dying in many instances. Dying will begin in the larger context of an
illness calendar already in existence, often in treatment centres where the public mandate is cure.

Redpath states that the boundary Schou refers to is imprecise and requires expert negotiation and decision-making to ensure the best outcomes for the patient and their family. Such negotiation necessarily entails competency by physicians and their teams, with institutional support from the hospital or facility itself.

       However, physicians are sometimes ill equipped to negotiate effectively among themselves and terminal patients may be inappropriately retained in an acute setting rather than transferred to palliative or hospice units specialising in terminal illness and end-of-life care (Le & Watt, 2010; Monterosso & Kristjanson, 2008; St-Laurent-Gagnon, et al., 2008). Further, as identified earlier, physicians are also often ineffective (and sometimes reluctant) negotiating directly with patients for a transition to palliative and hospice care at the end stages of their disease. Patients often only become aware of the finality of their condition indirectly through no treatment being offered, or their disease becomes unresponsive to treatment, or they experience one or more short-lived remissions (Beckstrand, Callister, & Kirchhoff, 2006). Sometimes patients only become aware after overhearing discussions between physicians and “reading between the lines” of what they hear (Redpath, 1998).

       Despite these somewhat longstanding concerns over providing appropriate care to terminal patients, significant difficulties persist. In more recent research, professional and institutional influences were found to inhibit patient care when key end-of-life protocol documents in the UK health system gave limited guidance on how to provide end-of-life care in critical settings (Pattison, 2006). There was little recognition of specialised palliative care’s capacity to assist complex symptomatic issues for patients within critical/acute settings, nor were any guidelines in place that could determine a timely transfer of care goals to palliation or appropriate patient handover to specialised end-of-life care. The assumption was that dying patients in critical/acute care would be managed there. Consistent with this research, dominant care protocols were written in the
privileged language of the medical profession and included the power dynamic in critical care between professions, families and patients, and impacted significantly on provision of end-of-life care (Skilbeck & Payne, 2005). Difficulties encountered included dilemmas at discharge and physician paternalism in decision-making. The technological environment was also identified as a potential barrier to good end-of-life care, and critical care nurses were at risk of assuming the dominant medical model of care, which is strongly influenced by a “cure” philosophy and goals of reversing illness. However, patients can deteriorate quickly and slide from a critical condition into futility where the process of dying may be rapid and difficult to manage (Curtis & Rubenfeld, 2001; Hillman, 2009b). Yet, rather than transferring patients to specialised palliative care, end-of-life responsibility is often left to critical care staff where the capacity to assist a dignified and peaceful death may be seriously hampered (Beckstrand & Kirchhoff, 2005).

Although physicians in Australia might be positioned within similar critical and palliative care environments as their UK counterparts, it remains unclear how influential factors might shape the way Australian end-of-life care is provided. The uniqueness and individuality of patients, their families and the physician, emphasises the context specificity of end-of-life care, particularly across settings. Accordingly, physicians need to negotiate care on a patient-by-patient basis, but how they do this will shape the end-of-life experiences they have. Physicians must effectively negotiate the turning point between critical/acute treatment and palliative care for the dying; quite a challenging task, especially when that boundary is often ambiguous.

### 4.4. The Critical/Acute Care Model

Although specificity both within and across different medical contexts generally implies that each situation is unique, in palliative and critical care where one is often regarded as philosophically and practically alien to the other, there are distinct similarities. For example, both specialties developed around the same time to meet a need by patients and their families for care at a time of extreme vulnerability. Practitioners in both settings frequently encounter the deaths of those they care for and need to manage
the implications of those deaths for patients, patient families and themselves. Furthermore, both specialties practice a “total” model of care, which extends beyond the immediate patient to also include family and loved ones, and where that model reflects an interdependency of medicine and nursing within highly developed teams (Randall-Curtis & Rubenfeld, 2001; Seymour, 2003).

Nevertheless, the similarities between these two specialties are considerably diluted when the rapidly advancing technological environment of critical settings often serves to dehumanise patients. For example, there is sometimes little room for palliative efforts when critical settings are saliently identified by their vast array of diagnostic and support equipment, their bright lighting and noise, and a lack of privacy, but particularly by an explicitly pervasive philosophy that promotes curative rather than comfort based goals (Randall-Curtis & Rubenfeld, 2001). The patient’s biological condition takes the foreground and, especially in acute hospital settings, dying patients often receive invasive and inappropriate medical treatments despite evidence of their poor prognosis being available to physicians (Afzal, Buhagiar, Flood, & Cosgrave, 2010; Ahronheim, Morrison, Baskin, Morris, & Meier, 1996; Faber-Langendoen, 1996; Faber-Langendoen & Bartels, 1992). Furthermore, unlike the central tenet of palliative care where people have a clear awareness of impending death, that awareness is often absent in critical settings and contributes to an overwhelming culture where efforts to accommodate practices that facilitate a “good death” that is peaceful and dignified may be difficult to deliver (Miles, 2001; Seymour, 2003).

Certain factors may particularly foster difficulties for managing death in critical care. For example, a growing proportion of critical care patients are elderly and suffering from an acute episode of a progressive long-term illness rather than the effects of infectious disease or sudden trauma (Hillman, 2011). When admitted to intensive care the expectation is for cure not palliation. However, an increasing number of elderly patients also suffer comorbid dementias like Alzheimer’s disease and critical environments are not
geared to adequately deal with such patients when they arrive due to other emergency or acute episodes (Afzal, et al., 2010).

Furthermore, 15 to 30 per cent of patients die during critical therapy with a significant amount dying shortly after discharge, and approximately 90 per cent of patients who die in critical care do so following a non-treatment decision involving withholding or withdrawal of life prolonging therapies (Hillman, 2011). Indeed, comparative data collected across two USA. Intensive Care Units in 1987/1988 and 1992/1993 showed a significantly increasing trend to withhold or withdraw life support for critical patients (Prendergast & Luce, 1997). For example, CPR was initiated in 49% of deaths in 1987/1988 but only in 10% of deaths in 1992/1993. Moreover, where physicians in 1987/1988 would often accept recommendations from surrogates (e.g. family members) to resuscitate patients they considered hopelessly ill, the later data indicated that, particularly in treatment decision conflicts, physicians were more willing to refuse such surrogate requests (Prendergast & Luce, 1997). This represents a rapid and marked change in critical care practices in the USA. However, it is also important to note that non-treatment is an unfolding process marked by significant ethical and diagnostic complexity and where each unique situation, often involving potentially irreconcilable interests, needs to be negotiated directly by medical staff (Seymour, 2000, 2001). Managing a “good death” in the critical setting may be quite a formidable task for physicians when a so called “good death” may be perceived very differently by patients and their families or, indeed, the critical care staff involved.

According to Seymour (2003), physicians also find that achieving a balance between delivering critical care and preparing the family for the possibility of death is a major issue because death challenges curative expectations. Words need to be chosen very carefully and a great deal of consideration needs to be given to what is said to patients and their families because many will naturally look for and cling to the smallest piece of hope. The formal disclosure of bad news, within critical settings, is generally the province of physicians rather than nursing staff, although nurses sometimes need to
assume this role and, when no formal decision has been agreed to, nurses also need to
forestall enquiries from patient families. The more formal relationship assumed by
doctors with patient families provides a more clearly delineated view of their
responsibility in regards to disclosing information and their role in providing care.
Seymour sees that the concerns of doctors are to clearly consolidate the preparatory
“groundwork” undertaken by nurses and ensure that they have been seen to do all that
was possible with regard to treatment. A unified professional response is important yet it
appears that there is an ever present concern with litigation, perhaps implicit only, but a
tendency to practice defensive medicine nonetheless.

There is also a broad contention that the concerns doctors have are further
associated with a belief that families should not assume responsibility for critical
treatment decisions (Curtis & Vincent, 2010; Faber-Langendoen, 1996; Prendergast &
Luce, 1997; Seymour, 2001, 2003). While this might be a noble (if not practical) gesture
by doctors to avoid inflicting additional burden on families at a particularly traumatic
time, such decision-making that might appear somewhat patriarchal is, nevertheless, a
fundamental property of critical care settings.

At the same time, however, physicians in critical settings are also positioned with
that onerous responsibility, willingly or otherwise, for crucial care decisions. The
intensive care physician is ultimately responsible for medical interventions, yet frequently
decisions must be made in the moment, especially for an emergency situation, with the
available information at hand. Unfortunately crucial patient information that could
strongly influence critical decisions is not always available or considered. For example, in
the event of an emergency, there may have been little time to discuss whether the patient
has made an advanced care directive (Palliative Care Australia, 2010a; Rhee, Zwar, &
Kemp, 2011), or issued a not-for-resuscitation (NFR) order for a recurrent acute episode
of their chronic illness (Hillman, 2011). Often, patients have not discussed these issues
with family or next of kin either and ambulatory care requires paramedics to resuscitate until a patient can be handed over to emergency.³

Intensive care specialists are also being increasingly involved in end-of-life care through the establishment of medical emergency team systems in many hospitals around the world (Chen, et al., 2008). This system and other similar systems were originally developed to identify deteriorating patients and provide a rapid response in order to improve outcomes. Research has shown that these systems can indeed reduce cardiac arrest and death rates in adult and paediatric settings (Chan & Berg, 2010; Chen, et al., 2008). However, many deteriorating patients, or those that are seriously ill, may simply be dying in a natural and expected way and where the provision of further active treatment would be futile and potentially inhumane (Hillman, 2011). Curatively-oriented ICU physicians are also not trained, motivated or resourced for palliation (Billings, Engelberg, Curtis, Block, & Sullivan, 2010; Curtis & Vincent, 2010; Meier & Beresford, 2006).

4.5. Evidence-based Integrated Practice Guidelines for End-of-Life Care

Medical end-of-life decisions require careful consideration and many physicians, particularly registrars and recent medical school graduates, or even physicians entering the specialised domain of end-of-life care from other health areas, have little experience in this respect (Hesselink et al., 2010; Shipman, et al., 2008). Furthermore, collegial support is not always available (Froggatt, 2001). Therefore, multi-professional practice guidelines for medical end-of-life decisions may help improve the quality of care for the dying through greater consistency and empirically informed treatment recommendations (Clayton, Hancock, Butow, Tattersall, & Currow, 2007; Woolf, Grol, Hutchinson, Eccles, & Grimshaw, 1999), but also support physicians in their decision-making process (Hesselink et al., 2012; Veerbeek et al., 2008).

³ Professor Ken Hillman, personal communication with the author, June 29, 2010, Campbelltown.
With continual refinement and adaptation, evidence-based clinical guidelines for practice are becoming more specialised and adapted to a range of specific disease and illness types such as dementia, chronic kidney or liver disease, cancer, stroke and so on, (Afzal, et al., 2010; Douglas, Murtagh, Chambers, Howse, & Ellershaw, 2009). They are also implemented across different terminal populations like those in acute and intensive care, palliative and hospice settings, nursing homes, and those being cared for at home (Paterson, et al., 2009; van der Heide, et al., 2010; Veerbeek, et al., 2008), as well as for children dying in paediatric settings (Matthews, et al., 2006).

Structured practice guidelines such as the Liverpool Care Pathway (LCP) have been specifically developed to facilitate end-of-life decision-making and are being increasingly adopted by Australian medical institutions and those in many other Western countries (Ellershaw & Murphy, 2005; Jackson, Mooney, & Campbell, 2009; Paterson, et al., 2009), as well as in some Chinese hospitals (Lo, et al., 2009). Furthermore, increased positive outcomes have been achieved for some terminal patients after implementing appropriate clinical guidelines in critical and acute settings (Paterson, et al., 2009) while general ward nurses in an Australian pilot study felt greater confidence providing care when using an integrated pathway plan with their dying patients (Jackson, et al., 2009). Still, international research is ongoing and Australian trials in NSW, Western Australia and Queensland, are striving to further develop world’s best practice guidelines for palliative care (Hardy, Haberecht, Maresco-Pennisi, & Yates, 2007; NSW Government Department of Health, 2009; The National Institute of Clinical Studies, 2005; Western Australia Cancer & Palliative Care Network, 2009).

Integrated practice guidelines like the LCP are generally implemented around the last few days or hours of life, usually the final 72-24 hours (Ellershaw & Ward, 2003; Partington, 2006), although some patients have been on this pathway for up to 23 days (Fowell, Finlay, Johnstone, & Minto, 2002). Common medical decisions initiate treatments to manage pain, agitation, respiratory tract secretions, nausea and vomiting, or shortness of breath (dyspnoea) that the patient may experience, but ultimately also
involves the withdrawal of nutrition and hydration, and the administration of sedatives to induce unconsciousness (Ellershaw & Murphy, 2005).

Nonetheless, integrated practice guidelines like LCP are still generalised, “tick the box” type structures, and can sometimes miss the specifics of a given situation and the individuality of patients within them (Kelly, 2003; Pinder, Petchey, Shaw, & Carter, 2005). For example, one patient in the UK died from pneumonia after being put on the pathway when doctors incorrectly diagnosed his condition as due to an aggressive relapse of his cancer (Spooner, 2010). Furthermore there is strong opposition by some palliative specialists, particularly in the UK, who claim that patients on the pathway are dying prematurely (Kmietowicz, 2009), particularly when doctors can withdraw fluids and drugs from patients if they are deemed close to death and put them on continuous sedation. The common signs used to determine whether a patient is close to dying include losing consciousness or developing an inability to swallow, but this could point to other problems, and some patients are “wrongly” placed on a pathway to death simply because they meet the “criteria” (McNicholl, Dunne, Garvey, Sharkey, & Bradley, 2006).

Forecasting death or predicting the final trajectory of illness is acknowledged as an “inexact science”, but sedating patients and withdrawing fluids could also mask signs of improvement (Froggatt, 2001). Indeed, patients sometimes rally at the end-of-life yet, particularly if kept in a comatose state; they are often assessed as being close to death without regard to the fact that the diagnosis could be wrong (Jones & Johnstone, 2004). Accordingly, if all the right boxes are ticked in the LCP, the inevitable outcome of the consequent treatment is death (Kmietowicz, 2009). On the other hand, it is exactly this difficulty of predicting imminent death that may cause some staff to overlook or not recognise signs that end-of-life is near, and this may then prolong the suffering of patients (Jones & Johnstone, 2004).

Additionally, standardised guidelines like LCP tend to abstract the patient and reify the disease or illness (Partington, 2006; Pinder, et al., 2005). As with dominant discourses regulating practice in critical and acute settings, physicians providing end-of-
life care within guidelines like the LCP may find that they are similarly constrained in

terms of the care they would like to provide. For example, there appears to be little room
in clinical pathways, as they currently stand, for greater collaboration with patients and
their families in the decision making process. Control still largely remains with physicians
and the institutions they practice from, even though research has clearly signalled the
increased need for collaborative end-of-life decision-making that includes patients and
their families in that process (Currow, 2003; Lickiss, 2003).

Pathway-guided clinical care at end-of-life supports physicians with evidence-
based practices; however, such practices have limitations and are not equally applicable in
all situations. Physicians may still need to negotiate such clinical care structures to meet
patient specificity regardless of professional and institutional imperatives.

4.6. The Medico-Legal Interface at the Bedside

As discussed earlier, end-of-life care is often shrouded in ambiguity. Sometimes
there is little distinction between killing a patient and letting them die (Douglas, 2009;
Douglas, et al., 2008). Some physicians providing end-of-life care confront the dilemma
of intractable patient suffering, and constraints in addressing it in the best way they can
(Magnusson, 2006). For example, even with the best pharmacology, there is suffering that
cannot be adequately dealt with (Quill, 1998). Yet physicians are thrust into positions
where they may need to render the patient comatose and/or withdraw particular life
sustaining measures that may be futile and inflicting needless suffering; but all with the
risk of hastening death. Treatment decisions are made with moral, professional and legal
considerations from the unique perspectives of both patient and physician. But the
treatment interventions that risk hastening death are highly procedural if they are to afford
the physician legal protection (Jotkowitz & Glick, 2009; White, et al., 2011). Procedures
are sanctioned within strict but generalised guidelines that the physician must carefully
apply to each different potentially death hastening situation. He certainly cannot
deliberately hasten a patient’s death even if that might be the most humane and
compassionate course of action.
The Australian bioethicist, Peter Singer, has written prolifically on the inherent ambiguity in end-of-life care for physicians, for example, acts of commission (active killing) versus acts of omission (letting die), as well as the philosophical and ethical rhetoric underwriting the Hippocratic Oath, and sanctity of life, personal autonomy and death with dignity viewpoints (Gruen, et al., 2007; Kuhse & Singer, 2006; Singer, 1995, 2002). He has also highlighted how end-of-life clinical decision-making and practice is increasingly becoming the domain of legal debate and deliberation and where physicians who would normally be considered intimately authoritative on end-of-life care are being guided by often-generalised court rulings decided out of context. For example, in the landmark “Bland case” in the UK, in 1993 (Tony Bland was in a permanent vegetative state since a football accident in 1989), the British House of Lords decreed that a “patient’s best interests” should now be the determining criteria for withdrawing or withholding life sustaining treatment.

However, doctors still need to make decisions on a patient by patient basis that are entirely context specific and even though rulings such as those deciding the Bland case may seem reasonable, they remain inherently ambiguous. Just who decides what is “in the patient’s best interests”? In some cases it is not even the patient. For example, the Western Australian courts recently decided the fate of quadriplegic Christian Rossiter regarding the cessation of life sustaining nutrition and hydration (Freckleton, 2011; Stewart, et al., 2011; Williams, 2009). Although unsuccessful in accessing a more active, and arguably more compassionate, means of ending his life either here in Australia or through the Dignitas Organisation in Switzerland, Rossiter was at least able to convince a court that continued treatment against his wishes was not in his best interests as far as quality of life was concerned. Unlike someone permanently comatose and without advanced directive, he articulated his wishes in respect of his “bodily death”, that his nursing home should be relieved of any legal responsibility for his welfare. It should be noted, however, that when considering Christian Rossiter’s best interests, the court was prepared by its ruling to allow him to slowly starve to death over a period of weeks (he
actually succumbed to a chest infection before this happened) rather than canvass any idea of using a means that could less distressingly expedite that outcome (Freckleton, 2011; Stewart, et al., 2011).

Doctors may well consider legal and professional imperatives when administering end-of-life care in Australia, but the context specificity of end-of-life situations and the individuality of patients (and their families) requires decision making that is equally specific. However, the positions legislators hold are seldom context specific, are inconsistent, and at odds with the laws they expect the courts to uphold, and often leave doctors who might be seeking legal or professional guidance to grapple with that ambiguity and lack of clarity. For example, Australian politicians favour the current prohibition on euthanasia and assisted suicide yet, Tony Abbott, an Australian Federal Parliamentarian who featured prominently in the debate over the Northern Territory’s euthanasia law, asked “How can the law improve what is currently left to the compassion and good sense of doctors, patients and families”? He went further to say that “supporters and opponents alike must regard the first government approved killing since the end of capital punishment as an awful milestone in Australia's history because, for better or worse, men are walking where angels fear to tread” (Magnusson, 2002, p. 266). The ambiguities inherent in such statements do little to reassure physicians practicing end-of-life care and continue to divide the community along political and religious lines. If one considers the extent of euthanasia and other end-of-life practices occurring in Australia, as they are reported in the academic literature, it would appear that Tony Abbott was either naively unaware that doctors do play God or he was suggesting that informal killing by doctors is acceptable as long as it is not openly acknowledged or regulated. Interestingly, his own parliamentary colleague and former president of the Australian Medical Association, Dr Brendan Nelson, while staunchly opposing any change in the law to allow doctors to assist patients to die, claimed that in his own medical practice he intentionally ended the lives of terminally ill patients, and was right to do so (Dow, 1995; Kuhse, 1995; Perron, 2011; Singer, 1996).
4.6.1. Professional and legal guidance. Some 15 years after the ill-fated ROTI legislation, the same lack of professional and legal guidance persists, leaving unsupported physicians to negotiate the uncertainty in end-of-life decision-making and practices (Magnusson, 2009). Australian legislators continue to debate issues of euthanasia and physician-assisted suicide in their state parliaments in an effort to address these controversial and difficult issues that won’t subside (Kelleher, 2011). For example, in November 2009, the Australian media reported that bills to legalise euthanasia were lost narrowly in South Australia by eleven votes to nine (Vaughan, 2009) while a conscience vote in the Tasmanian Parliament defeated a euthanasia bill along party lines sixteen votes to seven (Rimod, 2009; Vaughan, 2009; Wheeler, 2009). Furthermore, following overwhelming public support (90%), a similar bill was presented to the Western Australian Parliament in September 2010 but defeated 24 votes to 11 (Raphael, 2010). However, it is interesting to note in the Tasmanian case that so called “conscience votes” appear influenced by higher order political agendas and positions. Further, from a multilevel perspective, the macro political level is seen influencing the bedside practices (meso) physicians can engage in and their subsequent experiences (micro).

Indeed, euthanasia and assisted suicide remain intimately associated with end-of-life care (Lickiss, 2003; Randall & Downie, 2010). These topics are often raised by patients and their families, and dealt with by physicians. Some physicians support medical assistance to die through competent and informed patient decision making, and others reject it completely. But regardless of any particular position a physician holds in relation to these issues, the physician is tied to professional and legal doctrines all emphasising a position that sanctifies life (Biggs & Ost, 2010). However, the physician is also compelled to promote patient autonomy but patient autonomy does not allow patients to decide the timing or manner of their own deaths.

Some palliative specialists in Australian end-of-life care, highlight this apparently increasing conflict at the bedside and how evolving societal expectations placed on the physician are constrained by traditional medico/legal imperatives that reinforce defensive
practices (Hunt, 1998). Hunt reports that many doctors working with patients at end-of-life no longer consider discussion of euthanasia and physician-assisted suicide as taboo and, with an aging Australian population, the focus on these issues could only be expected to intensify. However, the current focus in the euthanasia debate still tends to be on the “intention” of physicians in relation to the timing of death but deliberate decisions that bring forward the timing of death cannot be avoided (Douglas, 2009; Hunt, 1999; White, et al., 2011). A better focus would be to ensure, as far as possible, that the wishes of each and every patient are being met (Hunt, 1998). This is particularly important when the physician’s role now is more frequently acknowledged as serving the patient rather than the patient being there simply for the good intentions of the carer (e.g. one who may see their role as preserving life for as long as possible) (Australian Medical Association, 2006a).

According to Hunt (1998), palliative care specialists with informed and wide ranging experience in terminal illness (and access to multidisciplinary expertise), should be consulted to assess the nature of a patient’s request for euthanasia, whether it is congruent with the patient’s character and situation or related to depression or suffering that may be alleviated through traditional palliative treatments which are acceptable to the patient. However, many physicians also regard the current situation as ambiguous and contentious, with the development of better guidelines for dealing with euthanasia requests urgently needed to ensure the wishes and interests of patients and their family are best served (Douglas, et al., 2008; Hunt, 1999).

Furthermore, some physicians not only see the deliberate shortening of life as sometimes unavoidable, but also completely dependent on context (Douglas, 2009; Fohr, 1998; Hunt, 1999). For instance, Hunt vividly described a patient of his, Gordon, suffering from progressive but advanced Motor Neurone Disease who wanted to end his life when his condition became too burdensome (Hunt, 1998). When that time came, Hunt wanted to honour Gordon’s wish and titrated the dosage of morphine and midazolam (to keep Gordon comfortable), but the desired effect could not be achieved. Gordon’s restless
condition required further increments of medication, which, in conjunction with the removal of his respirator (to help alleviate his restlessness), ultimately ended in a peaceful death.

However, this case illuminates the conflict physicians’ face between patient autonomy and medico-legal imperatives that prohibit intentionally hastening death. If Hunt claimed his intention was to simply withdraw futile and burdensome treatment and administer palliative medications, he receives the official support of the church, the law, and the medical profession; however, if he claimed his intentions were to bring about Gordon’s death (in line with Gordon’s wishes) he would be prosecuted for murder. Hunt may also, therefore, feel compelled to be less than honest.

Secondly, this case presents a further conflict between patient dignity in terms of needless suffering, and the same medico-legal imperatives. It is acceptable to withdraw futile or burdensome life support but not administer an injection designed to kill, but it may have been kinder to Gordon to leave him on the ventilator (so that he could still breathe) and administer a lethal or bolus injection. Arguably Gordon died pain free but from suffocation. However, the law makes the kinder act a crime and is therefore often seen as unjust and lacking compassion (Magnusson, 2006, 2009). Indeed, as described earlier, the West Australian quadriplegic Christian Rossiter tried in vain to legally end his own life in a more humane way but was overruled by an Australian court in 2009 which allowed him instead to slowly starve to death (Brice, 2009; Freckleton, 2011; Stewart, et al., 2011; Williams, 2009).

Finally, to further highlight the inequity and discrimination inherent in the law and end-of-life care, Gordon could have life sustaining treatment (ventilator) removed quite legally if that was his express wish, however, other terminally ill patients not on life support cannot. As evidenced by similar landmark cases elsewhere, like Vacco v Quill (Gostin, 1997), the law requires them to live on.
Providing end-of-life care in Australia according to the informed wishes of dying patients and their families, who may request assistance to die, continues to be resisted by those in positions of power. With some fearing an opening of the floodgates or setting up a slippery slope towards death hastening practices (Ashcroft, 2003), the safer ground for many Australian legislators and those responsible for discharging the law and framing accepted medical practice, is to adopt a position which is consistent with the dominant Christian values of Australian society and sanctifies human life (Magnusson, 2002, p. 48). But it is physicians who ultimately negotiate appropriate care at the bedside.

4.6.2. Principle of double effect. Physicians providing end-of-life care need to uphold the interests and rights of their patient (McNeill & Dowton, 2002); however physicians also need to ensure they do not overstep their professional or legal bounds. The inherent ambiguity in individual end-of-life practices sometimes requires physicians to take up a legal position that protects them from allegations of professional misconduct (and murder) in the event a patient’s death is inadvertently hastened (White, et al., 2011). The principle of double effect provides such a protective position and is pervasive within Western end-of-life medical contexts (Quill, 1998). This principle establishes the guideline where the active administration of potentially lethal doses of analgesics is acceptable when the primary objective is to alleviate suffering (Battin, 2005). If death then ensues it is of secondary consequence. However this issue becomes thorny when imminent death (and prognoses vary) is merely foreseen (even with 100% certainty) or actually intended. Although both acknowledge identical outcomes, the former is legally and professionally indemnified.

To further complicate the issue, suffering which is necessarily subjective is often much more than physical, and not well addressed by analgesics. For example, at the end-of-life many also suffer existentially, experience anxiety, loss of dignity through physical dysfunction, and loss of control and autonomy (White, Wilkes, Cooper, & Barbato, 2004). Indeed, only 5% of terminal patients cite pain as important for requesting euthanasia (Trang, 1998) yet euthanasia for non-physical suffering lacks research.
However, even physical suffering such as incessant and maddening itching (Allen, 1998) or symptoms such as uncontrolled bleeding from eroding lesions or a refractory coagulation disorder, or an inability to swallow secretions due to widespread oropharyngeal cancer, are beyond the best pharmacological efforts. The principle of double effect has been a convenient way of differentiating practices of euthanasia and physician-assisted suicide where the intent to end life is explicit, from other practices such as terminal sedation where it is often argued that death is merely foreseen (Quill, Lo, & Brock, 2004). But as discussed below, such arguments are complicated and problematic for physicians.

4.6.2.1. Terminal sedation. Terminal (or palliative) sedation is very closely linked to the principle of double effect (Crenshaw, 2009; Hauser & Walsh, 2009). It is provided, as required, usually in the last 12 to 24 hours of life, but sometimes longer (Cherny & Radbruch, 2009). When it is instituted in palliative care, it is usually regarded as a last resort measure when all other efforts to provide comfort through traditional opiate or benzodiazepine based analgesia are ineffective. Accordingly, the patient is given these types of medications at titratedly higher doses to produce somnolence and, where necessary, powerful barbiturates may also be utilised (Hauser & Walsh, 2009). In critical care, sedation may be used as temporary symptom relief of invasive treatment e.g. to alleviate discomfort of ventilators and intubation or PEG (percutaneous endoscopic gastronomy) tubes for nutrition, and sometimes to temporarily induce coma for those with traumatic brain injury (Curtis & Rubenfeld, 2001). But sometimes sedation is used to wean patients off ventilators and other life support equipment to allow death to occur (Cherny & Radbruch, 2009).

However, the symptomatic complexity and comorbidity for those at end-of-life sometimes requires sedation to be used as a means of maintaining dignity. For example, at end-of-life, patients often suffer delirium and confusion which sometimes results in agitation and behaviour that could compromise the safety of medical staff and the patient’s own welfare (Fainsinger, De Moissac, Mancini, & Oneschuk, 2000). Sometimes,
temporary sedation is also helpful to allow psychotropic medication to take effect and
stabilise, and prevent similar dangerous or undignified behaviour (Woods, 2004).

The problem with sedation is that on the one hand analgesics and sedatives can do
much to relieve suffering in the terminally ill, but on the other hand, they can hasten death
particularly when given in sufficient doses (Fohr, 1998). For example, most of these
drugs can cause respiratory depression and hypotension yet they can also prolong life
through a reduced stress response when pain is better managed (Blanchard, 2002; Cherny
& Radbruch, 2009; Hauser & Walsh, 2009; Hill et al., 1990). However they can also lead
to reduced consciousness, and thus reduced oral intake and dehydration (Hunt, 1999;
Quill, 1998).

Generally, nutrition and hydration are withdrawn when “terminal” sedation is
instituted (de Graeff & Dean, 2007), but this sometimes leads to potential conflict
between families and medical staff, for example some cultural practices require their
loved ones to still receive food, yet this carries risk of it being aspirated (Cherny &
Radbruch, 2009). In defensive end-of-life practices in the USA, total parenteral nutrition
(TPN) is sometimes provided with sedation to avoid allegations (and subsequent
litigation) that a loved one might have been starved to death, but carries problems of fatal
infection at intravenous sites, blood clots and other potentially deadly complications
(Clay & Abernethy, 2008). In Australia, TPN is a divisive issue for physicians and not
frequently used. Patients who are close to dying, are sometimes sedated and intubated at
end-of-life due to moist breathing, and patients might literally drown in their own lung
fluids if further fluids are introduced.

Certainly, sedation may be used for different symptomatic issues, at different
levels of somnolence and for differing durations. When used on a deep and continuous
basis that maintains the patient in a state of unconsciousness until death occurs, often
while artificial nutrition and hydration is withheld, it has also been referred to as “slow
euthanasia” (Douglas, et al., 2008; Gormally, 2004; Kuhse, 2004). However, this is
something palliative specialists frequently object to because they see this as an accusation
of intent to kill rather than alleviate suffering; a double effect distinction (Cherny & Radbruch, 2009). They further argue that even double effect is unnecessary because sedation is judiciously titrated for refractory symptoms and the alternative of not sedating would actually prolong needless suffering and distress, also potentially hastening death (Carvalho, Rady, Verheijde, & Robert, 2011; Hauser & Walsh, 2009). Yet the premise that pharmacologically induced unconsciousness can effectively control intractable pain or affective symptoms from dehydration is open to scientific questioning. Neurophysiological and functional neuroimaging studies have begun to unravel the complexity of human awareness of inner and external noxious stimuli after inducing unconsciousness with sedatives, and identified that awareness is not completely ablated (Noirhomme et al., 2010). If patients can indeed still suffer when comatose, physicians may have to rethink their end-of-life strategies and the merits of intentionally hastening death.

Sedation is therefore conceptualised very differently by physicians and is sometimes quite divisive across specialties (Broeckaert & Leuven, 2011; Douglas, et al., 2008). Moreover, there appears to be some professional one-upmanship by palliative specialists who suggest sedation should only be in their specialist hands otherwise it risks being inappropriately used and potentially attracts the slow euthanasia label (Hauser & Walsh, 2009). However, specialist palliative expertise is not always available, and non-palliative physicians need to sedate terminal patients who are refractory to all other measures. While most will do this titratedly, perhaps without the range of pharmacy available to palliative specialists, they will provide good symptom relief nonetheless, albeit perhaps with deeper sedation than their palliative colleagues might (Seale, 2010). However, divisive practices like sedation that are so closely linked to double effect, also provide opportunities for manipulation where intent might be obscured and a physician supportive of hastened death may accede to a patient requesting assistance to die.

To illustrate, after the ROTI Act was invalidated by the Australian Federal Government, one patient, Ester Wild (Kissane, et al., 1998; Kuhse, 2004), who had
fulfilled all of the ROTI requirements, could no longer terminate her life with a fast-acting lethal drug through the assistance of her physician. Her treating physician, Dr Philip Nitschke, satisfied legal requirements by commencing a program of terminal sedation and Ester Wild died four days later in a state of induced unconsciousness. Dr Nitschke was then subjected to a coronial enquiry to determine intent but was subsequently exonerated because such determinations without an admission are fraught with difficulty.

Yet, in another case, Swedish physician Dr Mats Holmberg, who opposes voluntary euthanasia, sedated two of his patients who requested assistance to die and was threatened with legal action for doing so (Tännösjö, 2004). However, he successfully argued that titrated sedation was the only option available to him to address intractable suffering; essentially a defence resting on double effect. Palliative sedation was regarded by many palliative experts in Sweden as euthanasia and therefore illegal (Tännösjö, 2004). It was only recently that an association of physicians in Sweden, published guidelines which allowed for palliative sedation to be administered even with an intent for the patient not to reawaken (Österberg, 2010) but, prior to 2009, providing palliative sedation was provided only very rarely and then in only exceptional circumstances (Strang, 2009).

It is important to note however, that in both of these cases, practices were manipulated and conceptualised to be consistent legally, professionally, but also with the beliefs and ethical standards of each physician. In both cases sedation was a convenient mechanism to provide relief of intractable suffering. Both cases were justified as in the patient’s best interests and with the unintended but foreseeable risk of death occurring (double effect). Both cases upheld legal and professional imperatives. Yet these practices were acceptable to both physicians even though one advocates voluntary euthanasia and the other strongly opposes it. These cases highlight how multilevel influences that may affect practices can be uniquely negotiated to achieve particular (and sometimes identical) outcomes and understandings.
However, although two physicians holding opposing philosophical viewpoints on euthanasia might negotiate similar outcomes, this may not always be the case. For example, terminal sedation invokes the principle of double effect by firstly alleviating pain and suffering and consequently the patient dies, but the principle of double effect is inherently problematic when death could be considered either intentional or merely foreseeable. There is very little difference between intentionally killing a patient to end their suffering and incrementally increasing analgesia or sedating to alleviate suffering when a fatal outcome is a foreseeable, if not inevitable, consequence (Douglas, et al., 2008). Either way, such decisions are still made “intentionally”. Furthermore, the distinction made between acts of commission (killing) and acts of omission (letting die) has a clear philosophical inconsistency because end-of-life decisions to actively administer or withdraw treatment are also made intentionally, and achieve the same outcome (Kuhse, 2004). Terminal sedation, therefore, is not just “allowing the patient to die pain free” because withholding nutrition and hydration could also be argued as intended to terminate life (Carvalho, et al., 2011). The patient may well have a terminal illness not of the doctor’s making, but the intentional act of rendering the patient comatose while dehydrating and starving them is the doctor’s. Accordingly, many traditional supporters of the sanctity of life doctrine still regard terminal sedation as an intentional termination of life and, therefore, euthanasia (Gormally, 2004).

Terminal sedation is additionally problematic when administered at the sole discretion of physicians due to patient incompetency or lack of an advance directive. Physicians may presume sedation is what the patient would have wanted and ambiguity arises over whether interventions are voluntary or involuntary. Nevertheless, induced unconsciousness and a “good death” are not necessarily the same because many patients endorse the importance of mental awareness at the end-of-life (Steinhauser et al., 2000). For example, awareness and an ability to communicate are important in allowing families and patients to say their goodbyes and, arguably, to better facilitate closure for those left behind.
4.7. Summary

Ambiguities surrounding end-of-life definitions and practices require careful negotiation by physicians, but also in ways that are specific to each patient and their situation. Physicians negotiate multiple influences at the bedside that shape the care they may provide to dying patients and their families. Physicians encounter requests for hastening death and also engage in practices where death is a foreseeable outcome, but must negotiate medico-legal imperatives, social and cultural influences, and professional ideologies that may constrain the end-of-life care they consider appropriate. There may be conflict among physicians and also between physicians’, patients and patient families over appropriate care goal transition. Physicians often seek direction to assist their decision-making, sometimes through guidelined practices such as the Liverpool Care Pathway, but also find these limited in their application. Furthermore, in terms of education and training, the skill and expertise of physicians is not consistent across specialities and settings, which implicates a resourcing and institutional element. It is important, therefore, to gain a greater understanding of the inconsistency in practices and different meanings held by physicians who provide end-of-life care in Australia, and how they experience this.
Chapter 5

Micro Level Considerations for End-of-Life Care:

The Personal World of Experience

Although many physicians may broadly describe similar experiences when providing end-of-life care, each experience is necessarily unique and occurs in a particular moment (Adler, 2007; Rich, 2005). However, specific contextual influences, such as the setting, patient and family differences, as well as personal characteristics of the physician and other professional colleagues, will affect how the physician may experience a particular end-of-life interaction (Adler, 2007). The experience will also depend on how the physician conceptualises the ideal provision of that care and how it was actually provided, how constraints were navigated, and on the supportive strategies and resources available to the physician (De Jonge & Clarke, 2009).

Physicians practicing end-of-life care in Australia come from diverse cultural and religious backgrounds and, although equally valid, their views around treatment decisions may well differ from those of patients, families and others engaged with the health system (Johnson, Kuchibhatla, & Tulsky, 2008; Spike, 2007), and be a source of friction (Johnson, 2006; Weissman, 2001). Furthermore, setting and institutional factors are implicated in the high rates of burnout, emotional stress and psychiatric morbidity experienced by some physicians and nurses working with terminal patients in critical and palliative settings (Keidel, 2002; Sabo, 2008). Although high workloads, difficulty accessing time off, and budgetary and time constraints, are endemic in Australia’s health
system (Dunwoodie & Auret, 2007; Girgis, Hansen, & Goldstein, 2009), they are only some of the possible contributors adversely impacting those providing end-of-life care. For example, physicians often need to provide psychological assessment and emotional support for patients and their families, but a lack of relevant psychological training impacts the expertise and confidence of many physicians (Trang, 1998; Ury, Berkman, Weber, Pignotti, & Leipzig, 2003) and psychosocial skills are often devalued in medical training (Sullivan, Lakoma, & Block, 2003). Physicians, like nurses, also form emotional attachments with patients and their families and suffer “compassion fatigue”, but seldom recognise or address their own requirements in relation to grief and bereavement (Keidel, 2002; Najjar, Davis, Beck-Coon, & Doebbeling, 2009; Sprang, Clark, & Whitt-Woosley, 2007). This chapter considers multiple influences affecting the “experiences” of physicians engaged with end-of-life care, and examines issues like burnout and coping strategies, interpersonal relationships and intrapsychic factors, physician skills and their understanding and negotiation of particular practices.

5.1. The Intrapersonal and Interpersonal Experience

End-of-life care emphasises multi-level nonlinear influences, where the uniquely intrinsic or personal aspects of the physician interacts with an equally unique external social environment. For example, interpersonal relationships conducted with patients, families and colleagues may influence the experiences of physicians aversively or rewardingly, while those experiences may subsequently foster avoidance or engagement, thus impacting future relationships and experiences. The skill and confidence of physicians, as well as their personal attitudes and beliefs toward particular practices, are reflected in their negotiation of end-of-life care.

Sometimes physicians are confronted with difficult end-of-life decisions from patients (and their families) who request assistance to die (Smith, 2009). For example, in specialised palliative settings alone, approximately 10% of patients desire death and ask for help in dying, even after hopelessness and depression have been addressed (Chochinov et al., 1995). However, if depression or hopelessness are inadequately dealt
with, up to 22% of advanced cancer patients (Breitbart et al., 2000; Tiernan et al., 2002), and around 44% of elderly terminal patients may request a hastened death (Hooper, Vaughan, Tennant, & Perz, 1997). The exposure of physicians in critical and palliative settings to issues of euthanasia, physician-assisted suicide and terminal sedation, requires them to not only interact with patients and patient families directly, but to also reconcile any personally dissonant beliefs and attitudes, yet physicians are often reluctant to engage in these types of discussion (Back, et al., 2002; Back, 2004). The beliefs and practices of some physicians may also be contrary to those of their colleagues and management, legal constraints, and the professional institutions that seek to promote the standards and protocols regulating end-of-life care (Johnson, 2006; Spike, 2007; White, Wise, Young, & Hyde, 2009). Accordingly, physicians holding non-normative positions around patient treatment are then often reluctant to confide in colleagues for fear of ridicule and ostracism (Weissman, 2001), and feel hospital management is largely unsympathetic to their needs and opinions (De Bal, Dierckx de Casterlé, De Beer, & Gastmans, 2006; Magnusson, 2002; Meier, et al., 2001). Requests to hasten death may pose personal and professional dilemmas for physicians and lead to increased stress as a consequence (Leung & Esplen, 2010; White, et al., 2009). Additionally, the illegality of euthanasia or assisted suicide places physicians within end-of-life settings in precarious legal, moral and ethical positions, especially when the boundary defining where terminal palliative care ends and euthanasia begins is not clearly delineated.

That ambiguity, particularly in relation to some end-of-life practices, may be a considerable source of conflict, especially if professional consensus is also lacking (Radbruch & Nauck, 2010; Seale, 2009). Yet, how physicians negotiate that ambiguity specific to each situation influences their experience (Lee & Dupree, 2008). Terminal sedation, discussed earlier, is especially problematic for doctors and nurses who struggle to agree on a definition (Crenshaw, 2009; Currow, 2003). Woods (2004) claimed the term itself is ambiguous with different meanings in different contexts, for instance it can also be used for symptom relief when conditions are far from terminal. Although legally and
ethically accepted in many countries, terminal sedation continues to conflict with personal and professional values and morals, religious beliefs and the views of colleagues and health care management. For example, nurses internationally found the practice emotionally burdensome, especially when it was not administered solely for intractable suffering, and had difficulty separating it from euthanasia (Blondeau, Roy, Dumont, Godin, & Martineau, 2005; Morita, Miyashita, Kimura, Adachi, & Shima, 2004).

However, in some countries, terminal sedation is also frequently used for non-physical and existential suffering (Rietjens, Hauser, van der Heide, & Emanuel, 2007) but those situations have scarcely been researched, particularly in Australia. This is somewhat surprising considering existential suffering and terminal anguish are commonly presented characteristics in the palliative environment and end-of-life care generally (Das, Chauhan, Gupta, Mishra, & Bhatnagar, 2009).

Still, for some, hastening death does not always weigh as heavily as alleviating suffering and distress. Indeed, research conducted in Japan found that most nurses experienced serious emotional stress when terminal sedation was not initiated for patients suffering refractory and intolerable symptoms (Morita, et al., 2004). Moreover, 18.7% of physicians in the UK attending a dying patient reported using terminal sedation particularly to address the suffering of younger patients, but also for requests to hasten death where quality of life was regarded as particularly poor (Seale, 2010). For these physicians sedation seemed a convenient mechanism to accede to patient requests and end suffering, (and perhaps also their own suffering). Clearly, there are divergent experiences and opinions in end-of-life care not only between professions but also within professions where different meanings are held around potentially death hastening practices.

Moreover, intrapersonal conflicts may also arise in end-of-life decision-making between a physician’s personal and professional values, for example, a compassionate belief that voluntary euthanasia is in the patient’s best interests versus a professional belief to promote life (Cohen et al., 2006; White, et al., 2009). Similarly, religiosity and sanctity of life imperatives may conflict with a humanitarian worldview that encourages
patient autonomy and a “right to die”, especially in church-based care facilities (Driscoll, 2001; Mitchell & Mitchell, 2009). Cultural and religious differences emphasised in multicultural societies influence patient and physician attitudes to end-of-life issues and experiences within the health care setting (Perkins, Cortez, & Hazuda, 2009). Although each situation can be quite unique, such differences sometimes demand disparate intervention strategies, for example allowing patients to die; or requiring that “everything is done” (Hillman, 2011). However some physicians, especially when dealing with real patients in real circumstances, do not accept such values unconditionally (Cohen et al., 2008). This suggests that physicians might embrace religious teachings in a non-imperative way, allowing adaptation to particular situations.

Nonetheless, differences of professional ideology are also acknowledged as sources of conflict for physicians providing end-of-life care (Leung & Esplen, 2010). For example, in general and critical/acute settings, an emphasis on cure is often at odds with the comfort emphasis of palliative care (Stolick, 2003; van Staa, Visser, & van der Zouwe, 2000; Wilkes & White, 1995). Conflict can arise between physicians and between professions and, indeed, patients and their families, especially if patients are required to undergo futile treatments or denied appropriate palliation (Kuhse & Singer, 1993; Lee & Dupree, 2008; Weissman, 2001). Physicians are not completely alien to a philosophy of providing comfort to patients and their families at end-of-life but, unlike their nursing counterparts, physician training emphasises a cure doctrine where death is often seen as medical failure (Clarke & Ross, 2006; Keidel, 2002; Rich, 2005; Weissman, 1999). Accordingly, differences in meaning around death can affect how physicians interact with patients, for example the powerlessness some doctors might experience with terminal patients may facilitate avoidance and their withdrawal from such patients (Meier, et al., 2001; Moreno-Jiménez, Rodríguez-Carvajal, Hernández, & Benadero, 2008). Physicians who attach emotionally or psychologically with patients and their loved ones may struggle to process grief despite the expectations of their profession to remain objective (Lee & Dupree, 2008; Lobb, Clayton, & Price, 2006).
It may be quite difficult for physicians providing end-of-life care if they are constrained by a particular professional ideology that inhibits the care they would like to provide. For example, death is accepted in specialised palliative settings (Byock, 2002; Stolick, 2003), but often denied and prevented in settings that are curatively oriented (Robichaux & Clark, 2006; Stolick, 2003). It remains unclear how physicians engaged in providing critical care in Australia experience their negotiation of end-of-life decisions, particularly in comparison to their palliative colleagues. However, a few non-Australian studies conclude that attitudes to death itself do not have a significant relationship to physicians’ caring for and about terminally ill patients, but that the relational impediments of family, lack of agreement among physicians and restrictions of the unit or organisational culture may be more problematic issues (Beckstrand & Kirchhoff, 2005; Dunn, Otten, & Stephens, 2005). Accordingly, the ability of physicians within critical settings to facilitate a “good death” for patients and their loved ones may be seriously impaired by the prevailing ideology which determines the care they may provide (Robichaux & Clark, 2006), as well as by the training and support they have access to (Hanson, Henderson, & Menon, 2002). The physical, emotional and psychological effects critical care physicians experience may be quite different to those of their specialist palliative colleagues who are, arguably, positioned within settings that foster practices of comfort. Such practices are more conducive to facilitating “good deaths”, and resolving issues of grief and bereavement for family members and themselves.

Indeed, nurses and physicians providing care within critical settings report experiences that are harrowing and painful, and which provoke feelings of extreme anxiety and stress (Seymour, 2003). However, this is also due to the intimacy nurses and physicians share with patients and their families and the difficulty they sometimes experience when trying to separate their personal and professional selves. According to Seymour, such experiences require subsequent efforts to “manage” their own emotions and maintain ongoing vigilance over their personal involvement to achieve a distinct boundary from their professional self, but the ability to do this is often dependent on
setting dynamics. Furthermore, the process of separation between the personal and professional self is difficult to sustain because personal involvement and expression of emotion is also a part of professional identity (Lee & Dupree, 2008; Rousseau, 2009b). For example, some nurses have reported that: “because we are human, we can’t help but to get close with dying patients and their families” (Seymour, 2003, p. 331), while a physician reported that: “although we can often remain relatively emotionless, there are times, often completely unexpected, that you can be particularly moved by a dying patient, especially if they were someone you might easily relate to” (Seymour, 2003, p. 333). That particular physician found that in those situations it was hard not to develop a deep emotional feeling and she found such experiences quite upsetting.

The critical care environment can be difficult for physicians and nurses, but some also report high levels of satisfaction, especially when efforts to provide comfort to dying patients in terms of basic care such as shaving, washing, mouth care, and so on are recognised and appreciated by patients and their families (Seymour, 2000, 2003). The physical care and careful presentation of the body becomes a means of affirming a heightened status and the individuality of the dying person. Nonetheless, consistent with the ideology of critical care, even this type of care is frequently referred to in terms that appear to marginalise its role as compared with the more overall management of patients (Seymour, 2003).

5.2. Physician Skills and Training: Challenging Requirements of End-of-Life Care

Clearly, there is a growing demand for medical end-of-life environments to undergo continual change and development according to the needs and expectations of patients and their families. Similarly, the subsequent expectations placed on physicians require them to continually develop their skills in order for them to provide effective end-of-life care and meet the evolving challenges of a dynamic and changing environment. For example, Kissane and Yates (2003) state that it is a common expectation in palliative care for all team members to be competent in their clinical response to patient distress. This includes recognition, diagnosis and management of distress, and skills in advocacy
and referral when particular professional help is required. However, the degree of specific professional training (both pharmacological and psychological) that non-palliative physicians providing end-of-life care are given, or the skills and expertise they may develop or have regular access to, is inconsistent across settings (Ewing, Farquhar, & Booth, 2009; Sullivan, et al., 2003; Ury, et al., 2003). End-of-life care often provides complex patient situations that are problematic both psychologically and physiologically, but both need to be effectively dealt with to facilitate as good a death as possible. The experiences of physicians will be dependent on how well they meet such treatment challenges within the constraints that apply (De Jonge & Clarke, 2009).

Currently, training inadequately supports the multidisciplinary expertise expected of physicians and nurses in end-of-life care (Becker et al., 2010; Hesselink, Pasman, Van der Wal, Soethout, & Ontwuteaka-Philipsen, 2010; Sehgal et al., 2008). According to Leung and Esplen (2010), a dominant biomedical model, particularly in non-palliative settings, does not provide guidance to physicians on issues that are predominantly psychosocial. Staff frequently feel out of their depth in addressing the emotional and psychological needs of patients and their families (and of themselves) when dealing with end-of-life issues (Fine, Reid, Shengalia, & Adelman, 2010; Gething, 1998). Zalcberg (1997) also argued for increased psychological expertise in end-of-life care because many requests for euthanasia are actually cries for help, reflective of depressive symptomatology. But, such diagnoses are sometimes overlooked and any evaluation of mental competency is frequently left to physicians rather than mental health professionals (Emanuel, 2005; Ganzini, et al., 2000; Papadimos, Maldonado, Trpathi, Kothari, & Rosenberg, 2011). The complexities of mental health are not emphasised in the medical training of physicians yet are areas they must often negotiate in end-of-life settings.

5.2.1. Existential distress in dying patients. Patient distress is common at end-of-life and generally defined as an unpleasant emotional experience arising from psychological (affective, behavioural and cognitive) physical, social or spiritual issues (Moadel et al., 1999). Such experiences require a coping response adapted to the
challenges of life. However, existential distress is more specifically defined as distress arising from confronting the essence of existence such as issues of death, meaning of life, aloneness, responsibility, freedom, choices and a sense of personal worth and dignity (Chochinov, 2002, 2007; Henoch & Danielson, 2009; Yalom, 1980). Existential distress is a substantial cause of persistent anxiety or depressive symptoms requiring intervention (Leung & Esplen, 2010). Yet, unlike physical symptoms, existential distress is especially problematic for treatment because it constitutes a threat to personhood, specifically, the sense of who a person really is and is often much more than pain, anxiety or depression (Cassell, 1982; Leung & Esplen, 2010; Moadel, et al., 1999). However, although physicians engaged in end-of-life care are frequently confronted with patients experiencing existential distress, many physicians find they struggle to address those issues in a satisfactory manner (Boston, Bruce, & Schreiber, 2010; Kissane & Yates, 2003; LeMay & Wilson, 2008).

Indeed, Cassell (1982) states that communication about death and dying is one of the most formidable tasks confronting many physicians and supports research where physicians who have been identified as poor communicators on these issues (often those without specialised palliative skills), sometimes prefer to avoid or disengage from dying patients (Back, 2004; Moreno-Jiménez, et al., 2008). However, a review of communication training workshops indicates that more conscious and intentional skills can increase facilitative behaviours and the satisfaction and confidence of physicians (Kennedy, 2005). Yet in clinical practice, these skills are surprisingly avoided, seen as non-essential, or constrained for a variety of philosophical, professional, personal and practical reasons (Heaven & Maguire, 1996; Schulman-Green, McCorkle, Cherlin, Johnson-Hurzeler, & Bradley, 2005; Wilkinson, Bailey, Aldridge, & Roberts, 1999; Zeytinoglu, 2011). Certainly some physicians, including those specifically engaged in Australian palliative care; acknowledge the importance of being open to listening to the spiritual/existential concerns of terminal patients, but that it is not their role to discuss such issues in depth (Clayton, Butow, Arnold, & Tattersall, 2005). Still, if
multidisciplinary expertise is not available, and direct questions are asked, physicians might be obliged to take that role and deal with these issues in the best way they can.

Many physicians also fear that prognostic awareness means full and truthful disclosure, but some do not wish to disclose their prognoses to patients or dwell on these topics due to their own discomfort or fears of further distressing patients (Leung & Esplen, 2010; Weissman, 2001). Although patients seek information on the trajectory of their illness, some physicians believe that a fully informed patient will achieve a self-fulfilling prophecy (Christakis, 1999), leading to further despair, disappointment and full isolation (Canto, Canaves, Xamena, & Amengual, 2000; Georgaki, Kalaidopoulou, Liarmakopoulos, & Mystakidou, 2002). Ignoring or avoiding patient cues of when, where and how to talk about existential issues may explain why so many referrals to palliative care specialists are felt to be too late and patients’ continuity of care to be poorly compromised (Bestall et al., 2004).

Yet, recognition, understanding and communication are paramount to ameliorate the onset and effects of existential distress. Symptoms that are not addressed correctly sometimes lead to a further deterioration in patients by manifesting in clear cut psychiatric disorders (Clarke & Kissane, 2002; Kissane & Yates, 2003; Leung & Esplen, 2010). If existential aspects are inadequately dealt with, any resolution of a patient’s psychiatric state will be temporary and relapsing (Kissane & Yates, 2003) and may also prompt requests to hasten death (LeMay & Wilson, 2008; Nissim, Gagliese, & Rodin, 2009). It would be difficult for a physician to gain a sense of reward and purpose from their work if they feel inadequately trained or unsupported professionally, and struggle to provide the care such patients need.

Still, research investigating actual remedial interventions for existential distress in palliative care is relatively scarce, and even more so in other settings (Henoch & Danielson, 2009), but a Japanese study of 162 terminally ill hospice patients found meaningless present in 37%, hopelessness in 37%, role loss 29%, dependency 39% and concern about being a burden 34% as common causes of distress (Morita, Tsunoda,
Inoue, & Chihara, 2000). In other research, Moadel et al. (1999) reported that spiritual/existential needs are not met in 25% to 51% of cancer patients while an exploratory survey reported more than 93% of cancer patients have at least some concern about the value of life and how long they might live (Klemm, Miller, & Fernsler, 2000). These are arguably significant numbers, but it remains unclear how doctors, in Australia and elsewhere, actually deal with such patient distress, or how it influences their interactions or their decision-making and the treatments they provide.

Addressing existential distress may be additionally problematic for physicians if patients also avoid initiating discussion because they sense discomfort in their physician around these issues. Further, some patients might not have the words to describe how they feel, perhaps do not wish to be a burden, fear breaking down or are ashamed admitting coping problems (Vehling et al., 2010), and physicians may be reluctant to broach these issues for fear of causing even greater distress to patients.

5.2.1.1. The demoralisation syndrome in terminally ill patients. If patients have nowhere to turn to discuss existential issues, they may become demoralised when commonly asked questions such as: “what will dying be like for me?” are not adequately answered by their physician (Kissane & Yates, 2003). Patient anxiety with death is normal, but some patients also review their life and feel there has been a lack of purpose or fulfilment and this may promote despair that their life has been wasted (Parker, 2004). Such perceptions may trap a terminal patient in a conviction that life is futile (Chochinov, Wilson, Enns, & Lander, 1998). Accordingly, rather than accepting impending death patiently and with a sense of ease as characteristic of patients who experienced their lives as fulfilling and satisfying, demoralised patients can await death with impatience and, because life was perceived as meaningless, may be eager to end it (Clarke & Kissane, 2002). Suicidal thoughts might develop in such patients yet they might not be clinically depressed and, indeed, physicians may regard those patients as having “rationally” chosen suicide as a merciful conclusion to their lives (Kissane, 2001; Kissane, et al., 2001). Physicians may, therefore, receive additional requests to assist such patients in those
goals. Yet, whether physicians sometimes comply with “rational” requests, or if they utilise strategies that may instil hope in demoralised patients and help them find meaning, or whether they have access to timely professional expertise to assist them is unclear. On the other hand, whether physicians (particularly those non-palliatively specialised) withdraw further from such patients is also unclear.

5.3. The Impact to Physicians Providing End-of-Life Care

End-of-life care carries great complexity in patient needs and provides physicians with specific challenges. However, despite the inherent challenges in caring for terminal and suffering patients, it might also be argued that it is exactly this complexity and clear need for specialised practitioners with access to appropriate resources that attracts physicians to train and engage in end-of-life care. Physicians may feel they can make a difference. Indeed, many physicians have reported that caring for the dying and terminally ill can often be a humbling but eminently satisfying vocation (Lee & Dupree, 2008; Rumbold, 1998). Many experience personal growth and awareness through the empathy they develop with patients and their loved ones who are confronting the final stages of life (Vachon, 2003). Walking with patients and their families during the most difficult time in their lives and working to decrease their suffering can be very rewarding for physicians. Furthermore, being instrumental in providing a caring, comfortable and easy transition into death can often help bring closure to the patient’s loved ones as well as for the physician and medical team who sometimes also need to process similar grief and bereavement (Wilkes, 1998). Such positive outcomes are particularly possible if patients and their physicians are also well supported by the management of the hospital or end-of-life facility they are involved with (Rumbold, 1998). Physicians who also collaborate and support each other may have especially positive outcomes, which further sustain them in more trying situations (Lobb, et al., 2006; van Staa, et al., 2000).

Nevertheless, end-of-life care can also be a difficult environment with significant negative impacts on the physical, emotional and psychological wellbeing of physicians, especially if those impacts accumulate and are not adequately addressed (Blomberg &
Sahlberg-Blom, 2007). The constant exposure to suffering and loss takes its toll if the physician is unaware of the need to care for self as they do for others (Keidel, 2002; Sprang, et al., 2007). It is also important to note that much stress in providing end-of-life care is also due to personal circumstances and not only the stress of dealing with the dying, specifically, the stresses related to institutional role conflicts, issues of power and control, and support (Beckstrand & Kirchhoff, 2005; Shapiro, et al., 2011). Furthermore, there are also significant psychological challenges unique to the physician and the situation they are engaged in that carry important implications for patient and physician health. For example, physicians need to be aware of transference and countertransference issues (Kissane, 2000; Redlich, 1970) where they may convey a sense of hopelessness and increase suicidal ideation in patients when struggling to deal with their own emotions (Kissane, 2000).

Yet, many physicians find a profession where they can provide care to the dying and terminally ill, and their families, appealing (Lee & Dupree, 2008). The beliefs that some physicians’ hold and the personal qualities they can bring to the profession often enable them to provide exceptional care while maintaining personal well-being (Rousseau, 2009b). Physicians who also gain meaning and a sense of purpose from their work are more likely to experience satisfaction from their efforts and remain motivated which further enhances the care they bring to the bedside (Pines, 2000).

5.3.1. Religion and physician spirituality. Religion and spirituality have been useful for physicians and nurses working in palliative care who sometimes struggle to find meaning in their work (Flannelly, Weaver, & Costa, 2004; Mickley, Pargament, Brant, & Hipp, 1998). For example, nurses attracted to hospice work were found to be more religious than colleagues working in other areas of health care including those in oncology (Millson & Dudley, 1992). Hospice nurses also more frequently reported providing spiritual care and had more positive perspectives regarding spiritual care giving (MacDonald, Sandmaier, & Fainsinger, 1993; Millson & Dudley, 1990; Taylor & Amenta, 1994). However, physicians in the USA who wished to provide spiritual care to
patients were often constrained by professional and institutional influences. For example, professional colleagues and peers did not consider it the role of bedside physicians and marginalised this work, and time was prioritised elsewhere (Chibnall, Bennett, Videen, Duckro, & Miller, 2004). Some Australian physicians also regarded spiritual care as a role for others (Clayton, et al., 2005). Although such work might be delegated elsewhere, constraints that diminish the importance of spirituality for those physicians wishing to provide holistic end-of-life care, and inhibit their practices, may dilute the sense of meaning in their work.

Spirituality and religious ideologies, so dominant in many end-of-life care settings, may actually attract physicians and nurses with those world views to hospice work. Furthermore, a world view that accepts death as a normal part of life regards death as having purpose and meaning, but it is also perhaps less confronting than it might be for physicians who try to avoid or prevent it, and then ultimately fail. Highlighting the complexity of multilevel influences to experience, the personal world view that a physician holds may strongly shape their professional practice and their subsequent experiences, but their professional world may also constrain the expression of that world view and adversely impact their health (Pines, 2000).

5.3.2. Physician burnout. Keidel (2002) defined burnout with many symptoms resembling depression, but especially identified emotional exhaustion and depersonalisation in hospice nurses. “Compassion fatigue” overlaps in meaning (Najjar, et al., 2009; Sprang, et al., 2007) and is usually attributed to family caregivers, however due to the multiple attachments formed with patients and their families in the hospice and palliative setting, it is also frequently experienced by nurses (Sabo, 2008) and physicians (Kearney, Weiningier, Vachon, Harrison, & Mount, 2009).

Nonetheless, high rates of burnout, emotional stress and psychiatric morbidity are associated with health professionals generally, particularly when working with terminal patients in the palliative setting (Keidel, 2002; Magnusson, 2002). Doctors, nurses and other allied staff often identify with particular patients through emotional attachment,
especially from frequent contact over protracted periods of time (Lee & Dupree, 2008). Health professionals sometimes struggle to process their own grief when a patient under their care dies with some, particularly doctors, further struggling to reconcile patient deaths with their professional ideology that often implicitly regards death as a medical failure (Clarke & Ross, 2006; Keidel, 2002; Rich, 2005). The emotional vulnerability of treating physicians is perhaps seldom acknowledged or addressed and despite efforts to maintain objectivity and professionalism, physicians respond to patients with emotions of their own (Kearney, et al., 2009; Meier, et al., 2001; Pellegrino, 1993). Such emotions may not be expressed overtly but are more often felt and internalised (Sprang, et al., 2007). Physicians, like nurses, feel frustration, failure and powerlessness when patients are beyond their expertise. Some internalise grief, fear becoming ill themselves and cope through avoiding or separating from their patients (Meier et al., 2001). There are obvious implications for patients and physician health if their unexamined emotions lead to distress, disengagement, burnout and poor judgement.

Indeed, physician burnout has been identified as a generator of requests for euthanasia, particularly if physicians are too tired or disinterested in exploring other terminal treatment options, and it is also responsible for some practical difficulties successfully completing euthanatic acts (Glare, 2003). As discussed earlier, other researchers have cautioned physicians to monitor their own personal attitudes toward patients and the clinical problem so as not to unwittingly transmit negative (countertransference) feelings in a harmful or coercive way as this could exacerbate hopelessness and suicidal ideation in patients (Kissane, 2000). However, it is important to understand how physicians experience requests to hasten death.

Such research, particularly in Australia, is scant. However, semi-structured interviews were conducted with 24 doctors involved with a Brisbane hospice to examine their role in dealing with a terminal patient’s wish-to-hasten-death (Kelly, et al., 2003). Doctors’ own experiences in providing treatment and care for terminal patients included distress and significant emotional demands. Although some doctors felt rewarded
Knowing they provided some reduction in patient suffering, most acknowledged limitations in what they could do for patients (especially emotionally). The prolonged nature of illness especially with patients expressing a particularly strong wish to die was most concerning for doctors, particularly when constrained by their own views and limitations. Doctors’ perceptions of their patient’s views toward euthanasia and hastened death were also frequently inaccurate and the need to increase doctor confidence through better communication skills was strongly identified; particularly when a patient’s wish-to-hasten-death is influenced by the doctor-patient interaction (Glare, 2003). Improved communication might lead to more effective interventions by better understanding patient wishes, but when physicians have felt confident in communicating with patients on these issues they have also reported their experience of end-of-life care as very satisfying (Jackson, et al., 2008).

Elsewhere, as with Belgian nurses who struggled to reconcile the administration of legalised euthanasia with their own personal views (De Bal, et al., 2006; Dierckx de Casterlé, Verpoort, De Bal, & Gastmans, 2006), doctors in the Netherlands also struggle to deal with patient requests for euthanasia despite the practice being accepted and legal for about 10 years (Georges, et al., 2008). Around 50% of Dutch GPs strived to avoid euthanasia and physician-assisted suicide because it was emotionally burdensome or against their own values. Yet, Australian doctors may currently have greater difficulty with the issue than Dutch physicians when it is not legally supported and ideologically contradicts their profession. Certainly, Kelly et al. (2003) identified the problematic nature of multiple influences underpinning requests by terminal patients in Australia to hasten death, and the need for these to be clarified, but how Australian doctors, particularly across different settings and specialities, actually negotiate and experience such requests (including those made by loved ones) remains largely unexplored.

Nonetheless, aversive experiences are not only due to receiving requests for death. Again strongly related to communication and professional ideology, oncologists in the USA who described a primarily biomedical role reported a more distant relationship with
patients, a sense of failure at not being able to alter the course of the disease, offering fewer end-of-life treatment options, and an absence of collegial support (Jackson, et al., 2008). These physicians felt unable to assist patients’ coping with and acceptance of death. However, physicians who viewed their role as encompassing both biomedical and psychosocial aspects reported a clear method of communication about end-of-life care, an ability to positively influence patient and family coping with and acceptance of the dying process, and also viewed provision of effective end-of-life care as very satisfying. Effective communication and professional ideology are perhaps linked, but both influence experience. When end-of-life care is provided in many (ideologically) different settings, these influences need consideration in research.

Other research exploring the experiences of nurses who provide end-of-life care in critical and emergency settings has found that they often struggle with issues of grief and bereavement (Milne & Millard, 2003; Rich, 2005). Nurses working with terminal patients often have little time to process grief or address any anxieties they might hold regarding their patients and the treatment they provide for them (Flam, 1999; Rich, 2005). Furthermore, rather than recognising and accommodating individual experiences of grief and bereavement, unhelpful stereotypical “gendered” constraints are often still perpetuated (at cultural, institutional and professional levels), where males are constrained in expressing emotion through weeping (Martin & Doka, 2000). Certainly, end-of-life patient care treats physical conditions but also provides emotional support and comfort for patients and loved ones, a task as demanding as it is complex, and where nurses with only cursory psychological training often find themselves overwhelmed (Lee & Dupree, 2008; Ury, et al., 2003). Rich also found nurses were sometimes the target of violence and litigation from bereaved family members, and increasing workloads and responsibilities placed nurses under further stress. However, it is unknown if similar effects might exist for physicians who often also share considerable emotional involvement with dying patients.
Palliative nurses working in Australian community, hospice and hospital settings also described the impact of “unrelieved” patient suffering as particularly debilitating to their own personal health and well-being when support was limited both within and outside the work environment (White, et al., 2004). The impact on nurses by patients classified as dying with unrelieved suffering was enormous. Such situations were difficult and uncomfortable and some wished they could avoid them. Some reported crying, others stress, one nurse contemplated euthanasia (but clarified she would not actually administer it), and another became depressed. One claimed she would leave palliative care because of burnout from continued unsupported engagement with such patients. Nurses also noted headaches, back pains, poor sleep and digestive problems, and some self-medicated with alcohol. Nurses sometimes brought work problems home and felt too depleted to give any more and consequently family relationships suffered. Arguably, similar effects may also be experienced by physicians, who have decisional control over treatment and bear responsibility for outcomes, but also need to negotiate setting and ideological influences.

Another investigation reported nurses working in palliative and acute settings in the UK experienced similar supportive deficiencies across medical contexts (Clarke & Ross, 2006). For example, although nurses often felt ill prepared responding to patients expressing their needs and concerns about end-of-life in the palliative setting (where patients mostly knew why they were there), it was particularly difficult in acute settings with older patients. Lack of experience severely hampered communication for critical/acute care nurses, but palliative nurses felt more confident broaching sensitive issues because there was a greater culture of openness and support. However, student nurses still found listening to patient concerns around death “quite daunting”. Time constraints and privacy issues were also identified barriers to listening and talking. Moreover, emotional exhaustion prompted nurses to avoid such discussion, preferring to get on with other duties. Clearly, different contexts are negotiated and experienced differently. Nurses have varied levels of experience and expertise, and the organisational support they can access also varies.
New research may find that the experiences of doctors in Australia parallel those of nurses. Although no evidence has been gathered, doctors might have different ways of dealing with the difficulties and stresses involved with providing end-of-life care. For example, the fact that doctors occupy a position of authority may give them greater confidence in their decision-making (Berger, 2010; Kon, 2010) and an ability to perhaps delegate certain responsibilities they find emotionally or psychologically burdensome (Calvin, Lindy, & Clingon, 2009). However, doctors also need to live by their decisions and, as previously identified, they are often reluctant to confide in colleagues for fear of professional ridicule or ostracism (De Bal, et al., 2006; Magnusson, 2002; Meier, et al., 2001; Weissman, 2001). It is unclear therefore; exactly how individual doctors negotiate each situation and debrief or deal with those stresses and what support they can draw.

5.3.2.1. Organisational influences to burnout. Burnout has also been described as the symptom of a system out of balance (Keidel, 2002). In reviewing the literature, Keidel found organisational factors affecting many Western health systems including Australia’s, which placed increasing pressure on palliative and hospice staff. Institutional financial constraints limiting support and training, and mandatory overtime meant staff only took holidays when their capacity to care was overwhelmed. Staff were often unsupported by management, being told to adapt and be creative. Pressures accumulated from multiple sources but the work environment was sometimes a greater contributor to burnout than the clinical status of patients.

Accordingly, Dunwoodie and Auret (2007) found a significant association between greater numbers of hours worked in palliative care and higher psychiatric morbidity risk for a sample of Australian palliative care doctors. Increased morbidity risk and longer working hours also related to greater emotional exhaustion and depersonalisation. Younger age further associated with increased burnout risk, with specialists about five times more likely to experience psychiatric morbidity and eight times more likely to experience higher levels of emotional exhaustion and depersonalisation than non-specialists. Research needs to further investigate these
unexplained findings; however, organisational factors were again implicated when tertiary environments (e.g. hospital-based palliative care) consistently showed higher risks for psychiatric morbidity, emotional exhaustion (seven times greater) and depersonalisation than both the combined hospice and community settings.

Organisational factors contributing to burnout in palliative care were also identified in the Netherlands (van Staa, et al., 2000) where research indicated the palliative setting was less stressful for medical staff than other units like intensive care. Perhaps in a country where euthanasia is legal, training better incorporates exposure to and acceptance of death and, indeed, euthanatic practices are available as an option to end prolonged suffering of patients and families and, by default, palliative staff. Furthermore, futile or heroic measures are perhaps less likely to be implemented. Emotional burden and stress may, therefore be somewhat alleviated. At the same time the ideological conflict of comfort vs. cure, often dividing medical staff, is not as salient. However, hospital palliative staff suffered burnout more than their hospice counterparts, further implicating organisational factors but, as in Australia (see Dunwoodie & Auret, 2007 above), this is unexplained.

In more recent research, a large cross-sectional nationwide survey with 740 members of the multidisciplinary Australian oncology workforce found they also experienced burnout and psychiatric morbidity with 32.8% of participants reporting high levels of emotional exhaustion (Girgis, et al., 2009). Higher levels of burnout and emotional exhaustion, depersonalisation and reduced perceptions of personal accomplishment, were predicted by greater patient contact, dissatisfaction with leave arrangements, and a higher need for communication skills training. Indeed, the top five causes of burnout related to organisational and training factors. These same factors and higher levels of self-reported burnout also predicted higher psychiatric morbidity. Oncology settings expose many Australian physicians to end-of-life situations but how these are negotiated and experienced remains unclear.
Other research also found low levels of personal accomplishment were frequently experienced by most Japanese oncologists and palliative physicians working in end-of-life care and contributed significantly to burnout (Asai et al., 2007). Although high cultural standards of achievement and reputation might be one factor, time constraints inhibiting doctor-patient communication and lacking confidence in providing psychological care associated most significantly with burnout.

The Australian Government has reported increasing shortages of nurses across most Australian states and working in oncology, where end-of-life decisions such as treatment withdrawal are frequently made, can be particularly stressful (Barrett & Yates, 2002). Although most oncology nurses report high levels of personal satisfaction and accomplishment, nearly 40% deal with workloads they consider excessive and blame inadequate staffing levels, unrealistic pay and lack of professional training and support as major factors. Most nurses (70%) also experienced moderate to high levels of emotional exhaustion and, of great concern, 48% could not commit to staying in the profession beyond the next 12 months. These results, especially if replicable across the country and across health settings, sound warnings to governments and health management to better examine this issue and establish measures and strategies that reduce burnout and enhance job satisfaction.

Similarly, Australia’s physicians are also leaving the public health system in increasing numbers (Australian Medical Association, 2003; Coyne, 2011). Indeed, all Australian Governments continue their struggle to adequately staff hospitals across the country and it seems that in a process of consolidation many services are moved from smaller hospitals to larger city and regional hospitals (Australian Medical Association, 2011). Furthermore, due to inadequate government support or financial incentives, many GPs and other specialists are closing their practices rather than provide an inferior or inadequate service to their patients (Australian Medical Association, 2003; Coyne, 2011). What is also concerning, are reports that due to unsustainable workloads and institutional expectations, physicians fear actually killing their patients due to “medic fatigue” from
overwork (Australian Medical Association, 2006c). For example, 88% of 113 Queensland hospital physicians who responded anonymously to an AMA survey experienced dangerous levels of fatigue while working, with 60% admitting making mistakes when performing procedures and 80% when prescribing medications. Such levels of fatigue are not surprising when many physicians are forced to work 58-75 hours per week and some physicians, especially in rural areas, working up to 168 days straight (including on call) without relief (Australian Medical Association, 2005, 2006b). As physicians either leave the profession completely or practice elsewhere, the additional load placed on the physicians that remain can only increase the potential for medical mistakes and the negative impacts on their own health and well-being. Yet, how physicians in Australia deal with deleterious organisational factors, as well as intrapersonal factors like psychological and emotional burden, has not been explored.

5.3.3. Coping with difficult experiences when providing end-of-life care.
Although continual engagement with the suffering of patients and their families is emotionally burdensome (Meier, et al., 2001), some palliative physicians claim that when they can alleviate suffering for patients and their loved ones, and help bring about a “good death”, it can actually be a rewarding experience with significant personal growth (Blomberg & Sahlberg-Blom, 2007; Kelly, et al., 2003; Quill & Battin, 2004). Further, the highly interactive relationships characterised by the close bonds and attachments formed with patients and families, sometimes have a cathartic effect on palliative staff. For example, nurses often felt they were part of the dying person’s family, even if only briefly, and were often helped (implicitly) by families in rechannelling their own emotions (Byrne & McMurray, 1997).

The need to separate personal and professional self is particularly crucial in difficult cases but, when available, a team environment with openness to discuss distressing end-of-life experiences is helpful for physicians and nurses in terms of resolution and moving on (Blomberg & Sahlberg-Blom, 2007). A supportive and collaborative professional team environment can also further support physicians with
difficult end-of-life decisions, especially where patients request assistance to die (Kelly, et al., 2003; Kimsma, 2010).

In paediatrics, where caring for dying children can be particularly stressful, time and institutional support that provides the physician with adequate strategies and resources are also crucial factors affecting end-of-life outcomes and experiences. For example, a thorough assessment of the patient’s and family’s physical, emotional, and spiritual needs and clarification of realistic goals and hopes not only improves the clinical care that the patient receives but also contributes to the sense of satisfaction and meaning that the physician can gain from the experience of caring for children at the end-of-life (Hurwitz, et al., 2004).

Sometimes physicians can draw a sense of meaning and accomplishment in the understanding that death has not been in vain. For example, organ donation has been one way to assist paediatric physicians and patient families in coming to terms with the unnatural and tragic death of a child (Czupek, 1995). There has been a greater (both symbolic and tangible) purpose in death when the life of another can continue and be improved through such a selfless and altruistic act. The child may pass on a legacy that transcends their death.

Memories are also particularly important, because they are often all that endures after death. One physician remarked that it is more the loss of life which brings him true sorrow, not the state of death or the act of dying (Smith, 2009). Often the dying act is fleeting and unwitnessed. However, this physician was struck with the finality of death, likening it somewhat to the nonexistence before birth. He became a mutual part of many dying person’s lives, and then they were no longer here.

Physicians, like nurses hold unique meanings around death and dying, but cope with stressful experiences leading to burnout in their own ways, sometimes with varying degrees of success. For some, spirituality was a sustaining influence when experiencing emotional exhaustion, with depersonalisation and diminishing empathy being lower than
for those with less spirituality (Vachon, 1987). Some reframed stressful experiences (Hurwitz, et al., 2004), or distanced themselves emotionally, gained support from family, colleagues and management (Blomberg & Sahlberg-Blom, 2007), while others internalised adverse experiences and withdrew socially, or self-medicated through alcohol abuse (White, et al., 2004). Schulman-Green (2003) identified eight common coping mechanisms, including medicalisation, dehumanising the patient, anger directed at the patient, use of euphemisms, use of humour, denial of the lack of skill, going numb, and talking to others.

Sometimes physicians compartmentalise a patient’s death and put it off until a later time when they are able to process it (Hurwitz, et al., 2004). One paediatric oncologist plants a rose or small plant for each child that dies under his care, or any other child that he has become particularly close to (Hurwitz, et al., 2004). That physician reframes the tragedy, considering it a privilege to have been involved in their care and afforded the opportunity to know them. Always acknowledging the “truly unique and special human being each child is”, he declares that he learns so much from them; it is actually a growth experience for him. Yet, when asked how he can do this work, he says that the child died as a result of the biology of their disease which would have occurred whoever the physician was; in essence he medicalises the death. However, he also describes a “village” where one is never alone looking after the patient – there are other professionals and also family. Support is crucial for this physician working in end-of-life care.

Another physician wrote a heartfelt letter to each of his dying patients, but never sent them (Rousseau, 2009a). In each letter he expressed his love, thoughts and emotions and relived each unique aspect of caring for those patients. It was cathartic and a very personal and private correspondence between his patient and himself. In publishing these letters posthumously he considered them delivered. This was his way of finding closure.
5.4. Summary

Each end-of-life setting is unique and physicians have different opportunities available to them professionally and institutionally, but also different personal strategies that they may use to deal with stressful influences when providing end-of-life care. However, Australian end-of-life care still suffers some of the highest staff burnout and turnover rates of the health professions. The emotional attachment experienced by physicians in caring for patients and their families are characteristic of end-of-life settings and the clinical status and subsequent loss of patients sometimes culminates in physician burnout. Organisational influences, the availability and efficacy of support strategies and intrinsic factors such as personality, may well mediate the effects of burnout. However, the individual experiences of physicians are also regulated to a large degree by broader social and cultural influences at many levels. Conflicts occur through ideological differences, which physicians must reconcile and are other potential factors leading to burnout. The effects to physicians may be enduring, implicating personal health and wellbeing, their social and family life, and also their ability to continue practicing effectively for the benefit of patients and others. Multilevel influences to experience are abundant in end-of-life care and explanatorily important.
Chapter 6

The Method of Investigation

The preceding literature review identified considerable ambiguity in how end-of-life care is represented and understood by physicians, great inconsistency in how it is provided across different medical settings, and significant diversity in physician experiences. However, comprehensive explanations of these experiences are elusive, particularly in relation to the Australian context.

Exposing some limitations for a greater understanding of end-of-life care, past research was found to be overwhelmingly quantitative, generally informing knowledge through survey based strategies. Certainly, that research has provided a wealth of statistical data on death hastening practices (Kuhse & Singer, 1993; Kuhse, et al., 1997; Magnusson, 2002; Neil, et al., 2007) including the use of sedation (Kuhse, 2004; Löfmark, et al., 2008; Tännsjö, 2004). Physician attitudes toward such practices have also been identified (Cohen, et al., 2008; Kuhse & Singer, 1988, 1992; Sikora & Lewins, 2007; White, et al., 2009), albeit with much unexplained statistical variance (Gielen, et al., 2009; Karlsson, et al., 2007; Wenger & Carmel, 2004). Physician experiences in end-of-life settings have also been quantified, predominantly focused on negative aspects such as burnout (Keidel, 2002) and the related emotional, psychological and institutional factors (Dunwoodie & Auret, 2007; Girgis, et al., 2009). Indeed, the frequent lack of consensus among health professionals, patients and patient families as well as ideological differences on what constitutes good end-of-life care, is a recognised source of conflict.
(Kmietowicz, 2009; Shipman, et al., 2008). However, research into positive or rewarding aspects physicians experience when providing end-of-life care has received much less attention (Blomberg & Sahlberg-Blom, 2007; Quill & Battin, 2004), yet this is important, especially in terms of understanding potential coping strategies and enhancing physician wellbeing.

Nonetheless, some qualitative research into end-of-life care has explored discursive aspects of providing that care (McInerney, 2006; Pattison, 2006; Skilbeck & Payne, 2005; Street & Kissane, 2001), some experiential and phenomenological aspects of providing that care (Byrne & McMurray, 1997), and philosophical and ethical aspects of end-of-life care (Magnusson, 2009; Singer, 1995, 2002), however, much of the research focus has been with nurses (Rietjens, et al., 2007; Skilbeck & Payne, 2005). Similar qualitative research conducted with physicians is also important for understanding how they engage with end-of-life care.

Moreover, end-of-life care research specific to Australia is noticeably limited compared to that conducted elsewhere. For example, much research, particularly that centring on death hastening practices, has been conducted in The Netherlands and Belgium where euthanasia and physician assisted suicide are legal. Less related research is available from the USA where three states now have legalised physician-assisted suicide programs, but even less still in Australia where such practices are illegal yet frequently carried out with relative impunity (Magnusson, 2002). Furthermore, much research is not contextualised to specific settings dedicated toward end-of-life care such as palliative or hospice, or critical and acute facilities or their specialist practitioners.

There is a clear need to investigate end-of-life care with a specific focus on physicians in Australia. A qualitative investigation that is grounded in a critical realist framework with a capacity to consider the interactive effects of multiple and complex social structures will be descriptively and explanatorily revealing of the diversity in physician understandings, practices and their experiences of end-of-life care, and make a valuable contribution to current knowledge.
6.1. Research Aims

The current research sought to better understand Australian medical end-of-life care and practices by exploring the individual experiences of specialist and non-specialist physicians engaged in both critical/acute and palliative settings. A crucial aspect of understanding their individual experiences, however, required some knowledge of how physicians understand end-of-life care and practices specific to certain contexts, but also how they actually negotiate care that is equally specific and subject to complex non-linear social influences. The investigation, informed by complexity theory (Byrne, 1998) and a critical realist perspective (Bhaskar, 2011), addressed these aims and provided an interpretive account of end-of-life care in Australia.

6.2. Research Questions

The above-stated research aims were guided by the following primary research question: How do physicians understand, negotiate and experience end-of-life care decision-making and practices in the context of Australian critical/acute and palliative settings? In order to adequately answer the primary research question, other supportive questions also needed consideration. Specifically, physician understandings were elucidated by investigating: What does end-of-life care mean to physicians and also what beliefs and ideological positions do physicians hold regarding terminal patients and the care they provide to them? The physicians’ negotiation and experiences of end-of-life care were further elicited through inquiring: How do these beliefs and positions shape their interactions with patients, patient families and professional colleagues and also how do physicians manage their experiences (e.g. how do they cope and maintain their motivation to continue practicing)?

6.3. Design

Hammersley and Atkinson (1995) stated that in a qualitative study, “research design should be a reflexive [rather than linear] process operating through every stage of
The activities of reviewing literature, collecting and analysing data, elaborating or refocusing research questions, and identifying and addressing validity threats are usually all happening more or less simultaneously, each influencing all of the others. This was noted for the present qualitative study where such flexibility allowed for a recursive process of ongoing evaluation that enabled appropriate adjustments along the way. Such an approach was also compatible with the critical realist perspective of this study which particularly emphasises non-linearity and emergence.

The primary research question was addressed using in-depth semi-structured interviews with both specialist and non-specialist physicians from Australian hospitals and hospices as well as private practices. The interviews were exploratory and guided by probing specific pre-determined questions around good and bad deaths, hastened deaths, and associated physician experiences (Appendix A contains the interview schedule). However the design acknowledged the complexity and uniqueness of human experience, which was explored in detail from a subjective perspective by also allowing for some participant direction. The design involved thematic analysis and interpretation to describe and explain the experiences of physicians and the meanings they hold around practices when providing end-of-life care.

Demonstrating recursiveness and the flexibility of the research design, the interview probe questions guided by the primary research question (and supportive questions) evolved as the course of interviews progressed. This is common in qualitative research, where the main research question is frequently general and provisional; indeed, Willig (2001) suggests that research is often a process of refining the research question and supportive questions. In the current study, the main research question remained consistent, however, due to the exploratory, semi-structured nature of the interviews, as well as the conversational style that allowed for a great deal of participant direction, probe questions were sometimes dropped when they no longer served any purpose, for example

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4 Hammersley and Atkinson use the term “reflexive” to denote circularity and a recursive process of interaction.
when themes in the data became saturated. Similarly, as participants provided large amounts of narrative in response to particular questions, they often exposed interesting and relevant paths of potential inquiry that were important to pursue further. This guided subsequent interviews and served to enhance not only the breadth of data obtained but also maximised its richness.

6.4. Recruitment

Formal contact was made to eligible physicians who were identified through articles they had written in the academic literature, the register of members of the Australasian Chapter of Palliative Medicine, the register of members of the Australian and New Zealand Society of Palliative Medicine, physicians personally known to the researcher and, in a “snowballing” strategy (Whitley, 2002, p. 395), through the referrals of medical colleagues from physicians following their interviews. Such a strategy was useful because of a potential reluctance of physicians to participate in research that canvassed material of a sensitive and sometimes illegal nature. A purposive sampling approach was taken because it was important to access physicians across specialties and settings that had experience in providing end-of-life care (Whitley, 2002, p. 395). A personal introductory letter was sent electronically to each prospective participant that identified their unique areas of specialty and interest and how they were of interest for my current research. That letter also reported my professional background and research interests in Australian end-of-life care. An official research information sheet also accompanied that introductory letter and provided details on how to arrange participation and contact me as the principal researcher (Appendix B). Ongoing liaison occurred to provide further information if requested and also to arrange a location and time for the interview.

From a total of 16 physicians contacted for research recruitment, 13 physicians with suitable experience in providing end-of-life care responded and consented to participate. They comprised two GPs, a respiratory/thoracic specialist engaged in critical/acute settings, three intensive care (ICU) specialists, and seven palliative
specialists. Interviews were conducted between December 2009 and November 2010 and generally took place in hospitals and hospices, mostly across the Sydney metropolitan area; however two were conducted in another capital city and two in a regional centre.

The participants varied in terms of their religiosity and beliefs, and values toward end-of-life care. For example, some had membership with organisations like Exit International and the NSW Voluntary Euthanasia Society, both of which are pro-euthanasia groups. Some participants had active church involvement, were of differing Christian faiths and more or less supportive of a “sanctity of life” perspective. Others held more secular views toward death and dying with some regarding themselves as atheists. Ethnic heritage varied between participants, although the majority of physicians were Australian born. Most of the interviewed physicians were also involved in academia and research and many were influential and highly respected members of their particular specialty. Some physicians had worked internationally, some also acted in advisory and lobbying roles to government, while overseeing care in large regional areas and occupying roles like hospital staff specialist also formed part of their responsibilities. Physicians worked in public and private settings that varyingly emphasised Christian or secular philosophies. Many physicians were also parents and family oriented. Gender distribution was slightly disparate with eight male participants, and ages of participants varied between 36 and 68 years. The individual experience of physicians providing end-of-life care was between around six years to over 40 years.

6.4.1. The participants. The following are short biographies - brief “pen portraits” of the participants who contributed to this research. These descriptions are based on field notes written after each interview and during coding and analysis, on demographic information given in the interview, and on readings of the interview transcripts. As well as providing some context for reading the foregoing extracts and interpretations, they also give a sense of the participants as people.

**Thomas:** is a GP in his early 40s who has been involved with providing care for the dying since 1995. He practices privately and also as a consultant in Area Health for palliative
medicine in both public hospital and hospice settings. Thomas told me he was attracted to palliative care because he felt he could make a difference in assisting the final hours, days or weeks of the dying and provide comfort, but also because…“it is satisfying when you are able to help a patient towards a good death”.

Aaron: is in his late 4s, and a thoracic-respiratory specialist engaged in applied and consultancy roles providing care for dying patients since the1980s. He holds strong Christian beliefs, albeit non-fundamentally, but acknowledges that…“in some exceptional cases euthanasia might be an appropriate action- if it was legal”.

Robert: is a palliative care specialist in his early 50s, working full time in hospice and end-of-life care since the 1980s. Robert supports voluntary euthanasia and, as an advocate of “patient choices” at end-of-life, his views have sometimes landed him in hot water: “it’s been quite stressful for me at times…(sighs) I’ve been criticised and people have tried to muzzle me… it’s challenged the palliative care community, and they haven’t liked it”.

Jeremy: is a palliative care specialist in his late 60s who has been involved in hospice and palliative care since the 1970s. As a practicing Christian, Jeremy declares he holds strong religious values. Motivated into a career in end-of-life care because…

…there was a lot of vigorous criticism in the medical profession in the 1970s, particularly, that we weren’t listening enough, that we weren’t looking after death and dying very well, which was true… and I had a strong interest in the care of people.

Gary: is a palliative care specialist in his mid-50s. He holds strong family values with a Catholic faith. He has been practicing medicine since the early 1980s and, after experiencing the death of a close family member when he was a medical student, was motivated into specialising in palliative medicine. Gary emphasises the “personal” in end-of-life care: “you need a human touch, an ability to connect…you reveal something of
yourself to them (patient and family) because their feelings are exposed to you…’it’s not just a medical relationship but a personal one as well’.

**Peter:** is a GP aged in his early 60s and has been caring for dying patients since the early 1990s. He strongly advocates patient choices at end-of-life and is quite outspoken supporting voluntary euthanasia, something he has been vilified for. His views are often at odds with those of his professional colleagues: “it annoys me and upsets me…that my profession has taken such a paternalistic and rather arrogant role, suggesting that they were the experts in the field of death and dying”.

**Kerrie:** is a palliative care specialist, in her late 40s. She began her career in medicine as a nurse working in oncology and specialised as a physician in end-of-life care about 15 years ago. Kerrie described her passage into palliative care:

> I believe palliative care is actually about living, and I decided to specialise in internal medicine – I consider it the highest standard of medicine. I wanted to work within tertiary referral and teaching hospitals, but acknowledging always that I can care. So in the midst of the chaos I can provide care for very vulnerable people…

**Jenny:** is aged in her mid 40s and has been a palliative care specialist for around 12 years. The need for a high level of skill, compassion and empathy reflected her reasons for practicing palliative care…“I thought I could do it…I’m very much interested in providing care for the whole person no matter where they’re going with their disease, and I felt that palliative care really provided that opportunity”.

**Keith:** is in his early 60s, a self-pronounced atheist, and an intensive care specialist with over 30 years of clinical experience. Keith is a pragmatic practitioner who will vigorously navigate particular care constraints in the best interests of his patients. He details his motivations but also how intensive care has evolved:
I was attracted to it because it was exciting and you keep people alive…but, gradually I’ve been more interested in the sometimes perverse…direction that we’ve taken in intensive care…where people are increasingly on this conveyor belt from home to the emergency department, to the ward, to the intensive care unit in the last few days of life.

**Maggie:** is aged mid 30s and has been a palliative care specialist since 2004. Maggie is passionate about her work and needs to engage in a number of roles to promote palliative care for the best interests of her patients:

> I think the challenge is delivering adequate bedside care but you’re also very much involved in strategy, policy …keeping palliative care on the map…and it seems to fall off the map on a regular basis…and that I think is the big challenge of this role…that you can’t be delivering quality at the bedside if you completely ignore the policies, you know, the preferred models of practice delivery.

**Gina-Leanne:** is an intensive care specialist, aged mid 50s, and has been practicing critical/acute care in Australia for over 20 years. Despite rapid changes in critical/acute medicine, she remains strongly motivated:

> …there’s a lot of difficulties in ICU, but you know, you do end up with a large number of people that come in sick, get better, and go out…so that is satisfying…and you can, make a little bit of difference to a reasonable number of patients, yeah…

**Andrew:** is in his mid-40s and has practiced intensive and acute care, and anaesthesiology, for around 20 years in Australia and internationally. Andrew is necessarily exposed to dying patients in the ICU something that appears quite ubiquitous across Western Health settings, yet he can provide comfort at end-of-life:
…the fundamental thing is to make sure people are not suffering – they say “I’m not suffering” that, that’s the same everywhere…so it’s fascinating I’m, I of course consider myself very privileged to be able to work in, or having worked actually in such different health care contexts.

Candice: is in her early 40s and began a medical career in oncology, but has specialised in palliative care over the last 10 years in community and hospice as well as acute hospitals. She illustrates the unique personal care that comforts dying patients:

…you become familiar with medicine, and then, as you get a bit older then I think the humanity kind of seeps in and you see how important it is to look after the person in a holistic way and… you know it’s a very rewarding job and I guess this is why I’ve stayed in palliative care, because we make a difference… yeah.

6.5. Procedure

The researcher conducted audiotaped in-depth semi-structured one-on-one interviews, each of around 60-90 minutes duration, which facilitated the collection of subjective information and inquired how structured social influences shape the negotiation (and experience) of end-of-life decision-making and practices by physicians. Initially, pilot interviews were conducted with a small number of physicians (N = 4) to assess the adequacy of the interview schedule in addressing the research questions. The interview questions generally remained unchanged; however, their supportive and subsidiary questions were somewhat expanded to capture greater depth in participant responses. As described earlier, further evolution of the interview schedule also took place across the entire span of interviews to account for other relevant and interesting paths of inquiry which emerged, while focus was reduced on areas regarded as more data saturated and producing little new information.

6.5.1. Data analysis. A thematic analysis was performed on the interview data (Braun & Clarke, 2006). Thematic analysis is regarded as compatible with a critical
realist paradigm (Williams, 2003) with the capacity to accommodate many different theoretical assumptions (Aronson, 1994; Roulston, 2001) and therefore flexible enough to provide rich and detailed descriptive accounts of often very complex data while allowing for interpretation of the research topic (Boyatzis, 1998). Accordingly, it was quite suited to the current research focus investigating Australian end-of-life care meanings, practices and experiences.

Furthermore, an inductive/data driven approach to analysis was used rather than an analysis fitting a pre-existing coding frame. This was more likely to produce rich descriptions (Patton, 1990) and was more useful in the current study because of the topic being particularly under researched and little being known about the views of participants.

Data analysis was conducted in a manner consistent with sound theoretical and methodological principles as outlined by Braun and Clarke (2006). This entailed making the epistemological and theoretical position clear from the outset, acknowledging researcher reflexivity and bias (reported below), and taking a rigorous approach to data collection, interpretation and reporting.

Braun and Clarke (2006) provided six phases of thematic analysis conducted by a recursive rather than linear process, where movement is back and forth as needed throughout the phases. The six phases detailed below were operationalized to suit the characteristics and requirements of the current study, in terms of the data and research question, and were engaged with flexibly rather than in a stepwise fashion. This facilitated an ongoing process of checking, rechecking and refinement.

6.5.1.1. Familiarising with the data. Audio recorded interviews were listened to many times, initially while returning from interviews. This provided an early opportunity to begin an elaborate system of notes and memos regarding my thoughts and observations of the interview process and for considering these in subsequent interviews and the interpretive analysis (often I would add my comments to the end of the voice file). Individual nuances like the participant’s tone of voice, pauses, emotionality, all contained
meaning that reflected a richness in the interviews and was important to identify and consider in analysis, particularly when the research aims were to investigate meaning and experience.

6.5.1.1. Transcription. The process of familiarisation continued with verbatim transcriptions of the recorded interviews. This was performed by the researcher to provide anonymity and de-identification of participants, but most importantly as another means of preliminary analysis and ongoing evaluation of the interview schedule (Silverman, 2010, pp. 210, 232). This was a key phase of analysis. Because of the need to listen to the recordings over and over through the slow process of transcription, meaning was interpreted at that time rather than merely providing only a written account of the spoken word. Accurate punctuation was important because of the influence it has on meaning. The elaborate system of notes and memos was further expanded in the transcription process.

6.5.1.2. Generating initial codes. Although initial coding in the form of notes and memos began at transcription of individual interviews, this process became more systematic once further data sets were available. NVivo software assisted in coding interesting and relevant features in and across the data sets. The initial coding process generated a large number of codes, particularly because the more data driven focus of coding did not exclude some more theoretical/epistemological considerations and subsequently data was initially coded (occasionally multiple times) for as many relevant themes and patterns as possible. This also included coding for inconsistencies and contradictions across the data set. Furthermore, each coded data excerpt was separately annotated with an interpretive account relevant to that code and the research question.

In a process of triangulation (Madill, Jordan, & Shirley, 2000), I engaged members of my supervisory panel during the analysis process where I argued the rationale for my initial coding frame according to literature, my epistemological and theoretical approach and, most crucially, the interview data itself. My subsequent analysis and
interpretation of the data was similarly grounded and, again, something I considered important to justify to members of my supervisory panel.

6.5.1.3. Searching for themes. After initial coding, potential themes were identified that allowed codes to be sorted and grouped. The codes were grouped into themes according to their dominance and similarity across the entire data set and the relationship between them. This generated a series of larger themes, most of which contained subthemes within them (and sometimes subthemes within subthemes). There was overlap between some themes and some codes that appeared not to fit the preliminary thematic structure were retained for later consideration. Names and descriptions were provided for each theme and subtheme.

6.5.1.4. Reviewing themes. A process of refining the preliminary themes began by examining those that showed elements of overlap. Each theme was reviewed to ensure that the data excerpts saliently and meaningfully identified with that theme and that each theme was discriminant with another. Some themes required reworking at this point to fit the data, sometimes creating a new theme and collapsing others, and sometimes problematic data excerpts were discarded. The reviewed themes were then applied across the entire data set to ensure meaning was accurately reflected. Overlap was thus minimised but what remained reflected the complex non-linear aspects of the topic being investigated. Another coding process was then initiated to capture data that might have been missed or considered irrelevant in the earlier coding processes.

6.5.1.5. Defining and naming themes. The final thematic structure underwent an extensive process of review. Each theme/subtheme was positioned to enable an unfolding and coherent story to be told that addressed the research question. Each theme and subtheme was assessed, named and renamed in an iterative process to ensure that it captured their essence and that each was internally consistent. This also involved ensuring that each data excerpt was an exemplar for that theme/subtheme with each theme/subtheme being succinct and not overly complex. Each carried a brief description of its scope.
6.1.5.6. Write-up and presentation (producing the report). Both the research design and the procedure of analysis were regarded as a recursive process. Accordingly, the write-up underwent a process of drafting, editing and redrafting to ensure that it provided a concise, coherent and logical story where relevant exemplars were embedded in a non-repetitive analytic narrative. The prevalence and importance of themes/subthemes was illustrated with a sufficient number of relevant data excerpts. Context was retained in the excerpts to provide a richer account which, in some instances, required them to be lengthier.

An interpretive account was provided of how physicians understood and experienced end-of-life care practices in Australia, with analysis focused on the research questions informed and argued by reference to literature and particularly by the epistemological and theoretical perspective adopted. Emphasising the importance of context and non-linearity, multiple interactive levels of influence were examined and informed by a Critical Realist framework (Bhaskar, 2011; Giddens, 1984; Potter & Lopez, 2001b) drawing on Complexity Theory (Byrne, 1998, 2005; Urry, 2003). To further enhance the explanatory capacity of analysis, other relevant theoretical psychological constructs and models were also drawn on. It is important to note that, unless stated otherwise, the physicians referred to in the following chapters were those participating in the current study.

6.5.2. Reflexivity. The detailed personal statement I provided in the preface identifies many of my personal views, motivations and biases influencing my choice of research topic and how I ultimately went about conducting myself and my research. It also highlighted some personal experiences of my journey into and through this research including a sometimes close psychological and emotional engagement with my participants, and is perhaps also somewhat predictive of how my personal journey will continue in relation to this topic long after the current research is completed. However, during this particular research journey, I have also become a “consumer” of end-of-life care in Australia with the recent passing of loved ones, and this has further served to
sharpen my views and beliefs around medically facilitated death and dying in Australia and on what research and clinical practice needs to work towards.

The importance of objectivity in research, emphasised by quantitative methods, is not considered as crucial in qualitative research (Silverman, 2010; Yardley, 1999). True objectivity is arguably elusive because thinking, feeling, human researchers necessarily bring some element of bias or influence into even the most rigorously controlled objective research designs. Often the purpose of research and, indeed, the subsequent research questions, stem from some degree of personal interest and are situated in a particular paradigm. Something must engage the researcher and research is seldom conducted from the sterile confines of a hermetically sealed environment, nor would its intended outcomes and applications have any real relevance to a world outside such an environment.

Nonetheless, the research I have conducted and report here demonstrated rigour and maintained established and accepted scientific and ethical protocols (Shenton, 2004). In spite of that, I strongly acknowledge that I am influenced by the research and necessarily influenced that research in turn through how it was conducted and reported. The interactions within my interviews are certainly reflective of a uniquely experienced dialogic relationship with my participants where rapport and data content were often negotiated and largely developed in the moment. I was sometimes quite moved by the emotion of my participants “in the moment”, and such an engaging experiential moment often prompted me to pursue and explore those emotive issues further. Semi-structured interviews that allowed for considerable participant guidance facilitated such a dynamic but also, I believe, enhanced the richness of the information obtained. Certainly, the narratives provided by participants in response to my questions were unique and specific, and frequently influenced the subsequent questions I posed. Since no two interviews were or ever could be the same, the data collected contained a richness of diversity and yet uniqueness when important similarities were identified.
However, being immersed in a unique dialogic relationship with my participants I also acknowledge that I potentially influenced the way they conveyed their understanding of end-of-life care meanings and practices, and chose to impart often very personal and confidential aspects of their experiences. I was positioned in a very privileged way, taken into the trust of my participants, who were so strongly interested in my research from the outset and engaged with it enthusiastically. The professional relationships that developed continue and are of mutual interest and, indeed, at the time of data collection were facilitative of snowballing further participants who were equally keen to engage with the research.

6.6. Ethical Considerations

The University of Western Sydney’s Human Research Ethics Committee granted approval to conduct the research (HREC Approval H7589) (Appendix C). In accordance with the National Statement on Ethical Conduct in Human Research (2007), informed and signed consent authorised participation and recording of interviews (Appendix D). Participants were guaranteed confidentiality and anonymity, being de-identified through the use of pseudonyms and the removal of links between names (including third parties) and data to protect those whose illegal activity may be revealed or discovered in research. The researcher also ensured participants (and others) could not be identified through their cultural background, age or gender, or the facility where they worked. As the researcher transcribed all of the interviews personally and de-identified all data at that point, that assurance of protection was provided.

However, the illegality and highly emotive nature of some of the issues being investigated by the current research also potentially raised other important ethical (and legal) considerations. Risk assessment was paramount to ensure participant (and researcher) well-being. Material was often canvassed that could distress participants, and had such situations occurred, permission to continue would have been sought or an offer made to take timeout or return to the question later. Participants also had the option to discontinue if they wished, and qualified debriefing was made available, if needed,
through the “Doctors’ Health Advisory Service”. The Australian Medical Association in each state of Australia provided this service. Furthermore, the researcher sought to ensure participants left interviews safely, and always followed up a few days later thanking them for their participation. Additional follow-ups were also made every four or five months as a courtesy to provide participants with an update of how the research was developing. However, ongoing contact with a select few participants continues and serves to maintain and further develop an effective professional network through introduction to other medical specialists and invitation to relevant end-of-life medical seminars and symposia, but also facilitates ongoing discussion and the exchange of new information. This contact facilitated dissemination of the same information as the researcher provided in formal presentations and did not have an impact on data analysis.

6.7. Summary

The methodological approach I have taken facilitated my research aims of exploring how physicians understand and negotiate multitudinal structured influences when providing end-of-life care in Australia. Physician experiences are inherent in that negotiation, and describing and offering an explanation for them were further central to my research aims and the main research question. The following three chapters provide individual analyses and discussions. Specifically, Chapter 7 investigates how physicians understand end-of-life care including the meanings and positions they hold around particular practices. Chapters 8 and 9 respectively, examine the positive and negative experiences of physicians in their negotiation of end-of-life care. Finally, in Chapter 10, I provide a conclusion to the thesis by drawing together and reflecting on the research findings.
Chapter 7

A Focus on Meaning: End-of-Life Care as Understood by Physicians

The preceding literature review highlighted the ambiguity and inconsistency in definitions and associated practices in end-of-life care, including those where death may be hastened, both in Australia and elsewhere. Physicians in the reviewed literature reflected considerable diversity in how they conceptualised and engaged in end-of-life care. The identified ambiguity and inconsistency is attended to in this chapter by providing an interpretive account that describes and explains the beliefs and understandings physicians in Australian end-of-life settings have in regard to the care they provide. Consideration is given to what guides physicians in making sense of and negotiating end-of-life decisions and practices.

Applying the critical realist perspective discussed in Chapter 2, specific situations or contexts embody multiple and complex, often non-linear, influences (Bhaskar, 2011, pp. 3-4; Mingers, 2004) that affect how physicians understand and provide end-of-life care. For example, physicians interact with patients, their families, and with other professional and allied health workers. Sometimes decisions are made collaboratively and in a multidisciplinary manner, and sometimes individually, but always as part of a unique context that includes personal, patient and family characteristics with their multiple cultural and spiritual influences. Institutional and professional dynamics also vary according to different health care settings, for example, emergency, intensive/acute, and
palliative, all have their own ideologies and prescriptions that regulate practice and, of course, legal imperatives also need to be considered. Still further complexity may be added by exercising agency (Giddens, 1979, p. 55); where physicians who differentially negotiate the various social structures they engage with provide other possibilities for understanding and providing end-of-life care. Such complexity and non-linearity of influences is demonstrated throughout this and subsequent chapters addressing physician “experiences”.

This chapter details the different end-of-life meanings and beliefs held by physicians, illustrating how their decision-making and subsequent interventions are subject to context. Four key themes are considered in this chapter. The first, “Control in End-of-Life Care and the Timing of Death”, focuses on the broad-reaching aspect of control, and details physician understandings and positions on practices in end-of-life care including those that hasten death. Various social and religious influences, as well as personal, legal and professional influences are examined. Practices of euthanasia, assisted suicide and sedation are also discussed. The second major theme centres on “Understanding Death and Dying” and how physicians conceptualise this in the context of end-of-life care. This subsequently leads to two other major themes, specifically how physicians understand “A Good Death” and also “A Bad Death”.

7.1. Control in End-of-Life Care and the Timing of Death

All of the physicians in this study described their particular understanding of “control” and its importance in end-of-life care. Control permeates many aspects of end-of-life care and physicians provided great elaboration of this theme. In particular, when considering control over the timing of death, physicians discussed their beliefs and positions on practices that hasten death. Physicians canvassed issues such as euthanasia, assisted suicide and sedation and how they conceptualised these. Physicians articulated the multiple influences to their understanding of, and position on, such practices. Most physicians identified religion and the sanctity of life position as a dominant influence in their personal ethical structure while others were guided more by patient suffering and
patient autonomy. Some physicians also considered the legal influences such as double effect and the active/passive distinction important in how they regarded these practices. All physicians further articulated how they understood and negotiated requests for death from patients and others.

7.1.1. Religion and sanctity of life. Religion and its concomitant sanctity of life position (discussed in Chapter 3) provide support to physicians who hold the belief that death should not be deliberately hastened. Control over life and death (and its timing) is with nature or the divine (Bruno, Ledoux, & Laureys, 2009). Accordingly, such a position precludes any acceptance of a request to die or any intentional autonomous action of the physician to hasten death. Although religiosity is characteristic of hospice and palliative settings, and a position held by nearly all palliative specialists, it also flows through broader political, legal and professional positions, and physicians across specialties held similar views.

To illustrate, Aaron (Respiratory/Thoracic Specialist) who works in critical/acute settings does not support euthanasia in end-of-life care: “I’d have a problem with active euthanasia or mercy killing, but from my religious standpoint and my religious beliefs in my medical practice, I obviously don’t practice it”. He identifies a religious structure that influences his views (and medical practices) but suggests euthanasia, while also describing it as merciful, is still an ambiguous issue for him: “I could see the rare situation where it would be appropriate but I don’t know if I would ever become involved in that”. He acknowledges that intentionally hastening death could be appropriate in some cases which highlight the unique nature of individual deaths and how each must be considered in its context.

Similarly, as a practicing Christian, Jeremy (Palliative Specialist) identifies the influence religion is for him: “I have involvement in the clergy and that dimension in terms of training and expectations. That’s not what I’m employed for…but that does obviously colour my views and attitudes and what I bring to this field”. Accordingly, he also fundamentally opposes intentionally hastening death. He holds the sanctity of life
position which regards euthanasia as deliberately inducing death rather than alleviating suffering:

I do feel personally very strongly…that doctors are doctors and not executioners, and if you want to legalise euthanasia then you appoint executioners. Please leave the medical profession out of it, and I don’t see euthanasia as the ultimate relief of suffering. I see that as inducing death deliberately.

Jeremy strongly defines the role (and identity) of doctors as medical practitioners and not executioners. Death should not be exclusively under their control: “I think that life is valuable and it’s not for us to decide the time for our birth or our death”. There is sanctity in life, and death as with birth is not a medical decision; he suggests life and death are subject to nature or the divine. Like Jeremy, Kerrie (Palliative Specialist) also holds the sanctity of life position and, consistent with medico/legal doctrine, rejects any support for an intentionally hastened death:

I don’t believe we should terminate life, I think it’s going to end for all of us…I think we need to be very respectful of life, uh, I can’t change the outcome but I can continue to care. I think these are very vulnerable people, and I think if we set precedents, then there’s lots of other vulnerable people in society where we’re effectively saying “Ok your life is rubbish, let’s end this”.

Kerrie mentions being “respectful of life”, it is not for her to terminate. She accepts the inevitability of death but how she can still care. She identifies those dying as “very vulnerable people” and fears a precedent if death is hastened. Kerrie clearly draws on the slippery slope argument. Similarly, and although patient suffering is a prime consideration for Gary (Palliative Specialist), it does not override his fundamental belief that control over the timing of death should not rest solely with him:

I can certainly understand they’re suffering and their family’s suffering, but… it’s just, an area I couldn’t go down, even if euthanasia became legalised, I’m not sure that’s something I could do…even if I knew it was relieving their physical
suffering. I think it’s such a minefield, you know, who you do this for…are you trying to end someone’s life because of the suffering of the family or…the patient…

Gary empathises with patient (and family) suffering but illustrates how the euthanasia issue is difficult for him. He talks about it being a minefield and identifies the slippery slope argument by questioning who he is actually providing euthanasia for, and that if legalised he would still have difficulty performing it. Around half of the physicians in the Netherlands who deal with requests to hasten death have reported similar reluctance to comply (Georges, et al., 2008). But Gary’s religious and family influences also emerge here: “it might be the religious upbringing in me that says it’s wrong to end someone’s life and I suppose, my own family, what’s right and wrong…my father was a policeman who….was very black and white”. Gary acknowledges multiple social structures of family, religion and law as influencing his views on hastening death and on what he considers right and wrong.

The multiplicity of interactive structures seen in Gary’s excerpts that influence his views can be explained by Ecological Systems Theory (Bronfenbrenner, 1989). This model recognises complex relationships in the environment between nested macro, exo, meso and micro elements (Bronfenbrenner, 1995). For example, religion and the sanctity of life position are embodied at a cultural and political level, enforced at a legal and professional level, and influences Gary’s family and his upbringing. He internalises those influences which subsequently shape how he regards end-of-life care. The influential power of religion and the sanctity of life position for controlling the timing of death, and subsequently influencing personal and professional beliefs, were similarly seen in the excerpts from Aaron, Kerrie and Jeremy.

However, contrary views to such commonly accepted positions on hastening death are also provided by some physicians who consider patient choice and autonomy most important in directing their position on controlling the timing of death. Indeed, Kohlberg’s highest stage of moral reasoning described abstract universal ethical
principles valid for all humanity regardless of concrete laws and social agreement (Kohlberg, 1969). Right action is defined by self-chosen ethical principles of conscience (Kohlberg, et al., 1983). In the following excerpts, physicians further describe their personal ethics by not only positioning themselves as a patient and being guided by what they would like in that position, but also a personal belief that control over death should be in the hands of the individual. For example, Peter (General Practitioner) illustrates his empathy for others: “I always think what would I want if this was me”? He places himself in the patient’s position, conveying a desire to be able to direct end-of-life care. Peter believes patients should have a choice to elect death if that is their wish, but in making the distinction between euthanasia and physician-assisted suicide, he encourages patient agency: “I think in principle I’d feel more comfortable that the person who’s acting is clearly acting of their own volition. You’re providing them with the drugs but they are taking the drugs, there’s something nice about that”. Peter indicates his preference to assist rather than control patient deaths. He considers death as “something nice” when it can be achieved through patient choice and volition.

Correspondingly, Robert (Palliative Specialist) further illustrates the intrapsychic of physicians, specifically the personal influences that could motivate a physician to intentionally hasten death: “I think if ‘patient autonomy’…was your guiding ethical principle…and your guiding treatment motivation was ‘compassion’…and, ‘mercy’…then, they would be two ethical and motivating factors…that could lead you down the road of helping those people, which are…I think, positive ethical principles”. Robert talks of personal ethical principles in terms of autonomy, compassion and mercy and these reflect his philosophy of promoting patient choices and helping people. Differing somewhat from his palliative colleagues, Robert does not rule out hastening patient deaths. However, holding such ethical principles might not be enough to accede to a request for hastened death:

It’s not just respect for autonomy, and compassion and mercy, but it’s also a certain amount of courage and willingness to take risk…and, all of those things
would need to line up…and, then of course there’s the means to do it as well and having access to that…which isn’t always…which could be a huge challenge.

Robert additionally identifies courage, willingness and risk, to hasten death. Certainly one needs to be willing to do something that is contrary to the beliefs of many others and might not always sit well with one’s own beliefs, but particularly courage to take the risk of social and professional ostracism and legal consequences. He also talks about access and means. It might be difficult performing a hastened death because of the suspicion it might arouse when patients are also monitored by others, where medication charts record patient dosages and pharmaceuticals are also securely stored and accounted for. Multiple structures might need to line up, for example, personal aspects, opportunity within institutional structures, professional collaboration and a means of protecting oneself professionally and legally such as double effect. Otherwise, attempts to hasten death may be unsuccessful (Magnusson, 2002).

Further identifying the importance of personal belief structures, some physicians who might reject the sanctity of life position or religious prescriptions will consider patient suffering as the determinant of whether death is hastened or not. Most will still stay within accepted professional guidelines, while others consider these of lesser importance compared to the suffering of patients and the need to do whatever is required. For example, when Peter (General Practitioner) is confronted by patient suffering, he regards control over death as a matter of choice and necessity, and not something under natural, divine or legal control. “Because I don’t really respect the ethic ‘not use deliberate means to hasten death’, I see no conflict in these instances and see them as being entirely compatible really…because relieving suffering sometimes involves hastening death”. Peter’s personal views on hastening death are not constrained by normative beliefs that preclude intent. Similarly, although not advocating the intent that Peter does, Gina-Leanne (Intensive Care Specialist) is also motivated by patient suffering and pain. She does not consider inadvertently hastening death problematic within the critical/acute setting she works in and its focus on saving lives:
If they’re obviously suffering…whether that’s with, pain…or whatever it is, and you know for certain that they are going to die and whatever it is that they’ve got is not amenable to anything…it’s not going to make a lot of difference really whether they die now or in 48 hours’ time, but I guess my aim is to make them comfortable and if in the process of making them comfortable that hastens their death well so be it.

Time appears relative in hastening death. In the course of a lifetime, 48 hours is insignificant for Gina-Leanne. Particularly with intractable suffering and a prognosis of imminent death, Gina-Leanne’s aim is to comfort even if medication plays a role in the dying process. She is clearly drawing upon double effect.

7.1.2. The active/passive distinction and double effect. Although many physicians overtly support the sanctity of life position on hastening death, when death is inadvertently (or otherwise) hastened, the active/passive distinction (Douglas, 2009; Howard-Snyder, 2002) is drawn upon by some physicians to conceptualise and account for their actions. Some consider a hastened death due to administration of narcotics differently to a death hastened by the withdrawal of life sustaining treatment. Similarly, the principle of double effect which focuses on the intent of the physician (MacIntyre, 2006), specifically whether it was to hasten death or merely address suffering albeit with death as a foreseeable consequence, provides another way of understanding and rationalising physician actions. Legal/professional structures influence the position some physicians hold on hastening death.

Many physicians state that they would not intentionally hasten death regardless of whether it is requested or not, but death sometimes occurs as a consequence of addressing patient suffering. This is something Thomas (General Practitioner) said: “look my goal is not to kill anyone but if I need to get on top of their suffering and they die, then that’s ok”. Sometimes physicians draw on the active/passive distinction when death is hastened foreseeably or otherwise, and Jenny (Palliative Specialist) illustrates this distinction: “not giving a life prolonging treatment is different to…uhm giving the medication, which
inadvertently might hasten death, so I think they’re different” Although outcomes might be the same, Jenny understands a more qualitative difference between withholding versus providing treatment that may hasten death. Furthermore, she also uses the word “inadvertently”, which implies double effect. Indeed, like Thomas above, most physicians in this study referred to end-of-life practices where their explicit intent was to alleviate suffering even though their patient sometimes died during that process. However, Keith (Intensive Care Specialist) draws on double effect while making the active/passive distinction to negotiate a patient request to hasten death:

I say, basically “look I can understand where you’re coming from but it’s not legal in this country to actively end life…but having said that, what you’re really saying is you don’t want this treatment escalated…and I’ll understand that and I’ll withdraw anything that we’re doing and make sure you’re not suffering”, and usually they’re happy with that.

Keith finds the distinction useful to somewhat accede to a request but protect himself legally and professionally. He emphasises the word “actively” when ending life, which connotes intent. It is almost a subversive approach where Keith needs to reframe the meaning of a potential intervention along legal and professional lines. He provides patients with a safer option that addresses suffering and hastens death. Keith illustrates how death hastening interventions can be manipulated by reframing their meaning relative to intent.

A strategy using the active/passive distinction is particularly possible for Keith because intensive care is curatively oriented and provides far greater scope to withdraw treatments. He illustrates this here:

I’ve got several…bits of paper with people writing “please let me die”…in shaky handwriting…many people don’t want to go on when they’re in intensive care, tubes, lines and painful procedures, and strangers…but, that sort of begs the question of euthanasia and that’s one that we avoid in intensive care. You might
say that’s a grey area and it probably is, withdrawing treatment is going to lead to
death but then we’ve escalated treatment up to that point, as opposed to taking
someone and…killing them.

End-of-life settings are not the same and intensive care is not a nice place to die. Patients
receive invasive procedures and therefore requests to die are common. Often they are
unable to speak, particularly when intubated, and provide Keith with handwritten notes.
However, the professional ideology of intensive care, more than anything else, makes
euthanasia a topic to avoid. Intensive care is designed to save lives not end them. Keith
talks of a “grey area” when withdrawing treatment but rationalises it as only taking away
something that was unnatural anyway.

7.1.2.2. Sedation helps the process of dying. Keith also said: “I’ll make sure
you’re not suffering”, suggesting that when life sustaining treatment is withdrawn other
measures need to be instituted to comfort the patient. Withdrawing life sustaining
 treatments or gaining control over complex and unremitting suffering, is commonly
achieved by sedating patients, but is a practice frequently linked to the principle of double
effect because death often follows closely behind its administration (Crenshaw, 2009;
Hauser & Walsh, 2009). Sedation is usually instituted in the final few hours or days of
life (Cherny & Radbruch, 2009). Physicians access a range of medications to induce
somnolence. However, physicians understand this practice in both consistent and unique
ways. Some physicians find it effective as a titrated symptomatic strategy that may be
permanent or temporary, while others manipulate the practice to bring about a hastened
death with legal and professional protection.

Although sedation is usually provided through anxiolytics like midazolam, or with
opiates, strong barbiturates are also an option. Sometimes patients who are particularly
intractable and close to death require sedation with phenobarbitone, something they will
not wake up from. Gary (Palliative Specialist) is acutely aware of the outcome of sedating
with phenobarbitone and therefore careful in its use: “When I use phenobarbitone to
relieve breathlessness, you know, the normal life expectancy is one day... so I’m in no
hurry to start that”. Gary describes what he said to a suffering patient who, as a nurse, was aware of phenobarbitone, but also someone who wanted to control outcomes: “she was someone who very much wanted to be in control, so I said ‘look…you’ve got to tell me when the breathlessness is so bad that this is what you need’”. Gary reflects his understanding of end-of-life care and the way he practices in terms of collaboration; he allows the patient to direct interventions which he considers appropriate to the situation. This contrasts somewhat with acute and critical settings where their technical nature inhibits patient control (Clarke, 2010; Hancock, et al., 2007; Miles, 2001). Yet, Gary is also cautious using such medications:

Obviously if someone is not particularly breathless or uncomfortable, I won’t use phenobarbitone to…sedate them, because I see it as a thin line between…hastening death with medication versus sedating to relieve symptoms, and I don’t see any moral problem with that, and there’s not a legal problem with doing it. So you have to look at what your intention is.

Gary clearly identifies double effect when he talks about intent; how this determines what is morally and legally acceptable. However, this excerpt also identifies the multiple structures that Gary needs to negotiate to provide an appropriate outcome for his patient. Legal and moral considerations are in play and also a personal sense of right and wrong when he talks about a “thin line”. Nonetheless, the notion of intent is slippery and potentially allows for manipulation of practices that hasten death. Indeed Peter (General Practitioner) describes sedation as an effective vehicle to disguise intent:

I mean it was slow. It has to be slow; it goes under the name of “slow euthanasia”. I said: “well how long it takes is really a legal issue. If I do it slowly I’m very safe”. If I come along and give you a massive morphine injection and say “here that’ll fix your pain” I can’t defend it. So I’ve got to be able to defend myself.

Peter provides an understanding of sedation as “slow euthanasia” but he clarifies for a patient how hastening her death through sedation needed to be slow if it was to afford him
legal and professional protection. He identifies the ambiguous distinction between a legal action that may hasten death (inadvertently) and one that is more overt but illegal.

Although the divisive nature of sedation was reported in the literature review and above, where some physicians also manipulate the practice to hasten death, titrated sedation remains an effective strategy for broad-reaching symptomatic control (Cherny & Radbruch, 2009). A number of physicians discuss their position on sedation to address breathlessness and delirium, and for maintaining dignity at end-of-life. Some talk about psychotropic symptoms due to medication, and rapid pain control addressed by a temporary use of sedation. Expertly titrated sedation used for these efforts was almost exclusively reported by palliative specialists, and also reflected the ideals of their professional ideology.

As an example, Kerrie (Palliative Specialist) describes how she uses sedation for refractory symptoms, particularly in relation to breathlessness: “increasing breathlessness towards end-of-life typically associates with the worst prognosis; people will die more quickly because they are breathless. Overwhelming breathlessness is terrifying for people…they fear it, and it’s the most common situation where one would commence sedation…general sedation”. Kerrie describes breathlessness as fearful and terrifying for patients but a common situation addressed by sedation. She acknowledges that prognosis is generally poor at that stage with limited life expectancy anyway, and therefore it is debateable whether sedation that comforts such patients actually hastens their death. However, Kerrie also regards sedation as valuable for maintaining dignity and describes this below:

Sometimes through situations not of a person’s making, their dignity is compromised…and given this is a vulnerable population, and they’re under our control, I think probably at this point…I need to treat the situation, treat the delirium with the appropriate medications, I need to make sure that if this person’s…of harm to themselves or to others, the nurses have, a way to intervene quickly…and that’s a time where I would prescribe extra sedation.
Kerrie finds that delirium often compromises a patient’s dignity where they may behave inappropriately and out of character. She provides nurses with sedation orders where they can manage such situations. However, she also identifies patient vulnerability and a duty of care with patients being under her control. There are suggested institutional and legal implications for her to maintain patient dignity and safety, and safety for others. Correspondingly, Jenny (Palliative Specialist) identifies a temporary use of sedation to stabilise patients: “I’ll use it often to get someone’s pain under control quickly, like if we’re using ketamine it can have significant psycho…give someone hallucinations and out-of-body experiences, and if they do develop symptoms you’d sedate them until their symptoms pass”. Patients on psychotropic medication need to be sedated to allow adverse symptoms to settle. She elaborates by also talking about dignity threatened by delirium and confusion, sometimes another side effect of medication: “I would use sedation until the cause of acute delirium was treated so the symptoms passed and then wake them up…so they wouldn’t lose their dignity at the time when they were becoming agitated in their confusion”. Jenny illustrates the titrated use of sedation and, like Kerrie, the importance of dignity at end-of-life. Sedation is an effective strategy for managing complex symptoms and when initiated collaboratively may also give patients some control over concerns of losing dignity, something they often fear the most (Chochinov, 2002, 2007; Chochinov, et al., 2002). Indeed, loss of control over the dying process frequently underpins patient requests to die (Chochinov, et al., 1998; Chochinov, et al., 1995; Ganzini & Back, 2003; Kissane & Yates, 2003).

### 7.1.3. Requesting death: The influence of others

In the literature review, many physicians were identified as receiving requests for death from patients and patient families on their behalf. Physicians in this study often described control as something that patients sought in order to mitigate the sense of helplessness they had over their disease or illness, or address their sense of burden to others. Patients often made requests to their physicians to assist them in a hastened death as a means of gaining control over their desperate situation.
The complexity in providing end-of-life care is often reflected by biopsychosocial influences (Munday, et al., 2003), which also emerge strongly when patients ask to die. Although a crucially important consideration, pain is not the only factor underlying such requests; in fact it is often well managed (Trang, 1998). At end-of-life, patients and their families are often uncertain and anxious with some also suffering existentially (Henoch & Danielson, 2009; Leung & Esplen, 2010). The patient-physician relationship adds another layer of complexity by influencing how such requests are understood by the physician (Suchman, 2006). For example, rapport and intrapsychic factors like empathy contribute to a uniquely emergent dynamic (Adler, 2007).

Physicians often need to engage with patients who provide many different reasons for requesting death. Regardless of the position individual physicians hold over accommodating requests to die, it is important for physicians to understand those requests so that they may recognise individual patient needs and consider strategies for addressing them. Indeed, Aaron (Respiratory/Thoracic specialist) makes this point: “it tells me that they’re at the end of their tether; that they’ve had enough, it tells me they’re at a level where they’ve generally thought about it”. For a number of physicians, requests for death were a cue signalling the need for further exploration. This is crucially important because although some requests for death are quite rational and understandable, psychopathology also sometimes underlies them. Jeremy (Palliative Specialist) points this out:

Of course despairing and distressed patients ask to be euthanased from time to time. My experience is that if we get behind the request as to what inspired it and the distress that indicates, and we’re able to honour that and address it…most patients will say, no…at some point will say not yet. I know one depressed patient who asked to be euthanased, where we in fact used three ECTs\(^5\) and appropriate medication, and three weeks later he said “thank you for not listening to me”.

Jeremy illustrates the slippery slope argument (the fear people will be killed when they could change their mind) and particularly the need to explore psychopathology. He

\(^5\) Electroconvulsive Therapy
regards requests as a cue highlighting patient distress. Jeremy does not discount the request but, rather, honours it and tries to deal with it, in this case successfully, through accepted medical intervention. A clinically depressed patient might not be rational (according to clinical standards) but he also hears patients say “not yet”, which suggests such a request might be more appropriate another time. Distress can also prompt rational requests to end life (Kissane, 2001; Kissane, et al., 2001) but this does not mean Jeremy would necessarily comply.

Thomas (General Practitioner) similarly understands some requests as due to psychopathology: “sometimes, it’s through anxiety or depression that requests are made. I will work towards finding the psychological expertise to help the patient even if I have to be the psychologist sometimes”. Thomas illustrates the multiple roles he adopts to deal with the complexity of requests for death. He needs to be a physician and a psychologist. Thomas identifies the need for psychological expertise at end-of-life but suggests it is not always available. Psychopathology is an important factor, but physicians do not necessarily consider all patient requests for death as irrational. This theme will further illustrate below how physicians often understand such requests as a way of patients gaining control over what many consider a hopeless situation. Requesting death gives patients a sense of empowerment by controlling the timing of death and providing mastery over their disease (Wineberg & Werth, 2003).

7.1.3.1. Waiting to die: Gaining control over uncertainty. Indeed, most physicians claim that patients who are uncertain and fear the progression of their illness are sometimes prompted to request a hastened death. Gary (Palliative Specialist) reports an example of this: “some ask because…I mean…some people are stuck in a terrible no man’s land where they’re waiting to deteriorate to reach that terminal final stage”. Gary describes the waiting and uncertainty as a “terrible no man’s land” but also how he deals with those situations: “I just explain that I’m not going to do anything to prolong their life…and that I can’t do anything to hasten the natural process, I’ll just continue to do whatever I can to relieve their symptoms”. Gary will not accede to direct requests on that
basis; rather he will continue to palliate and manage symptoms but not escalate treatment. He allows nature to play its role which takes the decision to end life out of his hands. Gary reflects his position on hastening death and clarifies this with his patient.

Similarly, Candice (Palliative Specialist) identifies an impatience for some patients of a delayed dying process, and the lack of control they have over it: “lots of people express concerns…about suffering too slowly, and it is a form of suffering; they wish the dying process would be faster…they can feel down, and demoralised, and lack control…all those things are normal things to go through”. Candice talks of an existential type of suffering that prompts requests to end life. She regards it normal that some patients feel down and demoralised, enduring a lingering death with no control over outcomes. It is precisely that lack of control, which Thomas (General Practitioner) identifies as underpinning requests: “in some cases people have issues of control over their situation; they don’t really know what’s happening, say its cancer or whatever disease they have, and they feel the only way to gain control is just to end things”. Thomas recognises that there is uncertainty for those dying, where “they don’t really know what is happening”. For some patients, an end to life is an end to suffering; suffering which includes the uncertainty they might be experiencing. However, patients sometimes make requests that are more benign and ambiguous, intended only to gain information about the uncertainty of terminal illness and the dying process.

Indeed, Kerrie (Palliative Specialist) believes requests sometimes carry ambiguous meanings, made by people who have little knowledge or understanding about their situation: “they’re not that uncommon, but it’s kind of like, I think it’s….kind of dabbling…and to try and find out information”. She regards some requests as attempts by patients to seek information about their impending death. This is one way for patients to gain control over uncertainty. But they might also be trying to sound out their physician as to what their views might be. Similarly, Maggie (Palliative Specialist) regards patient requests to hasten death as quite common and she also believes some requests carry ambiguous meanings not really intended to end life. She highlights the importance of
gaining an accurate understanding of the motives behind requests for death because it affects how physicians will experience and respond to them:

Happens fairly frequently…the most common thing, is that someone makes statements that they’re ready to die…and I don’t think that’s the same, I think that’s just…an acknowledgment, acceptance, and a lot of people are fearful when they hear patients say that, they think “oh they’re asking me to do something”…but it’s usually the conversation about “I know I’m in this place and, I’m ready”… and some people will say, “I wish it would happen earlier”…it’s just a realistic response to uncertainty, and waiting for something you’ve accepted is difficult.

Patients are uncertain and impatiently wait for death but Maggie differentiates between an explicit request to hasten death and a statement that a patient is ready to die. Maggie understands some requests more as an acceptance by patients who simply feel that they are “ready” to die and that it should happen now. However, she further illustrates how some physicians are fearful engaging with such requests when they understand them as intended to end life. The excerpt also suggests that, consistent with the ideology of palliative care, Maggie might be more able to explore the meaning behind such requests than colleagues in other specialties (Miles, 2001; Seymour, 2003), especially because, as she states, patients know why they are in hospice or palliative care and don’t expect curative measures to be instituted.

7.1.3.2. Pre-emptive/anticipatory motives. In some cases, requests to hasten death can be pre-emptive or anticipatory. Physicians understand that some people will make a decision to end their life before they reach a situation that they have little control over. Most physicians experienced such pre-emptive requests and Robert (Palliative Specialist) describes these:

That’s right, being pre-emptive about it. Some people are, still on their feet, and quite strongly saying: “NO, I want you to do something NOW…I don’t want to
end up in a nursing home, I don’t want to end up bed bound…I’d rather go now…while I’m still on my feet, than get anywhere near those situations”. So they’re pre-emptive about dying…before they really need help to die…to avoid ending up in something they really fear.

The pre-emptive nature of such requests reflects the need people have for controlling the timing and manner of their deaths. Patients fear ending up at the mercy of others or of their illness. Physicians recognise that patients wish to maintain their quality of life and dignity, and exercise control while they still can (Ganzini & Back, 2003; Ganzini, Goy, & Dobscha, 2008). Indeed, cultural sentiments for personal control over dying are reflected by the overwhelming public support for voluntary euthanasia portrayed in the Australian media (Allen, 1998; Ashby, 2003; McInerney, 2006). Such sentiments emerge influentially at the bedside but also early in the illness trajectory.

Correspondingly, Peter (General Practitioner) understands pre-emptive requests for death as reflecting cultural influences of an aging Australian society, where some people who are well but anticipate a grim future; decide to take steps to end their life:

Yeah, there’s no shortage of them, one couple came along and said, “we don’t want to wait around until one of us gets sick”, they were ninety years old…and they gave a story about how they’d witnessed grieving and loss of previous partners and they’d been together for fifteen years and both lost their previous partners, long term marriage partners, they both went through a very difficult time at that time, then they had fifteen great years and now they’re ninety and they’re saying “well hang on this is not going to last forever”, even though neither of them were sick, but we want to go on a suicide pact. We want to die together, and be together forever, we want our ashes mixed together and all the rest of it, now…that stuck in my mind…

Peter describes an incident of personal significance; one that “stuck in his mind”. He declares there is no shortage of people who wish to control their deaths, particularly while
they have the capacity to do so. Literally a suicide pact, such requests are motivated by personal experiences of a loved one dying. However, this illustrates a cultural shift in thinking that quality of life is more important than longevity, where illness is not the only determinant of requesting death.

Indeed, Peter believes the aging of Australian society links to advanced medical technology and is responsible for the diminishing quality of life some people experience. He understands people may not always look forward to living longer and are prompted to ask for death: “people feel increasingly that they are living…thanks to various medical services, breakthroughs, drugs, whatever…don’t really feel like they’re living at the potential they wish to be at. They’ve gone over what they saw as the time of their life”. Medical technology can be a double edged sword and Peter faces requests from people he believes are lonely rather than ill. Loneliness, particularly for the elderly, is difficult when gradually they lead a life of increased isolation: “often they’re very elderly and say ‘all my friends have gone and I’m by myself now. I live to a hundred and they all died when they were eighty…I don’t like the loneliness’”. Peter suggests that the quality of life, particularly its social aspects, is more important than its longevity, and his colleague Gary (Palliative Specialist) shares that view, saying: “lots of elderly patients, who are still far from death, have said to me they want help to die because they have no family, no friends, what’s the point in living”?

Certainly, a deteriorating quality of life sometimes prompts requests from people who are not terminally ill, but the quality of life is also mentioned by Robert (Palliative Specialist) as an important factor for patients who are in a terminal phase of their disease: “there have been situations certainly where patients intend…that…the terminal phase be shortened. This is actually quite a common occurrence encountering people who see very little point in prolonging life at that time when their quality of life…is pretty poor”. Patients frequently request a hastened death due to a deteriorating quality of life. Unremitted suffering in any form generally motivates a need for it to be addressed. However, patients sometimes also consider their suffering as affecting others, particularly
loved ones who bear witness to it and who might also be involved in their care (Gostin, 1997; Rosenfeld, 2004).

Accordingly, some patients consider themselves a burden on others and are motivated to request assistance to die. Kerrie (Palliative Specialist) describes this as a frightening prospect for dying patients: “that fear of being a burden is a very real fear, it’s a frightening fear”. Some patients have perfectly rational reasons for requesting death; where they fear the burden they will inflict on loved ones (McPherson, Wilson, & Murray, 2007; Rodriguez Davila, Vidal, Stewart, & Caserta, 2010). Most physicians identified perceived burden as something they needed to understand because of the possible remedial actions they might provide. Some physicians understand the fear of becoming a burden as due to the incremental loss of independence, where loved ones will increasingly need to take over the day to day activities and personal care of the dying patient. There is often also a dignity element involved.

Indeed, Thomas (General Practitioner) believes that some patients feel they are a burden when they lose their independence and can no longer help around the house: “someone who’s always been able to do everything, feels bad when they can’t; they feel a burden because they can’t mow the lawns or wash the house or whatever…they don’t want to be a burden, they want to die”. Being unable to contribute in the same way, influences requests to die by patients who now consider themselves a burden on loved ones. Their increased dependence on others is something they seek to avoid. Patients consider the value of their life contingent upon what they can still do physically. But, with utilitarian and neoliberal overtones (Davies & Gannon, 2006), sometimes patients further evaluate their life in cost/benefit terms as a drain on resources, and also as inhibiting the earning capacity of those caring for them (Konishi & Davis, 2001). Peter (General Practitioner) understands how financial concerns of dying patients underpin their requests to die:

Several of these recently where a person’s said, “I’m costing a fortune to stay alive, I’m taking this drug, this drug, this drug and I’m having this treatment, this
treatment, this treatment, and it’s eating up the money…I want that money to go to my daughter, she’s struggling, she’s a single mother…and I want her to have the money. I want to die. Because when I die it frees up the money, and it can go to her”. Now…that can be a little confronting…I’ve had two of these in not too recent times. So they’re talking about financial reasons for dying.

Patients who can no longer contribute financially to the family, and consider themselves a drain on the family income, feel they are a burden on their loved ones. Peter describes these types of requests as “confronting” but not uncommon. His description highlights how they may be reflective of an emerging utilitarian or neoliberal philosophy in cultural attitudes towards end-of-life care, where health costs are escalating and consideration of a greater good is emphasised. But it also demonstrates altruism from dying patients who consider their life economically unsustainable, and loved ones benefitting from their death.

Moreover, perceived burden may culminate in existential distress (Chochinov, 2002, 2007; Henoch & Danielson, 2009; Yalom, 1980). Jenny (Palliative Specialist) identifies that link and regards perceived burden as a major factor underpinning requests to die: “burden to others is a key reason that people...want to… hasten their death…and it’s very close to existential distress, because it’s this sense of loss of purpose and loss of control and…the impact they have on their family”. Jenny parallels perceived burden with existential distress particularly in terms of loss of control and purpose. She suggests existential distress is sometimes a causal factor of perceived burden and the dominant reason for most requests: “and it’s, the underlying existential distress that is the key reason for most people’s request; I would say the majority”.

Jenny believes that patients who are confronted with their impending death may question the value or meaning of life, particularly when it increasingly loses quality due to progression of their illness: “people say, ‘look I’ve had enough, can’t you just put me down’? ‘Is there anything you can do to make this process go faster’? ‘I’m really not living…I’ve lost meaning in my life, can’t you do anything doctor’”? Patients sometimes
reach a point where suffering and loss of meaning in life become untenable and patients no longer wish to endure or prolong life. However, she also investigates further with patients: “I will discuss it at that point with them, and discuss what I can do… and go through ‘why’ with them, and why they are requesting it, and we usually then set our terms together and an agenda”. Here Jenny indicates that she discusses her position on hastening death in terms of what she can do, and takes a collaborative approach to decisions on care. In her discussion, considerations of personal, professional and legal structures are implicit in influencing the negotiation of care between Jenny and her patient. Candice (Palliative Specialist) similarly related existential aspects and burden, saying: “people look back on their lives and realise, sometimes with great despair that life had little meaning for them…and now they’re only a problem for others and want to die”. Other physicians, particularly palliative specialists, also identified existential aspects of suffering as influential in requests for death. This may be due to setting and patient dynamics where, unlike many critical situations, people have time to contemplate their lives.

7.1.3.3. Dogs die a better death: Requests as control over vicarious suffering.
Suffering at end-of-life is recognised by physicians as far reaching (Currow & Hegarty, 2006). Family members also suffer, often more than their dying loved one (Kissane et al., 2003), and all physicians fielded requests from the family to hasten the death of the dying patient. End-of-life care, particularly for those in hospice or specialised palliative care has a holistic focus, where the welfare of family and loved ones are also a concern for the physician and other care staff. Physicians need to understand the suffering of family members who often stand by helplessly. They need to understand why they make such requests in order to consider strategies that might assist their grief and hardship.

Jeremy (Palliative Specialist) points out that requests to hasten death are frequently made by family members of the dying patient. They consider that their loved one is needlessly suffering a protracted dying process, but suffering is also implicit for those who endure vicariously at the bedside:
It’s not that uncommon, where families say things like: “look…if Dad was the family dog, you’d deal with it”, you know…“it shouldn’t happen to a human being; we treat our family pets better”. Those sorts of things get said, or you know, “how long is this going to go on for”?

Jeremy describes the common analogy many family members make of treating the family dog better. Families appeal to the compassion in their physician to be humane and end the suffering of their loved one. Kerrie (Palliative Specialist) also describes the analogy Jeremy provides, where patient loved ones say: “come on Doc, this is awful”, “Doc you wouldn’t leave your dog like this”, yeah “I’m a country person; we don’t let our animals suffer like this”. When families’ make requests to hasten the death of their loved one, sometimes it is to also address their own suffering.

Indeed, Maggie (Palliative Specialist) believes that most requests come from families, rather than patients, and suggests they are often made on that basis: “the majority of direct requests come from families, who are just struggling sitting in the room and watching…the physical process of dying”. Maggie understands that families struggle to watch the suffering of their dying loved one. She describes a process of dying that families might experience adversely but also one that they are sometimes unprepared for: “I think some of it is making sure you’ve done the preparatory work, so when those processes start to happen it’s not a shock; that you’ve talked with them about what to expect”. Maggie describes how she prepares families for their loved one’s death, consulting with them so that they know what to expect. Her circle of care is non-medicalised by also considering the welfare of the patient’s broader social structure. Her capacity to do this reflects the role of palliative care that allows time to talk with families around the distress they are experiencing, include them in discussion of the patient, and respect their views on suffering, even when they are odds with her own:

You can’t change people’s belief about…whether that physical suffering should or should not be there. I think at some point it has to be acknowledged that you can’t…do that but also acknowledge that…the physical aspect can be controlled
and that it’s more difficult for us watching in the room than for the person themselves, and sometimes getting them to reflect on it from that perspective helps.

Maggie makes her position clear that she will not hasten death on the family’s request, but also explains how she can manage the physical aspects of suffering. Providing that reassurance to families and a different perspective is sometimes sufficient to help them cope.

The key theme, “Control in End-of-Life Care and the Timing of Death” and its related subthemes, reflected the multidimensional complexity involved in Australian end-of-life care. This key theme captured the diverse understandings physicians held in relation to control at end-of-life. Physicians illustrated how they were influenced by, and positioned themselves within, interactive macro, meso and micro structures when engaging with dying patients and patient families. For example, religion and the sanctity of life position strongly influenced how most physicians regarded control over the timing of death, a position also supported professionally and legally. Others were more influenced by patient suffering and values of patient autonomy, while some would negotiate structures where they could be protected legally and support their patient oriented ideals. Physicians’ beliefs regarding control over treatment decisions, including those influencing the timing of death, were highly dependent on context, where control could be retained by physicians, given to patients, or collaboratively shared.

7.2. Understanding Death and Dying

Correspondingly, the influences physicians describe above in relation to control, and particularly practices that hasten death, are often fundamentally related to how they understand death and dying more generally (Kellehear, 2005, 2009; Moller, 1996). As discussed in Chapter 2, Sociocultural Theory suggests that physicians come to end-of-life care with a set of beliefs that have developed through social interaction over their personal and professional lifespan (Vygotsky, 1978, 1987). Their understandings
frequently reflect religious and other cultural beliefs, as well as influences from family and other social and professional networks (Bronfenbrenner, 1989, 1995). For example, Jeremy earlier declared his involvement in the clergy and how that “colours his attitudes and what he brings to end-of-life care”, and Gary recounted multiple interactive influences of religion, family and law. Although physicians often describe their understandings around death and dying with a particular uniqueness, their accounts also share similarity.

For most physicians, especially those more palliatively oriented, there is rightness about death. Some physicians find positive aspects in death, where death is seen in terms of a greater good or sense of purpose. Rightness of death is also considered in terms of when and how it should occur; and also where it should occur. Accordingly, the place of death is an important consideration. Other physicians regard death as a process of living. However, a few physicians, particularly those more curatively oriented, still regard death as medical failure. They also describe a general non-acceptance of death that often flows through the diverse cultural beliefs held by Australia’s multicultural community. The interaction of physicians with end-of-life care environments shapes how they understand the specific care requirements of their patients (and their families), and how they may subsequently intervene.

7.2.1. “Rightness” of death. Death frequently occurs as result of disease progression. Physicians understand that there comes a point when curative interventions are futile and only risk prolonging or increasing the suffering endured by patients and their families. Sometimes death is seen by physicians as an appropriate end to that suffering, as a good thing, where a decision is made to “allow” death to occur rather than prevent it. Such decisions are frequently influenced by a belief in nature or the divine, and not the physician, as the ultimate authority over timing death. Death occurs when it is right to do so, under the control of greater powers, and is welcomed and understood by most (particularly palliative) physicians as such.
As an example, Robert (Palliative Specialist) understands death as a parallel to birth, as a “transition of the life force”: “well, being at something like that, where you’re present when someone dies is quite…a moving experience. It’s a bit like when someone’s born too…it sort of feels…as though you’ve witnessed… a transition of life, of the life force”. Death, as with birth, is a profound and influential (almost humbling) moment for Robert, something he witnesses as “moving”. His colleague Gary (Palliative Specialist) identifies a causal link in his understanding of death and dying, believing death is determined by disease: “you know the disease had progressed to the stage where the time was right for that to happen”. He talks about the time being right for death; indicating control over death was with the disease rather than physician and that death occurs when appropriate. It is almost an acknowledgement that death should now be allowed to occur rather than making efforts to prevent or delay it as the ideology might direct in other more curative settings.

For Jeremy (Palliative Specialist), not all deaths are the same. He differentiates the type of death: “I think that death is…a normal event but premature death is not so normal and… a death that’s full of suffering is not acceptable, so that’s pathological death if you like”. As with Gary, Jeremy alludes to the appropriateness of death, but also that it is normal and not something to be feared: “we try and help people see that for the dying patient this was not dreadful, for the person dying it was all right given the illness they had and suffering they’ve been through. It’s ok for them to die”. There is rightness about death and Jeremy tries to help the surviving loved ones come to terms with it as such. He frames the death as an end to suffering, as if the patient would have welcomed it.

7.2.1.1. A greater purpose in death. In considering the “rightness” about death a number of physicians also identified positive aspects, where a greater good and sense of purpose may come from death. For example, some physicians regarded death as something they learnt from, which demonstrates a non-linear interaction of mutual benefit between the physician and their dying patient and associated loved ones. Although
generally the physicians’ purpose in end-of-life care is to provide comfort to others, the physician’s life is also enriched through the dying patient’s influence.

To illustrate, Candice (Palliative Specialist) mentions *dying as lessons for life*: “you learn how to prioritise, you learn…at the end-of-life when people look back on their lives, you learn as much about life and the choices people have made and perhaps the choices you might want to make”. Candice learns about choices and prioritising from those she cares for, considering these lessons valuable in her own life. For Candice, knowledge comes from death. Similarly, Jeremy (Palliative Specialist) finds positive aspects in death where, as with life, he considers the dying process a learning experience. “I believe that many resurrections occur where, from apparently horrid situations, some great good can come. And…you know there are lessons in life right up to the moment we draw our last breath”. Jeremy talks of “lessons in life up to the last breath”, somewhat reflecting Kübler Ross teachings mentioned in Chapter 4. However, Jeremy’s religious influences also emerge when he talks of “resurrections” from horrid situations suggesting some greater purpose in life (and death) such as transcendence.

Other physicians further considered organ donation as a positive way for death to benefit others. Especially in situations where deaths might have been considered *wrong*, in younger patients for example or those from tragic accidents, organ donation may be a vehicle for righting that wrong. Indeed, Andrew (Intensive Care Specialist) finds that there are possibilities for some sense of purpose or greater good to come out of death, where death is understood as *donation*. “Fully aware that you’re withdrawing treatment, the patient will die…with families that are keen to make sure there’s no suffering, I found these are also the families that would say…’yes, organ donation…would be a good…outcome of this situation’”. A selfless or altruistic act may enhance the life of others while providing a legacy from the dying patient and their family and a mechanism for dealing with grief. Through donation, life may literally come from death; in fact the Australian Government calls its national organ donation initiative *Donate Life* (Australian Government, 2011). By strategically using favourable language, the macro level of
government may change personal attitudes toward death and donation in our society, particularly if as Andrew believes; “it might still be a taboo here”.

7.2.1.2. A place to die. Cultural and professional diversity in understandings on end-of-life care means that the place of death and dying must be given similar consideration. Individual medical settings and their particular professional ideologies influence the type of deaths patients will have. Some settings are more suited to dying than others and many physicians contrasted those dynamics and the beliefs they held in relation to them. Likewise, patients and their loved ones also hold particular preferences on where the dying process should be managed and where death should occur. Although some patients wish to die in hospital, many more wish to die at home surrounded by loved ones (Abel, et al., 2011; Foreman, et al., 2006). Indeed, Candice (Palliative Specialist) makes this point: “if you look at the studies that exist, I mean people do change their minds at the end, but you know some studies will quote as high as 75% - 85% of patients want to die at home”. Candice’s understanding is influenced by scientific research but she also understands that other factors make a home death difficult to achieve: “but how do you do that when community resourcing for home palliation is so restricted”? She alludes to a resourcing priority directed toward institutionalised care despite evidence that community resource needs in end-of-life are greater. Accordingly, physicians need to negotiate the place of care taking into account their own beliefs, those of patients and others, and also what is possible within institutional and administrative structures.

Gina-Leanne (Intensive Care Specialist) works in a biomedical and curative setting where disease is the focus, however, she believes death in end-of-life care should also be appropriate to location, and planned: “I think we really need to be doing a lot more education and forethought and thinking and planning and discussing, so that people don’t end up dying in ICU”. She does not regard ICU as an appropriate place to die and discusses the importance of education and planning to allow death to occur elsewhere. Aaron (Respiratory/Thoracic Specialist) makes a similar point: “despite expectations that we can fix everything, people die here and many of us are unprepared for that…and its
cruel inflicting invasive treatments on patients that shouldn’t be here when there are better places to die…we need broad-reaching education”. He talks of professional and cultural expectations to cure and unpreparedness for death, while identifying a need to educate about the realities of intensive medicine and end-of-life care. Dying patients are often delivered to intensive care as a matter of procedure (Hillman, 2011), but inappropriate settings, and efforts to meet unrealistic care goals, sometimes prescribe interventions regarded as “cruel”. However, the emergency and acute nature of ICU may well render planning difficult when patients deteriorate rapidly sometimes. Andrew (Intensive Care Specialist) highlights some dynamics of ICU and why it is an inappropriate place to die: “Well you’ve seen this place…it’s not a good place to…die, it’s noisy and busy, there’s…minimal privacy…there’s really no room for relatives to sit down and have some time by themselves”.

Jeremy (Palliative Specialist) also talks about setting differences, contrasting the palliative ideology with the critical/acute: “we allow natural death… many patients are relieved that we’re not going to offer heroics”. Indeed nature should take its course and not be prevented through futile interventions. Jenny (Palliative Specialist) similarly takes the approach of allowing death to occur, saying that:

I would hope that it’s over for some people…would commonly, make a decision with the family and the patient not to treat…a potentially life threatening event, commonly an infection…with antibiotics…that’s not hastening death but it’s probably the most, I mean that’s how people die.

Jenny’s approach is assisted by a collaborative decision not to treat some life threatening situations. She indicates that infections and withholding treatment are most commonly how people die. She is consistent with Jeremy in not offering heroics and her understanding is that she is not hastening death; rather nature takes its course. A palliative care ideology can allow death to occur. The intrapsychic emerges here when she talks of hoping it was over for some people yet she must also wait for rather than hasten death:
but I don’t, entertain trying to hasten things”. Jenny believes she is not hastening death by withdrawing treatment, which from some viewpoints may seem counterintuitive.

### 7.2.2. Death is about living

A majority of physicians regarded death as merely the end of a dying process. When the inevitability of death is recognised and accepted, much can still be done for the patient and their family to enhance their quality of life. Palliatively specialised physicians in particular, focus efforts toward maintaining patient functionality through good symptom control to allow life to be lived for as long as possible. There are many strategies employed by physicians in end-of-life care that enhances the quality of life through enhancing the quality of dying. For example, they frequently negotiate administrative challenges to provide support through outreach and community care that assists patients and their carers who do not wish an institutionalised dying process. Physicians are directed by patient as much as clinical goals in achieving the outcomes important to patients. Survival or duration of life is no longer the important outcome for physicians.

In articulating her understanding of end-of-life care, Jenny (Palliative Specialist) focuses on life not death: “well the death is just the end. I believe that end-of-life care and dying is a process of living”. Her view is consistent with the palliative care discourse emphasising quality of life until death (Palliative Care Australia, 2011a, 2011b; Saunders & Baines, 1983). Candice (Palliative Specialist) shares Jenny’s view by similarly regarding end-of-life care as being about living and providing quality at end-of-life: “you know in palliative care survival is not the outcome…and …we don’t save lives, we make things better…we help people work out what is important for them”. Palliative care emphasises collaboration and Candice contrasts the critical/acute focus (of saving lives) with palliation and a patient-directed focus.

Maggie (Palliative Specialist) also makes a distinction between quality of life and longevity: “we’re very much focused on quality of life rather than duration…but I think…the majority of our decisions, the focus, goal of care is, is focused on quality”. Maggie identifies palliative goals designed to enhance the quality of living while Kerrie
(Palliative Specialist) reflects her similar understanding of palliative care as emphasising life rather than death: “Palliative care is actually about living, help the living live as well…for as long as possible, but also I’m…freed up by…acknowledging that I can’t change the process, I can care…death is inevitable…not necessarily a failure”. Kerrie considers dying in terms of living, for as long and well as possible. Supported by a palliative care ideology, she accepts the inevitability of death and does not consider it a failure; and she can still care. This knowledge is somewhat cathartic for her when talking of being “freed up” by that. “Yeah I’m sorry; 100% mortality associated with this life we have. We are all going to die”. Life and death walk hand in hand.

7.2.3. Death as medical failure. Consistent with the previous literature review, death is still regarded by some physicians as a medical failure. That conception is often clearly differentiated by the professional ideology held by physicians and the settings that promote them. For example, as Kerrie also explains above, death is accepted as inevitable in palliative settings and efforts are made to provide appropriate comfort and holistically oriented care. However in critical and acute settings, efforts are often still curatively directed and death is prevented rather than accepted. Physicians have extensive specialised training that emphasises this and have often devoted considerable efforts in saving the lives of particular patients. When death occurs it is sometimes unexpected and regarded as a threat to their professional position and expertise. They are reluctant to even discuss the topic. The beliefs held by physicians who are uncomfortable accepting death are often also influenced by broader cultural expectations, frequently promoted in the media, of what medicine can or should do. Indeed, Gina-Leanne (Intensive Care Specialist) highlights how curative settings are disposed to promoting a particular understanding of death. She regards unexpected deaths as a shock, pondering whether they could have been prevented. There is an implication that medicine has failed: “sometimes we go all out for some patients and it comes as a shock when they die unexpectedly…it leaves you wondering what went wrong”.

Similarly, Keith (Intensive Care Specialist) provides his perspective of how some physicians conceptualise death, illustrating professional taboos on death and dying: “So patients, they’re just passed along, because of expectations of society, expectations of my colleagues, reluctance of my colleagues to discuss death and dying…it’s time consuming…they’re not comfortable with it, often…fear of litigation”. Keith demonstrates multiple structures that influence understandings and practices. He discusses a reluctance and discomfort among his critical/acute colleagues to talk about death and dying because of societal and professional expectations to save lives. Physicians avoid by “passing patients along” to colleagues. The intrapsychic is influenced by cultural and professional imperatives but also further by legal considerations where physicians fear litigation. They are perhaps compelled to practice defensive medicine (by ensuring everything is done) and leave death to another colleague. Keith also mentions the time consuming nature of discussions around death and dying implicating institutional constraints and suggesting that there is also a fiscal/resource element involved in physician avoidance. Keith draws a link between intrapsychic and professional and cultural structures for his colleagues: “not being comfortable with death and dying, and being programmed to treat and to cure”. Keith describes a somewhat causal link in that his colleagues are (culturally and professionally) “programmed” to avoid death and dying, but the notion of programming further suggests a lack of agency on the part of his colleagues.

In contrast, Jeremy (Palliative Specialist) challenges the idea of death as “medical failure” by taking a pragmatic view of death: “I teach students and try to help patients see that death is actually healthy and normal. Death is after all a given and not a medical failure, I believe that passionately…but my colleagues have struggled with this often”. Jeremy understands death as normal and healthy, and conveys this view to his patients and medical students. He acknowledges the traditional but unhelpful medical ethic of death as failure and how his colleagues struggle when conceptualising death this way.
7.2.3.1. Non-acceptance of death. The cultural expectations of medicine were recognised above, but death is also a widely considered taboo topic in the multicultural Australian community. The focus of this subtheme is on non-acceptance by patients and family but it reflects on the practices of physicians who need to work with that non-acceptance of imminent death. Failure in this sense is not so much on death as a “medical” failure, but more a perceived failure of not achieving “acceptance” from patients and their family. Most physicians made some reference to this. For example, like her cross-disciplinary colleagues mentioned above, Maggie (Palliative Specialist) recognises that people have difficulty confronting death. She provides an understanding of death and dying and her role in palliative care:

There’s always people that will struggle…so I think there’s a sense that people need to be close to death accepting that that’s inevitable, and there will be people and their families who will be still…hoping for a miracle, sometimes till the minute of death…and I don’t think that’s a failure, I think…a lot of people will articulate that as, somehow you haven’t helped them navigate that person to that point… so I think you just have to accept that…you have to walk alongside people.

Maggie acknowledges that death is a unique event and that some people will not accept it, always hoping for a miracle. She does not regard it a failure if she has not been able to “navigate” a person to that point. The language of palliative care is further emphasised when she also talks of walking alongside people. This is a reference of empathy and respecting differences, but also suggests the role of trusted guide, someone who accompanies a person on their journey into death. Such metaphorical language may be influential in bringing comfort to patients who might consider themselves supported rather than abandoned. Maggie describes various structured roles and their possible identities; the personal as empathic guide and the professional as specialist physician.

Andrew (Intensive Care Specialist) also considers quality of life in the care he provides to the dying. Although the curative setting in which he operates carries the
expectation of saving lives, he particularly highlights cultural differences in how death and dying is regarded and accepted:

I think being in a multicultural community there are times when, families don’t...accept the fact that death is inevitable…and they, keep pushing for everything to be done…and without realising that, if you don’t accept the fact the patient is dying you’re just...prolonging death not prolonging life.

Andrew identifies a multicultural structure in Australia where there are a variety of views on dying and end-of-life care. He needs to negotiate cultural beliefs that are not always consistent across the population. He illustrates how some families will not accept inevitable death and “push” for everything to be done. Andrew regards this as only prolonging the death of the patient. He suggests that people may not realise that a life is essentially over; where the quality of that life, as he regards it, is diminished. Allowing the patient to die, particularly when death is imminent, is sometimes at odds with the views of some patient families who might cling to hope while there is still life. Personal and cultural beliefs of families, professional expectations, and moral and ethical factors come into play when deciding on treatment plans and demonstrate the complexity in end-of-life care (Adler, 2007; Bhaskar, 2011; Munday, et al., 2003). Andrew contrasts the differences here in Australia with Scandinavia where more utilitarian and liberal views might flow through cultural attitudes: “I think...communities, in Scandinavia and...I’m not sure whether it has to do with history or what...people, accept...death, and dying...much more easily than...families that I’ve met here”. Andrew mentions historical aspects that add an important temporal dimension where, consistent with Bronfenbrenner’s (1989, 1995) chronosystem, social attitudes toward a greater acceptance of dying may have developed differently in some societies. He highlights a particular diversity in Australian end-of-life care that physicians need to consider.

This key theme “Understanding Death and Dying”, and its subthemes, illustrated the beliefs physicians held on death and dying and how their understanding was shaped by multiple contextual influences. For many, there was a right time and place for death to
occur and death was often regarded in a positive light. Some considered death a process of living, but many physicians often met contextual impediments that prescribed specific but contrary ideologies and practices, where death was socially unacceptable and regarded as a medical failure.

Although physicians develop their beliefs and attitudes over a lifetime through direct social interaction (Bronfenbrenner, 1989, 1995; Vygotsky, 1978, 1987), discrete personal or vicarious experiences with death and dying may also influence how it is conceptualised (Bandura, 1986). For example, the after-effects of near-death experiences typically include increases in spirituality, concern for others, and an appreciation of life, but also decreases in the fear of death (Greyson, 2009), and this applies equally for those experiencing them only indirectly (Flynn, 1986). Certainly, experiences of this nature are possible for physicians in critical/acute settings where patients are frequently resuscitated and brought back from the brink of death. Indeed, Aaron (Respiratory/Thoracic Specialist) said to me: “I’ve been around long enough to see miracles happen”. His language suggests divine intervention and metaphysical influences. Ring and Valarino (1998) similarly reported that indirectly experienced near-death events foster increased spirituality and empathy; but also a strong belief in life after death. Likewise, prompted through a vicarious experience that challenged his beliefs, Trankle (2009) investigated a life after death event in which the experient, “visited” by her deceased father, lost her fear of mortality and developed an unwavering belief in life after death. Although events like these may sometimes be regarded paranormal, they cannot be dismissed because, as with spirituality more commonly, they influence personal beliefs and understandings and what may be brought to the bedside in end-of-life care.

7.3. A Good Death: One of Peace and Comfort

When physicians manage individual deaths, they are influenced by their own fundamental beliefs on death and dying as well as by a complexity of cultural and other influences. The understandings physicians have as to what actually constitutes a good death reflect such complexity in end-of-life care, where each situation, each patient and
each physician interact to produce sometimes similar, yet uniquely individual outcomes (Adler, 2007; Suchman, 2006). No two deaths are the same, nor are the relative (often multiple) influences in those deaths. Accordingly, the way physicians can negotiate and bring all of this together will affect how they conceptualise individual deaths and the processes leading up to them.

A good death is a preferred death by comparison to the alternative, specifically one of suffering and distress. A good death, as with a bad death, has far reaching impacts that go beyond the immediate patient and include family and loved ones, and the physician and others involved in the care of that patient and their family members (Ashby, 2009; Proulx & Jacelon, 2004). The experience of death is not a localised event. Physicians often described a very intimate but broad reaching social interaction that also included other professionals. However, a good death was also contingent upon the setting and specialty where death and dying took place. Accordingly, professional ideology influenced how physicians regarded a good death. But physicians also considered their personal views of a good death in terms what they would like for themselves, and sometimes those views further reflected cultural and religious influences.

A good death was frequently defined with qualities of “peace and comfort”. This flowed through numerous themes and subthemes that emerged from the descriptions physicians provided on their understanding of a good death. The quality of the dying process, more than the timing of death, was the primary focus for physicians. For example, multifaceted *symptom control* was of crucial importance and mentioned by all physicians in their efforts to bring peace and comfort to the dying patient. The ability to *plan and prepare* for death was another major consideration for physicians, and included the timely and appropriate *transition* of care goals. *Communication* was something most physicians also regarded as particularly important. This included communication among physicians within and across specialties, and also between physicians and their patients. Communication between patients and their family was similarly emphasised, where a sense of closure and peace reflected how physicians considered a good death.
An element of collaboration in decision-making that provided the patient (and their family) with some level of control was also important for many physicians. They frequently highlighted the need to individualise care as much as was possible within the settings they practiced from. In understanding death and dying as unique, this often included addressing existential issues and providing the capacity for spiritual considerations in care. A somewhat related theme of relationships that often developed in the end-of-life care experience included those between patients and their loved ones, and also with God. Sadness was mediated by the positives of renewing and repairing fractured relationships. All physicians emphasised the importance of such relationships in end-of-life care, and particularly in terms of a good death. These themes described by physicians as part of a good death are discussed in greater detail below.

7.3.1. Symptom control. All physicians, regardless of specialty, emphasised the importance of good symptom control. They often mentioned multimorbidity and symptomatic complexity that were crucial challenges in assisting a good death. Peace and comfort were frequently mentioned as the desired goals and outcomes of symptom control. Physicians often described the importance of biopsychosocial considerations where symptoms had multiple foundations and interactions. For example, Maggie (Palliative Specialist) regarded symptom control as elementary in end-of-life care, particularly “physical symptom control”: “I think it goes without saying that physical symptom control is important”. Symptomatic complexity is common at end-of-life and, acknowledging that a good death may be conceptualised in different ways, Andrew (Intensive Care Specialist) provided his perspective: “wow that’s a broad question…if you ask me as a doctor, then I’d say, that’s a death that would involve…hopefully no pain at all, pain should always be managed…uhm, and wouldn’t involve too much anxiety”. Andrew’s medical view of a good death is one that is pain and also anxiety free.

Correspondingly, Thomas (General Practitioner) recognises the multiple domains of symptom expression, and stated the importance of controlling myriad physical, psychological and emotional symptoms in order to assist good deaths: “A good death is
where the patient has a combination of physical symptom control…emotional control, where their issues of anxiety depression everything is controlled”. Thomas regards symptoms as more than only biomedical. Similarly, Gina-Leanne (Intensive Care Specialist) considers a good death as a product of multiple factors that might interact symptomatically: “a good death …would be one where they’re not in pain, they don’t have symptoms, they don’t feel distressed, they’ve had a discussion, they’ve had time to talk to their family and they feel…at peace with the decision”. She mentions a social aspect in conjunction with symptom control where family discussion may alleviate patient distress and provide peace for the dying patient and their family. Such a holistic focus reflects palliative ideals (Palliative Care Australia, 2011a; Saunders & Baines, 1983) and was important for Gary (Palliative Specialist) who similarly describes a good death in terms of patients finding peace through comfort, while also incorporating the patient’s family in his focus of care:

Achieving a peaceful death where you get someone very comfortable…sedated to some extent, looking like they’re sleeping and not distressed by the dying process, dying peacefully, and the family happy also…then that to me is, yeah…a good death and gives me a lot of satisfaction.

Sedation is an effective symptomatic strategy for Gary, and perceptions are important to him when he talks innocuously of patients “looking like they’re sleeping”. A *peaceful* death as Gary understands it is at odds with a *distressing* death. Furthermore, when he can facilitate a peaceful death his experience, like the family’s, is satisfying.

Some physicians regard symptomatic control in terms of quality of life, where efforts are made for the patient to continue living for as long and as comfortable as possible. A good death is also defined by the quality of life leading up to it. For example, Jenny (Palliative Specialist) describes a *process* of death where she highlights the importance of symptom control particularly in terms of enhancing the *quality* of the dying process itself. For Jenny, end-of-life is all about living rather than dying: “a good death is that the life leading up to the actual death, is lived with the best quality possible, and with
the best…symptom control to allow people to prepare themselves, and their families for the actual death”. Jenny uses expert symptom control to stabilise patients and allow them to continue living as well as possible. She provides an example of a patient with advanced mesothelioma:

He needed to feel as good as possible, just keep living. So I spent a lot of time…on getting his pain which was then complex under control, and then we started talking about the other stuff in his life, and really just helping him…and his family prepare for living…prepare for every holiday they went on, making sure that the symptoms of his disease wouldn’t impact on his ability to be with his family, which takes…organising, and did that for one then two then three holidays, they were all in a short space.

Jenny illustrates the time consuming nature of controlling complex pain issues at end-of-life, but when expertly managed, life may be extended and enhanced. She was able to assist her patient and his family to enjoy some holidays together. An emphasis on quality of life that allows a patient to live well for as long as possible also gives time to prepare for death, and Jenny highlights the importance of planning for this: “the actual death itself…should not be a shock, should be that everyone is well prepared, not necessarily ever accepting, but well prepared”.

7.3.2. Planning for death (and care goal transition). An ability to prepare for death and plan treatment options was important to most physicians. A good death was identified as one that was not unexpected, where appropriate care goal transition could take place and there was time to evaluate various treatment options. Sometimes this is problematic for physicians in critical/acute settings and in emergency situations where, for example, patients might be uncommunicative through intubation and sedation, or by cognitive impairment (Beckstrand, et al., 2006; DelVecchio Good et al., 2004). Collaboration with patients and loved ones was emphasised by a number of physicians in deciding treatment goals. Managing deaths through holistically focused care that included family members also further assisted their preparation for grief and bereavement. Time to
prepare and plan allowed resources and strategies to be identified (and negotiated) that could assist a good death.

For example, Aaron, (Respiratory/Thoracic Specialist) emphasises the importance of planning and collaboration early in the decision making process:

Planning’s essential, I mean, a lot of times the patient doesn’t have much input because they’re not in a state to have much input, which is why I think it’s so important, if you can… raise some of these subjects before their acute illness, so if that’s not possible then you need the family…particularly in an emergency situation. And there are times when there are no family, and times when you have to deal with the guardianship or things like that.

Aaron reflects the nature of emergency and acute settings and their inherent constraints, particularly around adequate opportunities for planning with the patient. He identifies the potentially problematic nature of acute or sudden and unexpected episodes where the patient is uncommunicative and decision making is then left to others, particularly when an advance plan or contingency had not been put in place earlier. Indeed, sometimes a rapid deterioration in the patient’s condition further adds to the difficulty of preparing for appropriate care in busy critical and acute settings. Andrew (Intensive Care Specialist) talks of planning and the unexpected: “a good death…it shouldn’t come as a surprise to everyone, that there’s actually been some time…just to recognise that, the patient’s life is ending, and so there’s a plan in place; people know what they’re doing and what they’re treating”. Andrew is also alluding to care goal transition here, where palliation may need to replace curatively focused interventions. But, he also considers planning with the family important: “I feel that I’ve done a good job when I had the time to sit down with the family, there was a plan in place, everything was discussed and they recognised that this is the…proper way of doing things”. Accomplishing a collaborative care plan minimises potential conflict by defining common goals, but it also brings Andrew some sense of achievement. He also mentions having the time to do this which reflects the busy nature of intensive care and its priority on saving life rather than managing death.
However, consultation and collaboration needs to include other physicians and nurses, and allied professions such as social and pastoral workers, who contribute to managing the dying process in the best way possible. It is important to know when treatment withdrawal should be made, particularly when aggressive interventions are becoming futile, and when an appropriate and timely transition to a palliative model of care should occur. As Keith (Intensive Care Specialist) says: “we need to know when to back off”. At the same time, Gina-Leanne (Intensive Care Specialist) acknowledges the constraints in ICU that can inhibit a good death. She talks about care goal transition and patient transferal:

A good death is one in which we know the patient’s dying and we can get them to a stage where they can go somewhere else…to die, where there’s no restrictions on visiting hours, where they can have what they would like…do what they would like, which is just not possible in a busy ICU.

Gina-Leanne illustrates the pervasive ideology of curative goals in critical/acute settings that determine available resources (including time). She suggests that it is not always possible to know when a patient is dying when efforts are directed to saving life. She importantly identifies the ICU setting as an inappropriate place to die or receive end-of-life care. However, recognition of impending death is essential so that patients can be stabilised for transferral into appropriate care where they have more control. The timely transition of care goals cannot occur without preparation and Gina-Leanne considers discussion and planning as important aspects in a good death: “A good death from an intensivist’s point of view is one that’s talked about, considered and planned”. Death should not come as a surprise; but, unlike a palliative setting where death is actually expected and part of the management plan, palliation is not intended as part of the ICU brief. Gina-Leanne makes this point: “it’s not what people are trained in, not what people chose intensive care to do, we didn’t choose to be palliative care doctors, it’s just that…a lot of patients die when they’re with us and we have to do it”. Gina-Leanne illustrates the changing structure of intensive care, where a lot of people die and expectations are placed
on specialist intensivists to palliate despite inadequate training and contrary motivations for entering their particular specialty. The earlier review of literature identified how patients often inappropriately end up in ICU due to an acute episode of a chronic condition (Hillman, 2011), or they are retained there, and specialist palliative expertise is difficult to access (Seymour, 2000).

7.3.2.1. Communication. Communication is regarded by most physicians as crucial in a good death. Gina-Leanne emphasised that a good death for an intensivist is “one that is talked about”. The ability to plan for death requires a capacity for communication. For dying patients and their family, communication and access to information are equally significant aspects in end-of-life care (Curtis et al., 2005). Communication between patients and loved ones provides a sense of closure, and peace and comfort. Indeed, Aaron (Respiratory/Thoracic Specialist) regards closure as important prior to death: “being able to say goodbye is a very important part of the dying process”. He believes communication between patients and their loved ones is essential at end-of-life, but that ability is not always possible: “the family would not like their relatives to suffer, but they would also like some communication, some human contact rather than just sitting by the bedside with someone that’s comatose”. Aaron emphasises meaningful human contact yet recognises communication may sometimes be problematic, where families occasionally wait for death beside a comatose loved one. There are suggested challenges to communication where great expertise is required to balance patient cognition with appropriate pain management strategies to avoided rendering patients comatose.

Similar considerations are expressed by Thomas (General Practitioner) who regards information and the capacity for communication as principal goals in achieving a good death, particularly one of peace and comfort:

Patients should be aware that they’re dying, be comfortable having dealt with issues concerning family or friends or whoever is close to them, and they have communicated, and ideally in the relationship between them…everyone is
comfortable with the whole idea of them dying and ready as well, and the patient
dies comfortably-peacefully.

Thomas identifies a need for patient awareness of their situation, a holistic focus
incorporating family and friends, and the importance of communication and support to
facilitate closure, peacefulness and comfort with impending death. Thomas illustrates the
many complex aspects to end-of-life care that should be considered in the specific
interests of patients and their families to achieve as good a death as possible. Most
palliative specialists recognised this also, and Kerrie (Palliative Specialist) similarly
identified the importance of communication and provision of information in assisting
peace and comfort: “I guess a good death is where the people around the deceased
person…are comfortable. Families feel more comfortable when they have information,
and know what’s going on, they have people to talk to, and see…the person looking calm
and peaceful”. Kerrie’s focus of care goes beyond the immediate patient and reflects the
palliative ideology which considers and provides for broader care goals (Palliative Care
Australia, 2011a; Saunders & Baines, 1983). Communication between patient/family and
physician allows collaborative and considered strategies in managing care but she also
identifies the specificity of care in terms of unique social dynamics and structures. Indeed
she talks about an ecosystem. “We’re all like little ecosystems aren’t we, walk around in
our own little support groups, so also to involve those people in discussions as well, I
think is real important”. Kerrie emphasises a collaborative approach to end-of-life care
that has the capacity to include family and others in discussions. Patients and their
family, thus maintain some control over end-of-life outcomes.

7.3.3. Patient control (and input to end-of-life decisions). Physicians stated that
when patients have input into their treatment goals and decisions, a more comfortable and
peaceful death might ensue. This was a major consideration by most (particularly
palliative) physicians. For example, Jenny (Palliative Specialist) says: “deaths are better if
patients are involved in decisions”, while Robert (Palliative Specialist) similarly suggests
peace and comfort may be achieved if patients are able to retain some element of control:
I think a good death is...one in which the patient is reasonably at peace with the world, with their situation, and that their loved ones are reasonably comfortable with their journey as well...so with a patient at peace, and a part of that is people just feeling in some reasonable sort of control.

Robert regards end-of-life as a journey (both for patients and loved ones) reflecting palliative care ideals in which patients are not marginalised but rather encouraged to collaborate in decision-making and treatment goals (Saunders & Baines, 1983). Patient control enhances their sense of dignity, and mediates their suffering and fear of becoming dependent on others (Chochinov, 2007), but also requires having access to information on their illness. Accordingly, openness and transparency (and sensitivity) by physicians is something they consider important, but is not always provided depending on the patient’s condition and also the setting from which care is being managed. Indeed, sometimes a good death means withholding information from dying patients, particularly if unable to convey it sensitively. Keith (Intensive Care Specialist) points this out:

A good death needs a system that’s open and transparent, while also being sensitive, and sometimes they [other physicians] don’t know what that means...like it’s easy to be perfectly blunt, but...sometimes, maybe you have to tell little white lies if you think they’re that sort of person.

Impending death, especially if sudden or unanticipated might be quite confronting for patients and their loved ones unexpectedly facing that realisation, and increase stress at a time when it is perhaps most damaging. Physicians may elect not to disclose some things. Culture may also specifically determine the flow of information within a family’s structure (Candib, 2002). However, Keith also implies that physicians may not be skilled in sensitively communicating from within acute settings, particularly when managing death is not the purpose of intensive care or the focus of training (Seymour, 2000, 2001). The level of control that patients have in directing decisions may be at the discretion of individual physicians.
Still, for Aaron (Respiratory/Thoracic Specialist) who also works in critical/acute settings, some level of patient control and input is important in end-of-life care: “a good death I think, is someone who dies with dignity, who dies without suffering…where…the patient and family have input into…the actual process itself, some role in their own decision-making, so that’s…I think, what would be ideal for myself”. Aaron mentions dignity and suffering as important considerations. Such aspects, however, may be more difficult for Aaron due to the curatively focused setting he operates within, where patients, especially in line with his specialty, are frequently intubated and ventilated. Collaborative decision making (that also includes the family) may also be more problematic due to the technical nature of the setting. It is interesting to note that Aaron conceptualises a good death as to how it might apply to himself. His understanding here is influenced by a personal belief structure, an intrapsychic perspective. Indeed, the importance Aaron places on patient control was reflected by other physicians, especially those in non-palliative settings, who similarly considered their own situation in terms of what they would like and what a good death would be for them. For example, Peter (General Practitioner) also conceptualises a good death as to how it would apply to himself:

I think watching people face death and go through this process…in various ways, some of them feeling like they’re facing very difficult situations, families left behind describing some of their deaths as good and some of their deaths as anything but that...you start to form an opinion about what you would see as being a good death.

Through empathy and the shared experiences of others confronting death, Peter illustrates how personal experience, even if only vicarious, may influence his subsequent beliefs and attitudes on what constitutes a good death. He further describes these below but regards control as particularly important.

6 Underlining added by author to denote physician’s emphasis.
It pretty much comes down to a person being in control, getting the most effective resolution of their unpleasant symptoms, as best as they can, but at some point also knowing that they can have that option of a peaceful death should it be desired and that they’re not in any way going to find themselves trapped…living out some kind of uncontrolled medical…scenario where they don’t have the option of being able to put an end to it. So it’s a person who’s in control….who may or may not take the option of ah, electing death.

Although Peter also mentions the more common definitions of a good death, he particularly regards good deaths as being about choices and not becoming “trapped”. Peter, who strongly advocates patient choices particularly in terms of them controlling both the timing and manner of their deaths, is also talking here not only about patients withdrawing treatment while they still have unimpaired cognition, but also implying a more direct intention to hasten death if that is their wish. However, intent has been shown in the literature review as a slippery concept, for example in double effect, and any intended or elected death as Peter describes would require very careful navigation within legal and professional structures.

7.3.4. Individualising end-of-life care. If patients are able to exercise control, they are more likely to receive care and die in a manner that they consider most appropriate, care that is individualised to their specific needs (De Jonge & Clarke, 2009; Proulx & Jacelon, 2004). Peter and Aaron both regarded a good death in terms of what they would like. A good death was also understood by most physicians, particularly palliative specialists, as one which was individualised and took unique patient and family dynamics into account. Physicians considered that care needed to be provided according to how life had been lived. A good death for one might be different to a good death for another. Physicians recognised the face behind the illness and regarded it important to maintain that humanity and individuality when providing care. For example, the traditional link between Christianity and hospice, where each person is considered a
valued individual, was reflected by Jeremy (Palliative Specialist) who regarded each
death as unique:

A good death is one that’s right for that person according to how they’ve lived
their life…but we are also dealing with living human beings and we have to
celebrate those lives and help patients where possible to celebrate their lives. I
think this is a good death…trying to see the person behind the illness.

Jeremy particularly emphasised an individualised death according to how life has been
lived and worked to maintain dignity and humanness by celebrating life. His goals are to
assist meaning for those that are dying; they are more than their illness. Similarly,
Candice (Palliative Specialist) said: “each dying person is special in their own way and
we need to find that, emphasise that and remember that…patients and families need to
know that”.

At the same time, a good death also means that the place of dying should match
the place of care, not only according to patient needs but also as best as possible to patient
wishes. Individualising end-of-life care in these terms is also something Maggie
(Palliative Specialist) mentioned as part of her aims: “I think, for the duration before
people’s death, and at the time of death, wherever possible we need to match both the
place of care and the place of death”. Maggie considered it important to allow patients to
receive treatment and ultimately die in a setting of their choice. Similarly, Jenny
(Palliative Specialist) said: “patients have better deaths if it happens where they want”.
Both Maggie and Jenny recognise that a good death is not one size fits all. Providing a
good death can be constrained by multiple factors in specific settings, where things like
privacy, time and personal control might be inhibited. Some patients want to die at home
surrounded by loved ones but others wish to die in hospital (Foreman, et al., 2006;
Palliative Care Australia, 2004), sometimes fearing they will become an emotional,
psychological or financial burden on their family (Konishi & Davis, 2001). Indeed, dying
patients frequently put the interests of their loved ones before themselves and, when
unable to, the existential suffering of some patients increases (Chochinov, et al., 1995).
However, others wish to be at home for their dying process, but in hospital for their actual deaths (Palliative Care Australia, 2004) and Gary (Palliative Specialist) said: “we try to work the system to accommodate where patients want to be”. A capacity to individualise care has important implications for a good death where, for example, appropriate and timely care goal transition from a critical/acute focus to one more palliative, or supporting dying at home, may better provide peace and comfort. Cultural and individual differences as to what constitutes a good death also need to be respected because some patients and loved ones might insist on aggressive treatment and exhausting every possible intervention, while others more readily recognise futility and advocate withdrawal.

7.3.4.1. *Existential considerations.* Most physicians considered addressing existential aspects important in a good death, with some also implicitly reflecting their personal belief structures. Physicians understood a good death as one where a sense of meaning or purpose could be found, where life was fulfilling for the patient and things they considered important were taken care of. Indeed, Robert (Palliative Specialist) said: “we help them look for what’s important to them now and after they’re gone”. Existential considerations for physicians included looking beyond the disease or symptoms and regarding the person in the bed as valuable and important, including up to the moment of and beyond death. For example, Jeremy (Palliative Specialist) identifies his care focused on the *whole person:*

I think part of helping death and dying is to recognise the person that’s in the bed, who they are, who they’ve been…but if they have been then they still are in a sense, so they are people who contributed to this world in their own way, who’ve got connections and attachments that have been meaningful, and to help them see the value that they’ve been, and that there’s a purpose, as much as that’s possible.

Jeremy emphasises that end-of-life care is about helping patients find meaning in their life and maintaining their self-worth and value, and resisting discourses and practices that dehumanise them. Palliative care embodies those ideals and goals, where empathy and dignity oriented care allow existential issues to be addressed (Chochinov, 2002, 2007;
Kissane & Yates, 2003). Jeremy earlier reported his involvement with the clergy and how it colours his views and attitudes. Thus when he talks about a “purpose” (in life and death), and “this world”, there is a suggestion that the purpose of this life might be preparation for another that follows somewhere else. Jeremy’s Christianity is influential in how he conceptualises end-of-life care and a good death.

Correspondingly, Andrew (Intensive Care Specialist) also acknowledges existential aspects: “I mean a good death in a more general sense…is like; one where you would feel that person had fulfilled his or her life”. Andrew regards a patient’s sense of fulfilment as important in defining a good death. However, in critical/acute settings such as Andrew’s, patients are often not aware they are dying (Hillman, 2009b; Redpath, 1998). Similarly, they may often be heavily sedated where cognitively they have little capacity to contemplate meaning of life, nor have time for this when intensive care, as curatively focused, often delays goal transition to palliative models of care (Seymour, 2003). An ability, therefore, to address existential needs, as important as they might be, may be determined by the setting and the patient’s condition. Certainly, spiritual guidance can be found in most medical settings and might be one way of assisting dying patients to find fulfilment or meaning. At the very least, there may be benefits for the patient’s family and loved ones.

Recognising this, physicians who considered a holistic focus important mentioned spirituality as often being central for both patients and their families. Spirituality is strongly related to the existential aspects of being and a meaning structure that can assist a good death (Braun & Zir, 2001; Flannelly, et al., 2004). Indeed, for Gary (Palliative Specialist), spiritual care may further supplement medical care focused on symptomatic issues in a more holistic approach. “Spiritual aspects might be important for some people and not others, and we certainly try and give people access to those sorts of things…access to spiritual care”. Gary considered spirituality as important for some people, which emphasises the unique but multiple requirements in end-of-life care and a capacity to recognise and provide them.
7.3.5. Healing relationships. A complex social dimension has been identified above as a crucial consideration in managing death and dying well. Social aspects weave throughout end-of-life care when communicating and providing information, or collaborating in decision making and negotiating treatment goals. Correspondingly, many physicians emphasised the importance of relationships at end-of-life. The sadness of death was tempered by positives of finding peace through strengthened relationships and, for one physician, by reaffirming those with God. Physicians often identified this time as one where estranged relationships were healed, where former conflicts were put into perspective and forgiveness took place. Families came together in the face of a common suffering and grief, and need for support, closure and acceptance. In this sense, healing relationships carried a significant existential aspect.

For example, Jeremy (Palliative Specialist) recognises existential and spiritual aspects in end-of-life care, but he also provides his particular understanding of relationships at end-of-life:

The miracles I see are not of diseases and pathologies melting away, but of relationships being restored. That’s what I see, so they have a chance to forgive those that need forgiveness, and receive forgiveness themselves…so they are at peace emotionally and spiritually.

Jeremy’s Christian views are apparent when he talks of forgiveness, spiritual peace, and miracles. He also alludes to relationships with God that might be reconciled. But he prioritises what he sees as important at end-of-life. Death cannot be avoided, but relationships can be mended and bring emotional and spiritual peace. His colleague Gary (Palliative Specialist) said this too: “you know I’ve seen many broken relationships heal…the death bed can become a place of peace”, and Robert (Palliative Specialist) similarly illustrates the importance of relationships in end-of-life care: “there might be a lot of sadness, but there can also be good things happening… relationships getting stronger in some ways, relationships that might have been estranged being healed, so there can be positive things happening”. Robert sees the sadness of death potentially
tempered by repairing relationships. In the face of death Robert, like his colleagues, talks about healing.

The key theme of “A Good Death” was identified by physicians as relating to broad reaching symptom control, planning for death and consideration of timely and appropriate care goal transition, and enhancing the capacity for communication at end-of-life. A good death was also understood as one where patients could collaboratively control decisions and outcomes as much as possible. Many physicians focused on individualising death and dying, where existential and spiritual aspects, and healing relationships were regarded with great importance.

The social nature of end-of-life care dominated throughout the key theme, with physicians describing great complexity in how they understood a good death. Again, interactive levels of influence are identified in the accounts physicians provided, with many factors affecting desired outcomes. The possibilities for negotiating good deaths in end-of-life care are also recognised as dependent on individual contexts, where the individual level of agency is also variable. Accordingly, some deaths are better than others and sometimes physicians are involved in what they consider bad deaths.

7.4. A Bad Death

Physicians often described their understanding of bad deaths with characteristics opposite to those they regarded in good deaths. For example, physicians often mentioned poor symptom control but also emphasised emotional and spiritual aspects that were frequently unrecognised or not addressed. Physicians included the distress of family and loved ones in their understanding of a bad death. Another major consideration was inadequate care goal transition where patients and families suffered unnecessarily. Sometimes existing care arrangements were inappropriate, or transfers to other units that could better manage death and dying were untimely or not considered. This was often reflective of particular settings and specialties. Indeed, professional conflict frequently underpinned problematic care goal transition and resulted in less than appropriate care
and deaths of suffering and distress. Similarly, contextual factors like *professional and other ideological impediments* influenced the care patients and their families received. Some physicians described the lack of choice that patients and families had in end-of-life care decisions as reflective of those impediments. However, *family conflicts* also influenced bad deaths where, for example, disagreement over care decisions within the family or with the physician increased and prolonged suffering and distress. A bad death was also understood as being *unfair*. Physicians strongly identified a non-acceptance of imminent death where individual patient characteristics and particularly the young age of some patients culminated in bad but also “sad” deaths. These themes are discussed in greater detail below.

### 7.4.1. Poor symptom management.

Symptomatic complexity is ubiquitous in end-of-life care (Breitbart & Alici, 2008; Sudore, Villars, & Carey, 2010). All physicians emphasised the need to engage with symptom control from multiple perspectives that included physical, psychological and emotional, and existential and spiritual components. Some physicians further considered family and others in their efforts. However such a broad reaching capacity is not always possible and subsequently influences the types of deaths patients have.

For example, Jeremy (Palliative Specialist) identified poor symptom control playing a part in bad deaths: “there are many situations that I can look back on now after 25 years in the field, where somebody has died without controlled symptoms, where we’ve thought that the death was not a good death”. Despite pharmacological advances, and his lengthy experience in the field, he talks of “many situations”, suggesting good symptom management remains problematic. Similarly, for Candice (Palliative Specialist), symptom management also included the emotional and spiritual aspects: “I guess it’s not so much the physical things that I see as symptomatic of bad deaths, but more the unaddressed emotional and spiritual needs of patients”. Candice illustrates the complexity of patient needs at end-of-life that manifest in their quality of death. Indeed, like his colleagues, Gary (Palliative Specialist) certainly recognised symptom control as crucial in
end-of-life care but also that bad deaths carry wider effects. The experience of a bad death applies not only to the patient, but also to families who bear witness to loved ones suffering uncontrolled symptoms and distress: “I guess a bad death is a death where the symptoms haven’t been controlled, and someone was uncomfortable and distressed when they were dying…and therefore they would have an unhappy family as well which is understandable”.

7.4.2. Inadequate care goal transition. Delayed transfer into appropriate care is problematic and frequently manifests in what physicians consider a bad death. Most physicians identify the problem colleagues have of accepting or recognising imminent death when they are still focused on curative strategies. Palliative specialists in particular emphasised how symptomatic expertise is sometimes lacking in other settings, or a rapidly deteriorating patient sometimes catches physicians off-guard with little time for considering and preparing other interventions. The results are sometimes considered devastating.

For example, Candice (Palliative Specialist) regarded goal transition to palliation as problematic within the medical profession: “we need greater awareness with our colleagues in other specialties who…uhm, our mind set is still so much in cure, and to make the transition to palliative care is harder”. A focus on cure that does not necessarily prioritise symptom management makes it hard for physicians to accept palliative goals, but affects the quality of dying. Similarly, her colleague Jenny (Palliative Specialist) talks about poor symptom control but particularly how it is related to untimely goal transition and transfer to expert palliation:

A bad death to me is…the dying process that hasn’t gone well, it’s been somebody who’s, either referred…late, with uncontrolled symptoms, not aware of where they’re at…they’ve either been referred because their disease has been so rapidly progressing no one’s had a chance to get on top of things, no matter how much they’ve been trying, that’s the frustrating difficult part…but the ones that stand out in distress are those who have had dreadful symptoms for quite some time…been
lying around in hospital, really suffering uncontrolled pain, dreadful symptom control and no one’s referred them until the nurse, or somebody has said…“Look, this person’s dying, can you get palliative care involved”, and you go out there and find it’s just…if they die before you get there you feel sadness…and if you get there and you just don’t have time to get it right-pain control’s not right, symptoms and the family aren’t up to speed…the whole thing’s devastating.

Jenny, like many of her colleagues, defines bad deaths in terms of poor symptom control. However, the valuable resource of time is emphasised as important in being able to get appropriate care to patients. She talks of a dying process, and as a palliative specialist this is her area of expertise. However, she confronts unhelpful institutional and professional barriers that inhibit the care patients require. Patients are often not referred to specialised care because they are not recognised as palliative, and they are often inadequately treated in the mainstream system. Being somewhat helpless when not appropriately consulted and then unable to provide timely (and holistic) assistance is something she regards as “frustratingly difficult”, “sad” and “devastating”. However, as others in her specialty have commented, her palliative expertise is frequently undervalued or even unrecognised in how it may help suffering patients.

7.4.2.1. Professional conflict. A number of physicians relate inadequate care goal transition to professional conflict. Often there is a lack of recognition in some curative settings of what palliative care can do. Sometimes it is through ignorance or personal beliefs of some physicians or professional one-upmanship that inhibits appropriate interventions or care goal transition. Palliative specialists described how they struggle to gain recognition and respect for their specialty among other colleagues. As a consequence, patients and their loved ones suffer. For example, Maggie (Palliative Specialist) makes this point: “dealing with colleagues who…really, don’t value us as a specialty and…won’t refer people who could benefit…or… ignore our expert advice when we provide it, because of their own personal beliefs or their lack of knowledge”.

Maggie describes a traditional structure that appears strongly resistant to change, lacks
recognition that death can be expertly managed, and which potentially leads to bad deaths. She adds: “I think the challenge is delivering adequate bed side care but…also keeping palliative care on the map…it seems to fall off the map on a regular basis”.

Her colleague Kerrie (Palliative Specialist) particularly identifies bad deaths due to professional conflict where the patient appears forgotten and sidelined, a situation that is sometimes worse with greater multidisciplinarity:

When there’s disagreement, between…parties involved. Sometimes, the critical and referral hospitals tend to be remarkable for the number of people, different teams involved in a person’s care…you may have five or six medical teams involved in the care of one person…this is often very confusing for families…who are struggling to understand just what the hell is going on…and those situations can be remarkable for one group saying “we must pull out” and the other group is saying “don’t be stupid, this person goes to intensive care”, and in the midst of it you might have someone with poorly controlled symptoms, who’s frightened, who’s dying, is not being expressed, patients and families don’t have freedom to discuss their wishes, their beliefs, and that can quite often be a traumatic and difficult death.

Multidisciplinarity can be useful in terms of the varied expertise it may bring for managing deaths, but it can become problematic if uncollaborative and uncoordinated in a common goal. Often such an uncoordinated approach fosters conflict between practitioners with care being compromised for patients caught in the middle. Kerrie claims bad deaths occur more in acute hospitals where expert palliative expertise is not always available or sought: “yeah, there’s been bad deaths…more so in acute hospitals…in my practice I also work there, and sometimes it’s just been chaos…and I’ve said, ‘why don’t I take this person and look after them here in the hospice’”. Kerrie identifies the dynamic of acute settings as chaotic, quite at odds with providing deaths that are peaceful.
However, she needs to be respectful of physicians in other specialties when transferring patients out of their care. She takes a swipe at colleagues from her own specialty who sometimes position themselves unhelpfully and promote further conflict: “I must say I find palliative care very annoying when they come in and rescue people from these dreadful situations, I find some clinicians can be really superior like ‘we wouldn’t do that because we’re the palliative care team’”. She identifies professional one-upmanship, noted also by other researchers (Rosenberg, 2011), which perhaps does little for the professional standing of her specialty among others, and potentially inhibits referrals. To avoid so-called bad deaths, Kerrie demonstrates agentic practices whereby using respect and appropriate language, ideologically (and practically) diverse professional structures can be successfully navigated in the interests of patient care:

It’s all about communication, saying I’m not taking this person over to the hospice to die, I’m taking them over to look after their symptoms and to settle things down, and to give everyone some time and space so that we can reconsider whether this person should come back here for more surgery, more treatment.

Above, we can see Kerrie emphasises communication and collaboration. She understands end-of-life care and hospice not necessarily as an end station, but rather a halfway house where patients might be symptomatically stabilised before receiving further treatment where appropriate. Essentially she buys time for the patient but also for physicians who may better consider their next move.

Yet, professional collaboration can be difficult when prescribed practices inhibit appropriate care goal transition. Indeed, Candice spoke about a “mind set” on cure. Physicians are sometimes influenced by the professional ideology of the setting they practice within or by institutional and administrative constraints that take control away from patients and direct the end-of-life care that is provided. Many physicians described how the gradual deterioration of patients further traps them in a situation from which there is no escape or capacity to influence the care they wish to receive. Some physicians involved in intensive medicine recognise its limitations in assisting death. For example,
Keith (Intensive Care Specialist) identifies unique contextual factors that influence patient deaths:

Whenever we go around in intensive care, nurses and doctors, we often stop and say “don’t ever let that happen to me”. So we’re pretty much on the same page, and...I can’t remember any...like excessively religious nurse or doctor in intensive care, we’re sort of...we generally feel as if the system’s taking this person too far, far, far too far; what the hell are they doing here, but it’s our job.

Keith illustrates how professional ideologies and their mandated practices, in specific settings, can inhibit provision of good deaths. In his field, patients are expected to be saved and invasive futile interventions are inflicted on dying patients who should not be there. Keith tries to position himself as a dying patient but accepts how the system influences him as an ICU practitioner; it’s his job. Again, multi-level influences emerge with professional and cultural expectations influencing care and how this may be at odds with his personal beliefs. He identifies the unique structure of intensive medicine as sometimes taking patients too far. Interestingly, when he mentions “excessively religious” nurses and doctors there is perhaps an oblique reference to sanctity of life and a suggestion that it is saved at all costs. Although a sanctity of life position does not generally advocate futile practices and unnecessary suffering (Gormally, 2004), for those holding fundamentalist religious views, suffering could be considered redemptive. Yet, the individual views physicians (or patients) hold may often only be expressed as far as prevailing ideological influences allow.

Indeed, influential setting and institutional dynamics are also reflected by Peter (General Practitioner) who understands a bad death as a sense of being trapped, without choices to direct care or end suffering:

I’ve seen plenty of bad deaths...people that have found themselves institutionalised for the management of their symptoms...and have become so incapacitated by their disease that they can’t get out of the institution...and who of
course have no option within that structure…to take steps to put an end to their suffering. So they’re effectively being kept alive, even though I suppose there’s often the situation where there’s limitations like do not resuscitate orders, but effectively they’re getting the sorts of treatments which are prolonging what they describe as their own nightmare, with no, improvement in sight…they have what they call good days and bad days but they know they’re trapped; and it’s that feeling of being trapped in a limitless and endless, ill-defined period that leads people to assume they are in an increasingly desperate situation…and as symptoms worsen they start to fall apart.

Peter describes a structure where decisional control over treatment and outcomes is out of the hands of patients, giving them no options over the timing or manner of their death. Patients are left to the mercy of an often unsympathetic medical system that is legally and ideologically constrained in allowing an elected or hastened death. He describes the “nightmare” patients endure, receiving unwanted and arguably futile interventions but, because patients have no contingency in place (or agency at that point) to put an end to their suffering, they must accept whatever the system offers. Peter also suggests the further deterioration of dying patients is influenced by an entrapping system where patients perceive no end in sight. His definition parallels other physicians’ accounts above where patients are positioned in situations that are completely inappropriate in providing good deaths and optimum end-of-life care.

7.4.2.2. Family conflict. A number of physicians further described how dying patients were sometimes at the mercy of family members who could not agree on care goals. The delay of appropriate interventions frequently prolonged and increased the suffering of patients (and indeed the conflicting family members) and signified a bad death. Family conflict often inhibited the care a physician could provide because next of kin or those with guardianship exert some authority over decision-making and physicians subsequently spend time and effort negotiating on behalf of the patient.
Providing appropriate care in a timely manner is something many physicians speak of. But physicians who might want to palliate are sometimes inhibited from doing so by the patient’s family. For example, Andrew (Intensive Care Specialist) mentioned earlier: “families don’t…accept the fact that death is inevitable…and, they keep pushing for everything to be done” while his colleague Gina-Leanne (Intensive Care Specialist) said: “families expect miracles…they bargain with you to please do more”. Similarly, Aaron (Respiratory/Thoracic Specialist) discussed poor goal transition and conflict with families in decision making as another example of what influences a bad death:

A bad death… is the situation I’ve seen quite a few times, where someone with a very poor prognosis, for example someone with end stage emphysema at home on oxygen, who is in hospital a lot, who for one reason or another we haven’t broached end-of-life issues so we don’t have a clear decision or for some reason we haven’t explored it, who comes in needs to be intubated if he’s to survive, and I want to palliate but he’s in no position to give an opinion and he has family who basically wants everything done no matter what.

Aaron emphasises the importance of communication, having the opportunity to do this, and then collaboratively arriving at appropriate care goals with a clear direction. He describes how different settings might inhibit the way he can manage a patient’s death and how decisional conflict with families in particular, can delay optimum care for their dying loved one. For example, Aaron might often only see patients in an acute situation when they are brought in by ambulance, sometimes with little capacity to communicate directly. Furthermore, when patients are admitted into emergency or acute/intensive settings, the expectation is that patients are not going to die (Curtis & Rubenfeld, 2001). Aaron shows he is sometimes influenced by the family who are still pursuing curative goals that might be futile and prolong suffering. He is compelled to manage death in ways that are anything but appropriate:

So then he gets probed, and tubed, and punctured and goes through all manner of invasive procedures when the overall prognosis is very, very poor and I don’t
think it’s appropriate but I do it because the next of kin or family wants to be as aggressive as possible for whatever reason or there may be other reasons beside the patient’s primary interests.

Aaron describes the dilemma he faces where he needs to focus on the interests of his patient but also reconcile differences with family members. Aaron needs direction and finds it tremendously difficult to act autonomously, or contrary to family wishes that are also without consensus:

Or there’s conflict within the family, like two or three people want to do this and two or three people want to do that, and that’s then tremendously difficult to deal with, and you know I think good communication’s the key. I see that as a pretty awful death when they basically go through unnecessary invasive procedures for an outcome that’s no different and they could be palliated and have a comfortable death…

Aaron’s dilemma exposes multiple levels of influence. For example, he needs to reconcile the professional (meso) considerations of a poor prognosis and the patient’s best interests, his personal (micro) views regarding what he considers “a pretty awful death”, and the views of family that might be influenced by manifold cultural (macro) and individual differences in regards to expectations and the obligation of acute medicine to save lives. This example demonstrates the complex social structures involved in one specific case and how individual care is not straight forward and general. But Aaron again emphasises the need for good communication, a problematic issue that appears with ubiquity in the literature (Back, 2004; Heaven & Maguire, 1996; Leung & Esplen, 2010; Schulman-Green, et al., 2005; Wilkinson, et al., 1999).

7.4.3. Death is unfair. The unfairness of death was mentioned by most physicians, particularly in relation to a difficulty of acceptance. Certain personal characteristics of some patients were identified by some physicians as leading to what they considered a bad death. For example, some physicians described difficult and angry
patients who would struggle and fight to their last breath and never achieve peace or acceptance. They often defined those particular deaths as reflective of the lives lead by such patients. One physician described such difficult deaths as sad rather than bad. Most other physicians identified patient age, particularly younger patients, in what they regarded as a bad death, where acceptance was just as difficult. Often their understanding reflected cultural influences and the taboo of younger people dying.

For some patients, accepting death is not easy. Some people confront death with anger and struggle to the last minute, somewhat reflecting Kübler-Ross Theory and her five stages of dying (Kübler-Ross, 1969). Candice (Palliative Specialist) believes: “some people do die angry, they don’t understand…I’ve heard it said that people die the way they have lived”. Certainly, an angry death is at odds with a peaceful one, but Candice works with this: “there are certain ways you cannot change, work with it as best you can and accept that’s the best death you might get with this person”. Jeremy (Palliative Specialist) also states: “some fight to the bitter end but, but you know fighters are allowed to fight”. He recognises the individuality of dying patients and accepts this: “as you have learnt so shall you die I suppose…we can’t correct everything, so people should be allowed to die as they lived in a sense”.

Candice and Jeremy mentioned that death sometimes reflects the life a person has lead and Kerrie (Palliative Specialist) also make this point: “you know, (laughs) people if they’re rat finks you know, throughout their lives…they’re going to be rat finks when they’re dying”. Consistent with a palliative model of care (Palliative Care Australia, 2011b), patient individuality in death is accommodated. Jenny (Palliative Specialist) also identified the difficulty of some patients accepting imminent death and described some of these bad deaths as sad deaths:

Then there are the “sad” deaths…where no matter how you prepare someone, the death is just overwhelmingly sad, and the patients themselves are not prepared and can’t accept…no matter how often you tell them what they’ve missed and they’re no longer cognitively intact to have the discussions with their family, and there’s
just…distress and sadness that is overwhelming. And then you feel…could I have made that any better for them?

Jenny talks of difficulty preparing some patients for inevitable death, who struggle with acceptance. She sometimes questions herself over outcomes, particularly when patients have lost the opportunity to say meaningful goodbyes that may bring the family together in a common goal of understanding and acceptance. However this also highlights the personal investment some physicians have for the welfare of patients. There is an emotional and psychological involvement, perhaps empathy, which is a unique but non-linear influence in the physician/patient (and family) relationship. For instance, her empathy towards patients and families may affect how they come to terms with death through her support and understanding, however, Jenny is also affected in the relationship because she later contemplates the adequacy of her care for them. She identifies their overwhelming sadness.

The unfairness of death in terms of acceptance is also identified by Robert (Palliative Specialist). He specifically mentions younger patients dying and existential issues as challenges to good deaths:

I immediately start thinking of younger people, who…were really struggling to accept, and their families struggling to accept, and also thinking of the types of patients who have unpleasant symptoms, and maybe the symptoms and the non-acceptance, sort of, comes together sometimes as an existential sort of distress, so…where there’s a lot of distress, you know, the opposite to peace, and…distress in the family as a consequence too because no one likes to see their mother or…wife or whoever you know, really distressed…so people who have tended to be younger, symptoms, existential problems.

In technologically advanced Western nations like Australia, culture and medicine tend to categorise early death as a taboo topic (Mills, 2004) and there is reluctance and discomfort discussing it (Back, et al., 2002; Back, 2004). Indeed, Aaron
(Respiratory/Thoracic Specialist) says: “it’s harder the younger a patient is because they’ve got their life ahead of them”. Robert further considers the young age of dying patients and their unpleasant symptoms as culminating in existential distress where acceptance is difficult to achieve. This may challenge patients, their families and physicians who need to work through these issues. He regards peace and distress as mutually exclusive.

However, often the age of patients directs medical care even if invasive and futile. For example, Gina-Leanne (Intensive Care Specialist) practicing in a curative setting said: “yeah, when they’re young we go all out for them”. This reflects cultural expectations, and those individually held by families and physicians, to cure the young “because it doesn’t seem right, it doesn’t seem fair, and there’s the common psychological expectation that everybody in the community lives their three score and ten years” (Robert).

The key theme “A Bad Death” was identified by physicians as often relating to factors contrary to those they understood as defining a good death. For example, poor symptom management was a major consideration. Inadequate care goal transition reflected professional and family conflicts, and particular ideological impediments that adversely influenced the types of deaths patients would have. Further reflecting multitudinal influences, some deaths, particularly for younger patients, were considered unfair. Although non-acceptance of impending death more generally was problematic, cultural taboos around younger deaths, and similar professional imperatives focused on cure, often culminated in what physicians regarded as bad deaths. The intrapsychic of physicians was demonstrated throughout the theme with empathy, but also psychological and emotional unease flavoring their accounts.

7.5. Discussion

In this chapter, a comprehensive account has been provided of the understandings and beliefs physicians hold around end-of-life care including their positions and attitudes
towards particular practices. With specific relevance to the Australian context, and both palliative and critical/acute settings, physicians frequently provided quite homogenous descriptions, but also demonstrated strong diversity in how they understand and practice end-of-life care, a diversity that is reflective of the specificity of context and a reality of no two deaths being the same.

Consistent with a critical realist and complex view of end-of-life care (discussed in Chapter 2), physicians are informed and guided by non-linear multidimensional structures that influence at macro, meso and micro levels, and which provide varying possibilities for negotiation (Munday, et al., 2003; Williams, 2003; Williams, et al., 2003). For example, political and religious doctrines inform legal and professional practices and influence personal beliefs and behaviour. Bhaskar (2011) and others (Byrne, 1998, 2005; Giddens, 1984; Mingers, 2004; Urry, 2003) emphasised the interactive nature of such structures, where individual contexts and the exercise of agency further influence in non-predictive ways, and thus adopting a systemic perspective provided a helpful explanatory framework for understanding the accounts provided by physicians. The explanatory capacity of analysis was further enhanced by also recognising an important temporal dimension, and drawing on the work of relevant theorists. For example, physicians develop their beliefs and positions around end-of-life care, and the ethical and moral compass which guides them (Kohlberg, 1969; Kohlberg, et al., 1983), across the lifespan through a range of social influences (Bronfenbrenner, 1989, 1995; Vygotsky, 1978, 1987). Direct and vicarious experience is another way of developing individual beliefs and positions on end-of-life care and demonstrates an important link between cognition and experience (Bandura, 1986). That intrapsychic link is further illustrated by influential biopsychosocial factors in the patient/physician relationship (Adler, 2007; Suchman, 2006). Importantly though, temporality and context suggests that the understandings and positions physicians hold on end-of-life care are not necessarily fixed or universal.
In the first key theme, “Control in End-of-Life Care and the Timing of Death”, physicians accounts illustrated how symptomatic complexity at end-of-life often manifested in suffering that patients, their loved ones, and physicians sought to control, both through accepted medical practices and also more permanently through practices intended to end life. This theme was illustrative of how end-of-life care is achieved through a complex interactive social structure where negotiation occurs between stakeholders with sometimes consistent, but also sometimes diverse positions, views and beliefs on how end-of-life care should be provided. Drawing on Complexity Theory (Byrne, 1998, 2005; Munday, et al., 2003; Urry, 2003) we see that even though physicians come to end-of-life care with certain beliefs; those beliefs are often expressed in a multitude of ways that do not necessarily translate into consistent practices and outcomes. Even a very clear and simple doctrine such as the sanctity of life position, which pervades political and medico/legal ideology, and is adopted by many physicians, has shown their interventions primarily designed and titrated to mitigate suffering, also sometimes hasten death.

For many physicians, religion and the sanctity of life position provided a strong moral and ethical structure which influenced their beliefs and guided their practices. Yet, these beliefs and positions, even though further validated by their professional medical ideology, especially in specialised palliative settings, were not always held rigidly. For example, some physicians who expressed strong Christian beliefs (such as Aaron) conceded that in some situations euthanasia (if legal) could be appropriate. Other physicians clearly rejected such a position, independent of their religious beliefs, and were driven by patient suffering and ideals of promoting patient autonomy and control. The excerpts in this key theme often showed physicians developing a personal ethical and moral structure that considered wide ranging factors according to specific contexts, and were not constrained in their beliefs or position on hastening death by more narrow but generalised medico/legal structures and prescriptions.
These findings suggest that even the Hippocratic Oath as the long established cornerstone of medical ethics (discussed in Chapter 4), which fundamentally rests on principles of beneficence and non-maleficence, cannot be a secure and binding ethical structure for all physicians in all situations. For example, it may be philosophically and practically flawed, and a source of dilemma when beneficence and non-maleficence could be mutually exclusive ideals. In some situations, “doing good” may mean inducing death, but this can also be seen as doing the ultimate harm. Acknowledging the flexibility of Kohlberg’s highest two stages of moral reasoning (Kohlberg, 1969; Kohlberg, et al., 1983), physicians might be encouraged to not only construct their own personally relevant Hippocratic Oath at undergraduate training, which has been suggested by some researchers (Isaacs, 2011; Veatch & Macpherson, 2010), but also further refine their ethical principles throughout their career. This may better reflect the specificity of end-of-life care.

The personal beliefs, morals and positions physicians hold, are strongly reflected in situations that hasten death. Although physicians commonly aim to address suffering, death is sometimes hastened as an unintended consequence of care and sometimes with intention. Death can be brought about through the active administration of treatments and/or their withdrawal. In such situations, the Principle of Double Effect has been useful for offering physicians legal and professional protection. Yet, as a medico/legal structure or guide, it is inadequate because it can disguise intent by those physicians manipulating end-of-life practices to bring about death. Dishonesty is encouraged rather than openness and transparency. As a narrow and generalised guide it does not consider the multiple biopsychosocial factors influencing a particular action by a physician engaged in a very specific situation. It does not consider the intrapsychic effects for physicians witnessing unremitting suffering, or the psychological and emotional pressure patients and others apply when requesting to end life.

Double effect further links with practices of sedation because death sometimes follows shortly after its administration. Indeed, Peter spoke about “slow euthanasia” and
Gina-Leanne said “dying now or in 48 hours doesn’t matter if they’re comfortable”. Yet, the expertise with its use may not be consistent across settings. For example, many Palliative Specialists detailed their practices of sedation, where the expertise with which they titrated to the symptoms was highly reflective of their specialised training. However, without expert titration, cognition and thus the communicative capacity of sedated patients may be compromised and, although some physicians in non-palliatively specialised settings ultimately develop that expertise, it may not be accessible to all physicians. Keith in ICU showed me one patient, saying: “I’ve got this guy at a nice level where he’s just out of it” but he also commented later, in relation to some of his colleagues, that: “we sedate really well in ICU; we use industrial strength doses”.

Sedation has been reported in the literature as a divisive issue (see Chapters 4 and 5) and with critical/acute settings now increasingly managing death and dying, developing expertise with sedation through training, or at least accessing expertise more readily through specialised palliative consultation, could be beneficial to patient outcomes and how physicians regard and utilise the practice. This suggests a focused resourcing requirement.

The beliefs and positions physicians held on hastening deaths emerged strongly in the accounts they provided on receiving requests to die. Requests were understood by physicians as being prompted by many reasons, reflecting the multileveled nature of end-of-life care. Patients, and loved ones on their behalf, made requests for death to gain control over the dying process or an anticipated dying process where quality of life was perceived as threatened or diminished. Some pre-emptive requests reflected cultural influences of an aging society, patient autonomy and neoliberal sentiments. The physicians’ accounts demonstrated the complexity behind many requests for a hastened death and the need for them to be competently addressed. For example, requests are often “cries for help” (Zalcberg, 1997) reflective of psychopathology. Consistent with literature (Chochinov, 2007; Chochinov, et al., 1998; Ganzini, et al., 2000; Kant, 1987; Meier, et al., 1998), many requests are underpinned by existential concerns including loss of
dignity and patient fears of becoming a burden to others. Yet, often physicians with little
or no formal psychological training need to intervene, for example, Thomas a GP said:
“often you can’t get expert psychological help and I have to be the psychologist”.
Certainly, most medical settings have access to social and pastoral workers, and specialist
palliative physicians commonly address or obtain support for patients with these issues.
But in other settings, particularly those more curatively focused, such expertise might not
be available round the clock and, in some instances, patients presenting with these issues
may not be treated if physicians are not trained in recognising such symptomatology, or
are constrained by resources. Moreover, the experience of dying often extends beyond the
immediate patient and families making requests cannot simply be ignored because
broader care requirements are not consistent with a biomedical or curative ideology.
Others around the patient suffer vicariously from witnessing their loved one’s suffering
(Bandura, 1986), often suffering more than the dying patient (Hebert, Arnold, & Schulz,
2007).

Physician understandings on requests for death are also mediated by
biopsychosocial factors that emerge in the patient/physician relationship (Adler, 2007;
Suchman, 2006) and which influence how requests are negotiated. For example, rapport
and empathy play a role, but many physicians avoid such discussion (particularly
critical/acute physicians as Keith pointed out), feeling uncomfortable and ill-equipped to
deal with requests. Indeed, Palliative Specialist Maggie said: “lots of people are fearful
when they hear patients say that, they think ‘oh they’re asking me to do something’”.
Although some physicians develop expertise with time on the job, younger more
inexperienced physicians in non-palliative settings might not effectively negotiate
requests and avoid instead. This signals a need for developing physician communication
skills and end-of-life education, and resourcing appropriate multidisciplinary expertise
across settings.

In the second key theme, when physicians described their “Understanding on
Death and Dying”, it became clear how, consistent with Sociocultural Theory (Vygotsky,
1978, 1987), their fundamental beliefs were developed across their life spans through a range of social influences. For example, Jeremy’s religiosity flowed throughout his accounts, when earlier declaring it colours his views on end-of-life care. Indeed, from parental influences at a young age (Gary similarly identified his religious family structure) religion also became a life-long vocation for Jeremy not incompatible with the Christian underpinnings of hospice and palliative work (Saunders & Baines, 1983). Robert further illustrated the intrapsychic of “direct experience” and how influentially an emotionally intimate and empathic social interaction can shape beliefs around death and dying.

For many physicians, death occurred when it was right to do so, determined by natural (and sometimes divine) causes. Accordingly, such a view was sympathetic to “allowing” death to proceed and particularly mentioned by palliative physicians with their comfort-based rather than curative focus. Certainly, (life-sustaining) treatment withdrawal occurs in critical/acute settings, but because people know why they are in palliative care there is not the heavy expectation of saving life placed on the physician. Bronfenbrenner (1989, 1995) would suggest that the macro (cultural) and meso (professional) expectations around death and dying vary by (relate to) setting or context.

All physicians mentioned the importance of the place of death, and how personal patient preferences were often met by structured impediments. Many patients wish to die at home (Abel, et al., 2011; Foreman, et al., 2006), but resourcing in terms of outreach capacity was identified (e.g. Candice) as manifestly inadequate. The meaning of death often took on an institutional flavour where cure vs. comfort ideologies determined how patients would die. Critical/acute physicians all described how their setting was inappropriate as a place of death. Yet, through expectations of cure, managing dying patients became their task by default where, rather than palliation, “cruel” interventions were sometimes inflicted on patients. A need for physician (and public) education was identified by these physicians, so that planning and discussion could allow for timely goal transition and transfer into appropriate care. Impending death is often not recognised, or it
is denied. With a system geared to delivering increasing numbers of dying patients to critical-acute settings (Hillman, 2009a, 2011), the problem of appropriately managing death is a particularly pressing matter. Appropriate care goal transition has long been problematic at end-of-life (Le & Watt, 2010; Seymour, 2003), but some consideration is now being given to address this. The recent position statement issued by Palliative Care Australia (2011b) identifies goals of making specialised palliative care more accessible across settings and increasing palliative skills for physicians (and other health workers).

Further contrasting professional ideological influences to how physicians understand death and dying, many Palliative Specialists considered dying a process of living where they focused on quality of life and providing a capacity for this. An emphasis is on the whole person, not only the disease.

Physicians also considered a greater purpose in death where, reflecting Kübler-Ross teachings (Kübler-Ross, 1969), death was considered by some as lessons for life. Physicians illustrated the complex social dynamics of the physician/patient relationship, declaring they often learnt from their patients. Organ donation was considered by some as a way of patients leaving a legacy, where death was not in vain. Yet, Australia’s small donation rate (14.9 donors per million people) by comparison to other countries, despite government initiatives designed to address this (Australian Government, 2011), may be further hindered by the prevailing “opt in” system (where one is assumed not a donor) (Johnson & Goldstein, 2003), and culturally phobic attitudes toward death (Byock, 2002).

The aversion to death and dying is similarly expressed at the professional (meso) level, where many (particularly non-palliatively specialised) physicians still regard death as medical failure. Rather than allowing death to occur, some physicians fearing litigation are compelled to practice defensive medicine (Cunningham & Wilson, 2011; Studdert, et al., 2005); to be seen as doing everything possible. Culturally phobic attitudes toward death and dying are thus further perpetuated institutionally. Also, when patients die or become terminal it may come as a shock and lead physicians to avoid. Kübler-Ross stages
of dying, particularly “denial”, apply to physicians and families as much as they do to patients.

The non-acceptance by families of imminent death was also considered problematic by physicians who considered this their failure. Setting differences again manifested where the role of specialised palliative care was to “walk alongside” and help “navigate” patients and families toward death. There was no time or any focus for this in a busy ICU. Moreover, the capacity for such care was further differentiated along professional lines with palliative physicians taking a collaborated approach with patients while, due to the technical nature of the ICU setting and physician training, care decisions were more under the exclusive control of physicians.

Multitudinal influences affecting meaning emerged strongly throughout the key theme of “A Good Death”. In many cases though, physician accounts demonstrated intrapsychic aspects, where they often regarded good deaths as to what they would want for themselves. Their beliefs were sometimes developed through vicarious means; being at the bedside and also interacting with families of dying patients (Peter’s account described being “trapped”). Thus, drawing on Bandura’s (1986) work and recognising the importance of “experience” in developing meaning was helpful in understanding the complexity of meaning presented by physicians in end-of-life care. It was important to understand what exactly constitutes a good death because physicians also often described these as something they experienced positively.

Peace and comfort overarched how physicians regarded a good death. This idea appeared strongly when considering broad-reaching symptom control that included biopsychosocial domains, and also applied to family members and significant others of the patient. A capacity for communication, closure and healing relationships, as well as providing patients with some degree of control over decisions (and sometimes the timing of death) were other crucial qualitative considerations. Similarly, individualising end-of-life care for patients, and addressing existential and spiritual aspects, also underpinned a
good death. Yet, such a holistic focus and dealing with complex symptomatology again appeared strongly regulated by institutional or setting factors.

Physicians in the critical/acute setting described Good Deaths with similarity to their specialist palliative colleagues, but they often mentioned barriers that challenged them. For example, it was difficult planning for death and appropriate goal transition when patients sometimes deteriorated quickly or, particularly when patients were comatose, their loved ones frequently pursued futile but aggressive treatment. Aaron spoke about difficulties seeking guidance on crucial decisions. His excerpts suggest the potential usefulness of Advance Care Directives (ACDs) playing a greater part in end-of-life care. This may also then inform DNR or NFR orders for paramedics and hospital “crash teams” that are obliged to resuscitate (Chen, et al., 2008). However, cultural (and professional) reluctance to discuss death and dying may be a factor in their currently limited use (Rhee, et al., 2011).

Maintaining patient awareness and cognition was another problem at end-of-life where expert titration of sedative medication was not a universal physician skill. Critical acute physicians were left with the task of expert palliation, something they said they were not trained or motivated to do. This further suggests a need for providing access to expert palliative expertise or developing these skills, particularly when patients are often inappropriately admitted to ICU (Hillman, 2009b, 2011) or retained there (Beckstrand & Kirchhoff, 2005; Seymour, 2000).

Many physicians also mentioned how important retaining control over decisions would be for their own deaths. Yet, collaboration as a palliative care ideal is often noticeably absent in the accounts of critical/acute physicians. This may well be due to the nature of their setting and also the patient types and conditions they need to deal with. However, problematic communication skills are again implicated. Keith spoke about telling “white lies”, sometimes a necessity when information cannot be delivered sensitively.
The Christian background of hospice and specialised palliative care further distinguishes from other settings by the ability to individualise care that does not medicalise patients, and allows a capacity to deal effectively with existential issues. Even though some palliative physicians do not see some social and pastoral aspects as their responsibility (Clayton, et al., 2005), “dignity oriented” care and a patient-centred approach defines specialised palliative work (Chochinov, 2002). Physicians caring for the dying in other settings are also exposed to such patient needs but, without relevant training, multidisciplinary expertise (when available) needs to be sourced elsewhere. The need for critical/acute settings to meet its changing dynamics as a place for end-of-life care is again indicated. A good death is particularly more achievable with expert palliative care (something which becomes even clearer in “bad deaths”).

In the final key theme, “A Bad Death”, physicians’ accounts frequently illustrated qualities contrary to how they understood a good death. For example, poor symptom management as well as untimely care goal transition were paramount concerns of physicians. Bad deaths were also highly contextualised by setting and influenced at multiple levels. But conflict over care decisions, both collegially and with families, reflected cultural and professional taboos and avoidance of death (Mills, 2004), especially with younger patients (Orloff & Huff, 2010). Accordingly, some bad deaths were also considered “sad” and “unfair”. The interpersonal aspect of negotiated end-of-life care was emphasised by physicians, and further illustrated by intrapsychic elements such as empathy where they sometimes developed a particular closeness with patients and patient loved ones. Gaining this understanding on bad deaths was important because they were not a localised event. Physicians also experienced them negatively.

Consistent with the critical realism of Bhaskar (2011) and others (Giddens, 1979, 1984; Lopez, 2001), contextualised social structures provide unique opportunities for exercising agency. The capacity for physicians to influence particular outcomes is not the same in each situation. For example a biomedical approach in critical/acute medicine struggles to provide for broad-reaching and complex symptomatology. Addressing
existential and wider social and emotional aspects are beyond its scope. Although physicians in these settings sometimes assist good deaths they often need to do the best with what they have (in terms of training and resources) and that is not always adequate.

The problematic nature of effective end-of-life communication and collaboration presented challenges for care goal transition. A professional lack of recognition (and ignorance) of what specialised palliative care can achieve persists despite evidence-based outcomes showing death and dying can generally be well managed (Kon & Ablin, 2010). Palliative physicians negotiating care on behalf of their patients devote much clinical time overcoming institutional barriers (and collegial conflict) to “keep their specialty on the map” and their specialist expertise valued. Often the ideological influence of “cure”, and avoidance of death and dying, poses particularly enduring obstacles for effective end-of-life care. Some critical/acute physicians recognise this, declaring ICU is not where they wish to die.

These physicians mentioned conflicts over care goals, referring to a system that took patients “too far”, where prescribed practices directed efforts focused on saving life. Some Australian critical/acute facilities are trialling structured pathway programs, like the Liverpool Care Pathway (discussed in Chapter 4), that guide end-of-life decision-making. These can minimise professional conflict, however, their use has seen some patient’s deaths being hastened (Spooner, 2010). This suggests they require further development with a capacity to individualise care, but may become useful in settings where dedicated palliative care is unavailable or difficult to access. Throughout the literature review, and in the analysis to here, an end-of-life system that generalises care has been found problematic, but in many cases such a guide may be more beneficial than not having one at all.

Moreover, effective communication conducted early in the illness trajectory was particularly emphasised by some critical/acute physicians as helpful for diffusing conflict. But, critical or emergency situations sometimes inhibited that capacity. Bad deaths were sometimes influenced by family conflict with the physician, and within families.
Pressured by families reluctant to accept impending death, some critical/acute physicians felt constrained; being compelled to pursue futile interventions despite their better judgement. Physicians like Aaron and Andrew who seek direction for the best way of providing care may find ACDs helpful (if utilised more frequently), especially in minimising conflict over discrepant care goals.

Consistent with the preceding themes, the specificity of death was reflected in how physicians regarded a bad death. Sometimes death was considered unfair. Sometimes death was considered a reflection of how life had been lived. Multiple influences affected how care could be provided and death was understood. Cultural taboos (Mills, 2004) and denial of death (Kübler-Ross, 1969), professional factors, and the micro level of patient/physician interaction (Adler, 2007; Suchman, 2006) were important explanatory considerations.

7.6. Summary

The research aims have been considered in this chapter by presenting rich descriptions of the complexity in end-of-life care meanings as they are understood by physicians in Australian critical/acute and palliative settings. At the same time, an explanatory account has been offered to better address the first part of the primary research question (and the first three supporting research questions) seeking to elicit how physicians understand and negotiate end-of-life care decisions and practices. The analysis in this chapter has thus also provided a way of understanding the corresponding ambiguity and inconsistencies physicians reported in the literature. Within this chapter, physicians have sometimes further articulated considerable personal significance by providing an emotional dimension. Their experiences, often linked to how they understand and negotiate care within influential structures, will be further explored in the next two chapters.
Chapter 8

Positive Experiences of Physicians in End-of-Life Care

In the literature review I identified a scarcity of research relating to positive aspects of physician experiences when providing end-of-life care in both critical/acute and palliative settings. This was particularly so in relation to Australia where no apposite research has been conducted. Yet, an understanding of such positive aspects has implications for enhancing physician well-being and their continued engagement with caring for the dying and their families. Identifying positive aspects of experience may balance or mediate those experiences which are more aversive. For example, supportive structures and coping strategies may be identified that physicians can draw on. Although some of these may be specific to individual physicians and settings, many may also be relevant for physicians more generally across end-of-life settings. A supported and motivated physician might also continue to bring the best possible care to those who are dying and their families.

In the current study, physicians described their positive experiences when providing end-of-life care at the bedside, but also from other aspects of their work when not directly providing care to the patient. For example, end-of-life care included interacting with families and colleagues, and conducting research, which supplemented their bedside work. For many physicians, simply being involved in end-of-life care was a positive experience for them. When reporting their positive experiences physicians identified motivating factors that prompted their initial and continued engagement with
caring for dying patients. Something about their work motivated them to go there every
day and gain great satisfaction from a career that many pursued with a great passion and
which frequently became their lifelong vocation. It was important to ascertain why some
physicians kept doing their work because, in the literature review (Chapter 5), I identified
many physicians in Australia suffering burnout and other detrimental effects (Dunwoodie
& Auret, 2007; Girgis, et al., 2009), and leaving their profession in large numbers
(Australian Medical Association, 2003; Coyne, 2011).

In this chapter, the rewarding or positive experiences of physicians providing end-
of-life care, as they reported them, are explored and detailed. It should be noted, however,
that physician experiences fell along a continuum. Sometimes their experiences were
quite neutral, and sometimes neither positive nor negative but involved aspects of both.
The physician’s experience of a particular situation could be mixed. Only their
experiences that were clearly negative or aversive were excluded from this chapter, and
subsequently examined in the next chapter. Furthermore, the palliative setting was
frequently contrasted with the critical/acute, with consideration given to the negotiated
aspects of care and physician experiences of particular decisions and practices. Different
settings often elicited different physician experiences because of different patient types
and different possibilities for negotiating end-of-life care.

The major themes of this chapter include “Privileged Relationships in End-of-Life
Care”, “Doing what they Love”, and “Doing a Good Job: Providing the Good Death”.
The first major theme centred on the quality of relationships physicians enjoyed with
patients and others. The second major theme investigated “Doing What They Love”, and
further identified what motivated physicians in their work. Physician experiences were
elicited through numerous subthemes that contrasted unique characteristics of palliative
and critical/acute settings. The final major theme centred on “Doing a Good Job:
Providing the Good Death”. Being able to personalise death and dying, and affect the
timing of death, was experienced positively by many physicians. This theme emphasised
the negotiated aspect of a good death including those practices which hastened death.
Negotiation was also considered through the autonomous and collaborated actions of physicians with dying patients who requested death.

8.1. Privileged Relationships in End-of-Life Care

The relationships physicians develop with their patients and patient families play a significant role in their experiences when providing end-of-life care (Adler, 2007; Suchman, 2006; Suchman & Matthews, 1988). Many physicians regarded these relationships as a privilege. People that receive palliative care are generally at their most vulnerable because they are confronting imminent death. Families are also often fragile not knowing what to expect, and seek support, comfort, and information (Jennings, Ryndes, D’Onofrio, & Baily, 2010). Physicians described their often intimate emotional involvement with patients and patient families and the trust they placed in the physician to help in a time of great need. Some physicians also described the sometimes enduring nature of close relationships that extend beyond death. A number of physicians also considered relationships at the professional level a privilege. Physicians enjoyed the collegial support and collaboration they found when practicing end-of-life care and that importance in terms of mentorship. It was noteworthy, however, that the types of relationships physicians considered a privilege were often characteristic of particular end-of-life settings, and they detail these differences below.

8.1.1. Trust and connecting emotionally. All palliative physicians in particular, described their relationship with patients and patient families as a significant and pleasurable emotional experience. In contrast to their critical/acute colleagues, palliative physicians frequently connected emotionally with patients and patient loved ones in a relationship of deep trust and understanding. All of these physicians felt especially privileged that they could develop such relationships in their work. Candice (Palliative Specialist) describes these relationships: “you know it’s a real privilege when patients and their families open up to us. They give us so much trust and you feel so close to them. I love that, it’s really special”. Kerrie (Palliative Specialist) also describes the closeness she develops with dying patients and their families, demonstrating that she understands the
vulnerability, fear and confusion patients and patient loved ones have: “they’re so vulnerable, often really frightened and confused…they trust us and you empathise…you understand them. You can’t help but get close sometimes, and that’s such a lovely part of my work”. Similarly, when talking of a collaborative relationship in end-of-life care, Robert (Palliative Specialist) illustrates interpersonal connections where he is “taken into” the family; trustingly accepted as one of their own: “you get great satisfaction, when people can be cared for by their family…they’re surrounded by love, in their own environment…its, quite moving…and quite a privilege to be taken into that family situation, being trusted and seen as a guide”. A critical realist ontology (discussed at length in Chapter 2) recognises that there are many potential context specific identities and roles that physicians may take up (Bhaskar, 2011, p. 171; Rorty, 1980, pp. 361-362). Indeed, Robert mentions the satisfaction he feels being intimately involved in the role of “trusted guide” and assisting families to look after their dying loved one at home. He describes the environment as one of love, where he feels privileged and moved, and closeness with the family. Through empathy, a connection forms that fosters trust and understanding, and a growing emotional attachment.

The experience of empathic “connections” is sometimes mixed, encompassing both sad and happy elements, particularly when death occurs. These are profound experiences for Robert and not unpleasant. He sees death as an important milestone in the family, feeling a “sense of the moment”. He identifies intrapsychic elements where he is moved when he “sees the emotion in the family”; there is an empathic experience he regards with fondness: “it can be quite emotional, because you see the emotion in the family, there’s emotion here but it’s not happiness, it’s not sadness, it’s…moving, like you feel the…sense of the moment, it’s a profound, important milestone in the family”. Robert describes the mixed emotions at the bedside of a deceased patient where the family might have a bit of a joke interspersed with tears: “people can actually be joking around the dead body and having a bit of a laugh…being light as well, you know, they might have tears in their eyes, one second and having a bit of a joke the next”.
Often bonding takes place through the intimate involvement with families at such a special moment in their lives, and Robert illustrates the ideology of palliative care that allows physicians to become deeply involved in what are often very private and personal (sometimes traumatic) family affairs: “it’s lovely being part of those situations, where you enter into a family…you empathise…you feel like you’re part of something special, that special moment in people’s lives….there’s a certain bonding around that experience that’s very, very rewarding in our work”. Similarly illustrating the palliative ideology, Gary (Palliative Specialist) also regards developing good relationships with patients and their loved ones as integral to his role in end-of-life care and is something he enjoys:

You really meet some lovely people in this job, and…in a sense it’s very different to, you know, other aspects of medicine because there’s a real emotional intimacy to what we are doing…you’re looking people in the eye and telling them that they’re dying and, explain what is going to happen to them and how we’re going to manage that and answer their questions, and so it’s…I guess…for me it’s a great privilege to be able to do that for people.

Gary talks of meeting some really nice people in his job, but characterises the relationships developed in his specialty as ones with “real emotional intimacy”. Looking somebody in the eye and telling them they are dying is often quite disconcerting for physicians outside of dedicated end-of-life care settings (Ahern, Doyle, Marquis, Lesk, & Skrobik, 2012; Back, 2004; Hancock, et al., 2007; Moreno-Jiménez, et al., 2008; Steinhauser et al., 2001) but Gary regards it a great privilege to be able to do that, to gain their trust and provide the information they require and inform them of how he is able to care for them. He also identifies the psychological and emotional influences at work in his close relationship with patients and their family at end-of-life, which act in a bidirectional (non-linear) fashion:

You reveal something of yourself to them and their family because their feelings are exposed to you, so…it’s very hard to just stand there and take it all in and give
nothing back…especially when death occurs…it enhances the relationship if it’s not just a medical one but a personal one as well.

Patients and their families expose their feelings to Gary and he reciprocates. He talks of relationship characteristics in terms of professional meso and personal micro structures. Specifically, he believes the professional relationship is enhanced when supplemented with personal aspects, and finds it hard not to give something back.

Maggie (Palliative Specialist) also highlights the emotional intimacy that Gary identifies in physician/patient relationships. Like Gary, Maggie similarly considers relationships important in her provision of care, and also describes the directness of patients and the confidence they place in her. They are very personal and private conversations: “it’s certainly…a privilege when they confide their thoughts and wishes in you…they’re very direct…I mean when people ask you very directly how long they have to live, often they’re very direct, private conversations”. Maggie enjoys the privileged relationships that are part of specialised end-of-life care and which foster opportunities for resolving the issues that are concerning for patients. She reflects the micro level of personal relationships and also the meso level of evidence-based or guideline-directed care when talking of “ticking all the boxes”; “when you can have that confidential conversation…one-on-one…and work through that…respectfully…it’s important in the care you provide…when you can tick all the boxes…and resolve these issues for patients…it’s a good feeling you get at the end of the day…yeah”.

8.1.2. Enduring relationships. Many palliative physicians and one general practitioner also mentioned relationships that endured, sometimes beyond death. For palliative physicians especially, getting to know patients and their families with some depth was considered ideal but not always possible. Such relationships were nurtured by physicians but were subject to individual dynamics and context. No physicians in the critical/acute setting mentioned relationships of this type, possibly reflecting the technical, busy and often transient nature of their setting.
Illustrating the characteristics of his setting, Gary (Palliative Specialist) described making time for the loved ones of dying patients he had treated:

This morning I ran into someone visiting a patient…I looked after her husband three years ago, and someone was in just recently that died, but the family were in saying hello so you stop and have a chat, you can’t just walk past them…which is really lovely…and you make time for that.

Gary identifies a small network of interconnected patients, where he assists the dying process for a number of different family members. He finds it lovely that the families of deceased patients continue to visit, stop and say hello. Jenny (Palliative Specialist) noted this too: “I love when a family member still drops in to say hi or sends a card or even just flowers to the ward…some relationships are special and really last”. Similarly, Thomas (General Practitioner) also regards the relationships that endure after death as “special”, saying that: “as a GP you develop a relationship with families often over many years, and these continue…and strengthen even when someone dies. Your relationship with the family gets closer and I love how you become part of that…it’s special”. The relationship between physician and the family does not end when the patient dies; in fact it often strengthens, with Thomas taking up the common and somewhat traditional identity of trusted family doctor.

Sometimes, opportunities to develop ongoing or deep relationships are not always possible, but short relationships are still considered worth pursuing even if not quite as satisfying. Jeremy (Palliative Specialist) enjoys close relationships with the dying and their families, considering them ideal in end-of-life care, but some are only brief: “some we get to know very well and have a very close relationship with…others we only know very briefly…we don’t have the advantage of forming a decent relationship and a depth of trust, which is what ideally we’d like”. Jeremy identifies relationships as important for developing trust and how time is a crucial element in that goal. However, forming relationships is not always straight forward: “we still get late referrals and appropriate referrals, but where possible we like to have a chance get to know people in some depth,
as much as they will allow, and as much as is appropriate”. Jeremy enjoys getting to know people but acknowledges professional (meso level) constraints, where referrals might not be timely enough to develop depth in a relationship. He also identifies (micro) interpersonal aspects where patients, even if appropriately referred, might not allow such a relationship to occur, and then only as much as is befitting. The element of trust is crucial in enhancing end-of-life care (Chochinov, 2007; Heyland et al., 2006) because it underpins collaboration but it develops in a unique relationship of rapport and empathy.

8.1.3. Professional relationships. Although some palliative physicians spoke about relationships at the professional level which they considered a privilege, these relationships were particularly emphasised by all physicians engaged with critical/acute settings. Relationships were sometimes described as “life changing” but more often reflected a supportive network of physicians reliant on each other. Team work was a characteristic of professional relationships.

Important professional relationships are not only experienced positively at the bedside when working directly with patients and patient families, but can also be quite positive in a mentoring and training context. Jeremy (Palliative Specialist) talks about professional relationships that were formative moments in his medical career with end-of-life care:

I’ve been lucky to have spent some time with the giants of palliative medicine…and some of the earlier hospice people who have written some of the foundational work in palliative medicine…which was life-changing for me. It’s been interesting and a privilege to know some of these people.

Jeremy’s career has taken him on an interesting path where he has worked with some of the luminaries in hospice and palliative medicine. Those experiences were life changing for him and he considers himself lucky and privileged. Learning from the “giants” in palliative care has been influential in how Jeremy engages with (and subsequently experiences) the specialty. Good mentoring experiences, through observational learning
and receiving helpful instruction, are known to enhance self-efficacy and competency (Bandura, 1997b), and motivate sustained goals that are experienced enjoyably (Bandura, 1991a; Bandura & Cervone, 1983).

Relationships at the professional level may also be important in providing optimum end-of-life care by translating into a supportive and informative professional network. Physicians and other professionals may learn from each other. For example, Andrew (Intensive Care Specialist) said: “there are many professionals involved with those we can cure…and those we can’t…you meet people from all walks of life with different expertise and you learn so much from them…like our meeting today for example”. Similarly, Keith (Intensive Care Specialist) discusses the beneficial relationships he has with colleagues such as nurses:

Especially over the last ten years with dying, I think I do make a difference, and it’s interesting that a lot of the nurses wait until I’m on now, so that I can handle those issues [death and dying in ICU]…but I’m lucky, I think I’ve learned a lot from them as well…and from listening to relatives, reading their response, trying to pick up…different ways of delivering the same message.

Experience can be a great teacher and Keith articulates how he has learnt much over a ten year period increasingly focused toward “dying”. However, as much as nurses are guided by his expertise, Keith also considers himself lucky to learn from them. He identifies an important bidirectional relationship where he picks up a lot from nurses. They are a valuable resource when they are often longer at the bedside and deal more frequently with families than physicians do (Seymour, 2003). Experience with social influences of patients, families and other professionals are formative in developing expertise that Keith adapts to each situation, and helps him “make a difference”.

Like her colleagues above, Gina-Leanne (Intensive Care Specialist) also identified the importance she places on good professional relationships:
I also love…it’s a team, very much team work…there’s you and the nurses and the registrars and the physios and the OTs and…you’re all working with the same aim of getting the patient better, as much as that’s possible…I have some great colleagues, I think in intensive care you’re very dependent on your colleagues because you take over from each other all the time…uhm, I have some great people that I work with.

Gina-Leanne emphasised the importance of team work and the dependence of each person on the other. She talks about great colleagues working toward a common goal of “getting the patient better”, albeit “as much as that’s possible”. Certainly, she identifies the multidisciplinary nature of ICU and its curative focus, but ICU is recognised as increasingly taking on the end-of-life care role (Hillman, 2009a, 2011; McKeown, et al., 2011; Seymour, 2001) where curing dying patients symptomatically is just as important as for those who are not dying.

It is noteworthy in this key theme that only specialist palliative physicians reported connecting emotionally with patients and patient families, and the positive experience they gained from this. By contrast, when physicians that were engaged with critical/acute settings spoke about similar emotional aspects when providing end-of-life care, they described their experiences with dying patients and others in terms of emotional burden and identification, and distinctly negative. The critical/acute environment has been identified as incompatible with developing deep relationships, often emphasising clinical objectivity and distance, and inadequate for providing end-of-life care (Curtis & Rubenfeld, 2001; Curtis & Vincent, 2010; Seymour, 2000, 2003). Patients are often uncommunicative, and the ideology of cure with its biomedical focus does not provide the capacity for a depth of relationships. Patients are expected to leave. Accordingly, relationships of an enduring nature with patient families were not reported by these physicians. However, all critical/acute physicians regarded good professional relationships among colleagues as important to them and something they enjoyed.

Palliative physicians also regarded professional relationships important but, with some
contrast to their critical/acute colleagues, often experienced cross-disciplinary relationships quite negatively. They often needed to overcome barriers such as lack of professional recognition. The negative experiences mentioned here are examined in the following chapter.

Maslow’s (1943, 1987) work shows us (through a hierarchically structured needs-based approach) that physicians are drawn toward particular relationships. Broadly speaking, the close, empathic and often enduring relationships physicians enjoy provide the physician with a sense of belonging and affiliation with others. We particularly saw this with Robert and Thomas who became “part” of the patient’s family; but all of the palliative specialists sought and enjoyed very close relationships with patients and patient families. Further, these relationships and those at a professional and collegial level provide esteem needs of achievement, competency and recognition, while also satisfying cognitive needs of understanding and knowledge through mentorship. Indeed, all of the critical/acute physicians spoke of collaborating with and learning from a multidisciplinary range of colleagues, and achieving common goals.

The work of Bandura (1986, 1991a, 1997a) and others (Bandura, Caprara, Barbaranelli, Gerbino, & Pastorelli, 2003; Caprara, 2002; Caprara et al., 1998) on “empathic self-efficacy” further highlights how some physicians with a capacity to regulate their emotions may actually pursue and enjoy close empathic relationships with dying patients and others. Palliative care becomes their lifelong vocation. For example, many of these physicians spoke about emotional and interpersonal aspects as “lovely” and “special” in their work; indeed Robert spoke of being “moved” and experiencing “mixed emotions”. With some complexity, emotional self-efficacy combines with interpersonal self-efficacy to determine prosocial behaviour and empathic engagement, which in turn influences satisfaction (Caprara & Steca, 2005; Guido, Caprara, Eisenberg, & Steca, 2009). On the other hand, physicians who avoid such relationships and find dealing with death and dying uncomfortable may lack competency or desire for developing empathic self-efficacy (Heuven, Bakker, Schaufeli, & Huisman, 2006). Accordingly, they may be
motivated to practice critical/acute medicine where they gain greater satisfaction (and clinical self-efficacy) from the professional relationships they can draw on and achievement goals oriented toward saving life. The following key theme will further consider these assumptions.

8.2. Doing What They Love

All physicians were motivated by doing what they love. Some were motivated to help suffering, some through personal interests and others by challenges. All of these motivating aspects were experienced positively by physicians. Many mentioned how they “loved” coming to work each day. Satisfaction and enjoyment promoted initial and continued engagement in their particular medical specialty. For example, the individual settings that physicians practiced from carried distinct attractions that allowed them to experience the care they provided rewardingly. This major theme, through its subthemes, captured those intricacies with physicians contrasting critical/acute and palliative settings when describing what they love doing.

In contrast to their critical/acute colleagues, “helping others and making a difference” was characteristic in the positive experiences reported by almost all palliative specialists. A sense of altruism flowed through this subtheme, and strongly highlighted palliative ideals of empathy and an ability to provide a comfort approach to care (Deebs, 2010; Jakobsson, et al., 2007; Waldrop & Kirkendall, 2009). For palliative physicians, the capacity to practice “holistically focused care” was a motivating factor for their entry into specialised palliative care and a factor in their continued enjoyment caring for the dying and their loved ones.

Other aspects like “technology” and rapid results were considered particularly attractive by all critical/acute physicians, but some palliative physicians also mentioned using less invasive technologies as something that assisted greatly in their work. These physicians challenged the traditional perception of palliative care being technology free in its comfort-based approach. Many physicians also regarded the “intellectual challenges of
complex illness” as something they enjoyed. Illness complexity is often representative at end-of-life (Munday, et al., 2003) and all palliative physicians found the multiple domains of illness expression as challenges they willingly pursued. A biopsychosocial and holistic focus to care that also considered patient loved ones in its scope was frequently supported by “research interests”. This was another motivating factor for these physicians who expressed a particular passion for end-of-life care. A number of other physicians also identified particular challenges that motivated their continued engagement with dying and critical patients. For example, most critical/acute physicians found the “uncertainty of intensive medicine” particularly appealing. Unlike the palliative setting where patients are recognised as dying, diagnostic and prognostic uncertainty was regarded as enjoyable by critical/acute physicians. Some reported taking a detective role and dealing with rapid day-to-day changes, and another found fundamental ideological changes appealing.

Many physicians, regardless of specialty, spoke about the enjoyment they gained from their work, and often considered themselves fortunate to be able to do something they loved. For example, Gina-Leanne (Intensive Care Specialist) describes her work as a labour of love: “I guess that’s where most, some of us at least have been very fortunate…that we have a job that we love”. She considers herself fortunate to do something that is personally enjoyable; something that she implies is perhaps elusive for many others. Keith (Intensive Care Specialist) also loves coming to work each day: “I’m enjoying what I’m doing, you know, and… I can come to work and do a job I love, how good’s that”? When I then asked Keith if a perception of making a difference was also something that motivated him, he acknowledged that but described more self-interested reasons for entering into medicine: “I don’t know, I think I am, but I don’t, well…yeah, I think that’s important as well…but I’m not, I’ve never kidded myself that I did medicine to help others, I did medicine because I love doing it [laughs]”. Then with intended humour: “yeah and if other people benefit, that’s a side effect”. Making a difference is important, albeit a fortunate by-product for those who might benefit, but Keith suggests he is not motivated altruistically in practicing medicine. He just loves doing it.
Like their critical/acute colleagues above, physicians engaged with specialised palliative care also described their motivations for entering (and staying in) their chosen profession. For example, Robert (Palliative Specialist) explains his somewhat unplanned entry into palliative care: “I got swept up into hospice care”. As if going along for the ride, it appears hospice work might have found him, sweeping him up. But hospice care, that also engaged his academic and research interests, was something Robert was also well suited to:

Enjoyed the work and people said you’re good at this, you should keep doing it.
So I was encouraged to keep doing it and kind of fell in to it and ah [chuckles] have stayed in the field ever since, with study and research along the way. Really fell into the work.

Robert says he “fell into the work” indicating that the field of end-of-life care was something that emerged rather than stemming from some long-held ambition. He mentions his enjoyment and expertise, something noticed by colleagues who encouraged him to continue, while Maggie (Palliative Specialist) describes how palliative care was a long held interest of hers that she still loves “doing”: “even when I was much younger…still at school, a neighbour and friend was a nurse working in palliative care and I’ve had an interest in this kind of medicine ever since, and love doing it”.

8.2.1. Helping others and making a difference. Although some physicians described a personal interest for practicing medicine, most palliative physicians also described being motivated by passion and a privilege of helping others, and seeing their efforts “make a difference” to those that were dying and their loved ones. In that context, some physicians spoke about “getting it right” and the pleasure that brings for them. The ideology of palliative care supports a focus on individualised care (Palliative Care Australia, 2004, 2011a) , where getting it right and making a difference (according to patients wishes) is particularly possible.
Kerrie (Palliative Specialist) speaks glowingly about her specialty and of the pleasure end-of-life care brings her:

I know it’s corny but I feel very privileged working with very vulnerable populations because it’s amazing how people open up to us and, tell us their fears and dreams, and sometimes...we actually...get things very right for people...and that’s a pleasure, there’s a lot of humour, there’s a lot of sadness, it’s a very nice area of medicine to work within if one’s prepared to jump in and be with people, and be with other staff members as well.

Kerrie talks about mixed emotions but also that end-of-life care is a nice area to work in. She reflects the palliative discourse of “being with” people and how this is a privilege for her. Close relationships, both collegially and with very vulnerable populations are something she emphasises, highlighting the crucial interpersonal aspects of caring at end-of-life. Alluding to individualised care, she talks about “sometimes actually getting it right” for dying patients, implying perhaps that other areas of medicine with different priorities might not be as successful at this. When she talks about “jumping in” she further contrasts palliative physicians with those physicians who have an aversion to death and dying, and avoid instead. Likewise, her colleague Candice (Palliative Specialist) identifies similar rewards in practicing palliative care which motivate her to stay: “you know it’s a very rewarding job and I guess this is why I’ve stayed in palliative care, because we make a difference…yeah”. She sees a positive result for her efforts, believing she is making a difference. Candice also considers herself a supportive companion of dying patients. Such roles are promoted by the palliative ideology where patients do not experience death or its journey without caring support: “it’s...letting them come to a place of calm rather than, you know walking the walk with them rather than for them...just being by their side, being a companion…it’s very rewarding to feel you’ve made a difference…a real bonus”. Candice talks of “being by their side”, allowing rather than directing patients to find their place of calm. The collaborative but considerable patient-directed focus of palliative care becomes evident and allows recognition of patient
individuality. She finds that a very rewarding aspect of her work, a real bonus, because she feels she has made a difference in their lives.

Like his colleagues above who talk of “jumping in” and “being with people”, Jeremy (Palliative Specialist) identifies a personal interest in the welfare of others as motivating his career in end-of-life care: “I guess I’ve always had an interest in the care of people, and a passionate interest in the pharmacology and therapeutics of symptom control”. Although a personal interest, it is one he focuses on caring for others. Jeremy is also passionate about symptom control, something that is integral to specialised end-of-life care where multidimensional comorbidity and complexity are characteristic of illness.

Notably, this theme was not reflected in any of the reports by critical/acute physicians. Certainly these specialists also make a difference to the lives of others. This omission in their accounts may be suggestive of the clinical objectivity and personal distance expected of these physicians by their specialty and its rather strict biomedical focus.

8.2.1.1. Holistically focused care. The complexity involved in individualised end-of-life care is best managed by a focus that includes multidimensional aspects (Munday, et al., 2003; Palliative Care Australia, 2011a; Williams, 2003; Williams, et al., 2003). A holistic focus is synonymous with specialised palliative care and something emphasised by all of these physicians in the end-of-life care they provided, but also mentioned as strongly motivating a number of them into a career in the specialty. For example, as Jenny (Palliative Specialist) says:

I thought I could do it. And I’m very much interested in providing care for the whole person no matter where they’re going with their disease, and I felt that palliative care really provided that opportunity…it interested me and I went with it, and I enjoy it.

She describes an element of self-confidence in her ability but also that palliative care as a specialty facilitated her medical interests by providing a way of caring for the “whole
person”. This contrasts with single organ specialists and other physicians working in settings with a more biomedical focus, something which was not unnoticed by Jeremy (Palliative Specialist) who said: “you know we don’t look after diseases on legs...there’s a person there. That’s where the focus should be. This type of specialised care is a complete package and I wouldn’t enjoy doing anything else”.

Similarly, Kerrie (Palliative Specialist) describes her motivation for practicing palliative care. She talks about being intrigued with a multidisciplinary field of medicine that could provide individualised care: “my first experience…as a medical practitioner in palliative care…actually as a medical student was when…I was intrigued by this, this concept that a multidisciplinary team could provide care for one individual”. The notion of team work focused on one individual has parallels with Gina-Leanne’s description of ICU dynamics but, perhaps contrastingly, is more holistically focused than critical medicine can be. For example, broader psychosocial considerations are reflective of palliative care goals, where physicians also have a highly empathic engagement with dying patients and their families.

8.2.2. Technology. One important component of a holistic focus to care can be the use of technology. A patient’s illness and symptom management at end-of-life may be assisted by technology that enhances patient comfort and informs difficult and complex treatment decisions. Vital signs may be accurately monitored, medication may be titrated, and appropriate equipment may be prescribed that can ease a patient’s suffering. Diagnostic technology can assist physicians making decisions that may affect the quality of life and progress of a patient’s dying process.

Technology is noticeably characteristic of critical/acute settings where particularly intensive medicine is recognised as expensive and highly technical (Curtis & Rubenfeld, 2001; Seymour, 2000, 2003). Regardless of whether patients were imminently dying or not, all physicians in these settings regarded their experience with technology and the expertise available in highly positive terms. They could often produce rapid results for patients. Indeed Aaron (Respiratory/Thoracic Specialist) makes these points, talking
approvingly about the technology in critical/acute medicine: “we’ve got great technology, great colleagues and great drugs. With things like breathlessness for example we can jump on it very quickly”. Aaron mentions breathlessness which is a common, often comorbid, illness at end-of-life but how he can attend to it very effectively through access to “great” resources. Patients in ICU are often intubated and ventilated, and sedated to some extent. Similarly, Gina-Leanne (Intensive Care Specialist) describes the unique appeal intensive medicine holds for her, with technology and rapid results as central aspects:

Lots of nice machines that go beep and ping and…yeah, I think that’s probably the main thing, you can do things instantly, like when you’re a physician and somebody’s got high blood pressure you give them a tablet and see them in a fortnight’s time…you know, if you’re with me and you’ve got high blood pressure stuff me I’ve fixed it in five minutes.

Gina-Leanne describes the instant gratification of intensive medicine where, unlike general practice, results are often seen quite quickly. She considers the technological support she can access as “nice”. Gina-Leanne talks of “fixing it”, but it should be remembered that not all patients will be cured in intensive care and dying patients also get high blood pressure and other symptoms that need to be managed rapidly (Curtis & Rubenfeld, 2005).

Another physician, Andrew (Intensive Care Specialist), recognises the sometimes invasive nature of technology in end-of-life care but considers it “great” in helping him stabilise patients for transfer: “the technology can be invasive sometimes but it’s great for me in stabilising some patients who had a very acute episode and then try to transfer them into palliation”. In the literature I reviewed, it became apparent that many patients die in critical/acute settings, often from an acute episode of a chronic condition (Curtis & Rubenfeld, 2005; Hillman, 2009b). The process of emergency care, from home to the hospital, is one of continual handover by medical teams until patients ultimately arrive
(sometimes staying) in ICU (Hillman, 2009a, 2011). Andrew talks of “trying” to transfer them into palliation, as if recognising that ICU is not an appropriate place to die.

Certainly, technology is a defining characteristic of critical/acute medicine. Those physicians have great expertise in its use, albeit primarily oriented toward saving life. However, some physicians in palliative settings who emphasised a comfort-based approach did not dismiss the importance of appropriate technology in the interests of symptom control and diagnostics. For example, Candice (Palliative Specialist) said: “I like the simple things like pain pumps that give some control to the patient for regulating their medication”; and Maggie (Palliative Specialist) will not let patients suffer urinary retention at end-of-life just because of a palliative ideology supporting an aversion to technology:

If you have urinary retention it makes no logical sense not to use a catheter to relieve that symptom, I think it’s a silly argument to say that an IUC is invasive and they’re dying, but urinary retention is worse, an awful thing to experience, and if we have the technological ability to relieve that suffering by using a piece of equipment, we should be using it…palliative care shouldn’t be completely technology free and I’m really glad I have it when I need it.

She is glad to access appropriate technology when she needs to, particularly to address patient suffering. Without technology, her experience of end-of-life care with some patients would not be so positive if she were compelled to address “awful” suffering by less efficient means.

Technology can also be helpful in making decisions that may affect the timing of death. Indeed, Gary (Palliative Specialist) will prescribe imaging to assist diagnostic efforts and treatment decisions. “I find MRIs and X-rays really helpful in deciding on the, you know, the management plan which could include not treating certain things to allow someone to pass away more quickly”. Similarly, Kerrie (Palliative Specialist) finds

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7 Intraurethral catheter
imaging technology almost indispensable in diagnosis particularly for patients with suspected spinal cord compression: “with cancer mets, many patients get spinal compression and MRIs are great for helping me decide on whether radio, or physio, or pain relief is the way to go...I feel better when my decisions are well-informed”. Although oriented in a comfort care approach, Kerrie considers technology “great” in assisting difficult treatment decisions that may affect patient comfort.

### 8.2.3. Intellectual challenges of complex illness.

End-of-life care is regarded as complex (de Jonge, Huyse, & Stiefel, 2006; Munday, et al., 2003) with interactive biopsychosocial considerations unique to each patient and each context (Adler, 2007; Engel, 1977, 1980). Such considerations extend beyond the patient to include patient loved ones and others, and characterise specialised palliative care. Most palliative physicians were attracted to the specialty by the challenges of complex illness and the need for very specialised medicine. The challenge was regarded as enjoyable, particularly when also coupled with a research component that has advanced their specialty and resulted in “some beautiful work being done”.

Maggie (Palliative Specialist) describes being attracted to palliative care through the intellectual challenges posed by complexity in illness: “I love the intellectual challenge of complex medicine, not just the complex physical aspects of illness...for someone with multiple illnesses, all the domains and how that changes over time...that partly attracted me to physician training in the first place”. She talks about multiple domains and change, which highlight complexity and emergence in end-of-life care. Co-morbidity of illness is common at end-of-life (McKeown, et al., 2011; Palliative Care Australia, 2011b) and often expressed across biopsychosocial domains. This is also recognised by Candice (Palliative Specialist) who identifies the common characteristic of her patients as sufferers of cancer, particularly in terms of symptomatic complexity, but how she can help their dying process:

I guess most of my patients are cancer patients and...the oncologist would have said to them “there is nothing more any of us can do, we cannot operate, give
chemotherapy give radiotherapy, you’re going to die and this is how much time statistically you have”, and so you get someone who is very…fearful, someone who…doesn’t know what’s going to happen next, and I guess as you walk the journey with them and you alleviate their symptoms physically, physical and emotional, it’s you know, it’s very rewarding to take…all that fear, and unpleasantness away.

Candice discusses how patients are transferred into her care after being told they will die and that there are no more curative options available. Some patients are often fearful, uncertain and still suffer significant physical and emotional symptoms, but she addresses those issues for patients and, drawing on the palliative care discourse, “walks the journey” beside them. As a supportive companion she finds it very rewarding to be able to alleviate the fear and unpleasantness dying patients are experiencing. Similarly recognising such multilevel care requirements, Kerrie (Palliative Specialist) identifies how well positioned palliative care is in looking after the dying, finding it exciting to be involved in a progressive field of medicine: “really beautiful work is being done in symptom control and the optimum way to provide care; it’s a very exciting time to be in palliative care”.

8.2.3.1. Research and academic interest. Kerrie alluded to research that underpins advancing clinical practice and Robert also mentioned earlier that he conducted “study and research along the way”. This is something that most palliative specialists were involved in and something they regarded quite positively. Although most critical/acute physicians also had an active research and academic side to their medical career, only the palliative physicians devoted attention to this topic in their interviews. This may have been due to the importance they placed in research for gaining recognition and credibility within the medical community as a relatively new stand-alone specialty (Australasian Chapter of Palliative Medicine, 2011), and further developing specialised expertise dedicated to end-of-life care.

Maggie (Palliative Specialist) pursues intellectual challenges through research and academic interests which complement her clinical work: “I think the academic work…is
what is actually sustaining my clinical practice…I wouldn’t have it any other way”.
Maggie suggests research and clinical practice are somewhat symbiotic, where one informs the other. Research into end-of-life care is something Maggie finds pleasure in: “when I’m writing papers at night I enjoy that”. Similarly, Jenny (Palliative Specialist) said: “I like the balance that research brings to my clinical work”; while Candice (Palliative Specialist) also regards the increasing research being done in her field as very stimulating: “it’s also very stimulating, you know it’s, an area of medicine where you’re only starting to do quite a lot of research”. As a relatively new specialty, palliative care is making great strides in helping those that are dying and their loved ones through empirically supported practices. My review of the academic literature showed end-of-life research growing at a rapid rate.

8.2.3.2. The uncertainty of intensive medicine. The complexity in end-of-life care, regardless of the setting, presents physicians with specific challenges. In Australia and elsewhere, intensive and critical/acute medicine is undergoing an ideological shift where it is now more frequently becoming a setting for end-of-life care (Angus, et al., 2004; Curtis & Rubenfeld, 2005; Hillman, 2011; McKeown, et al., 2011; Meier & Beresford, 2006). Accordingly, physicians trained in saving life are now more frequently managing death and dying. Most critical/acute physicians reported great uncertainty as a challenge that strongly motivated them in their specialty. Uncertainty was something they looked forward to and change was not necessarily a bad thing. Day-to-day change, considered more as variety, was enjoyable as were the more enduring or structural changes at an ideological level.

Gina-Leanne (Intensive Care Specialist) particularly loves the mystery of intensive medicine; being motivated by uncertainty and a sleuthing or detective role: “the best part about the job is it’s like a detective novel, you know, the patient comes in and they’ve got all this conglomerate of signs and symptoms, often hardly any history, and coming up with a diagnosis”. Gina-Leanne regards her job as something of a detective novel with the
diagnosis as the end of an investigative puzzle, something I then suggested seemed like a Sherlock Holmes thing:

Yeah it is I’m a great Sherlock Holmes fan, I love getting a new patient without much history but with a whole bunch of signs, and a whole bunch of blood tests, and then…apply all the stuff that you’ve learnt and come up with the answer, you go “bloody hell that was good, right where’s the next one?”…that’s what I love.

She talks about applying what she has learnt, observing and conducting tests and putting it all together to find the answer. She especially loves the diagnostic challenges presented by some patients. The lack of history she mentions may be due to her patient demographic, where patients are often brought in because of an emergency or acute situation. Contrastingly, palliative patients often have a recognised diagnosis of dying with a history of illness progression. However, both settings admit patients with life threatening conditions that present symptomatic complexity and diagnostic challenges (de Jonge, et al., 2006).

Indeed, Aaron (Respiratory/Thoracic Specialist) said: “even if they’re dying, it’s really satisfying when you get someone presenting with really challenging symptoms, working your way through them, and getting a good result…there’s always something unknown and different happening in here”. Similarly, Andrew (Intensive Care Specialist) finds uncertainty and the rapid, day-to-day changes particularly appealing: “the best part of my job is, not any day is like the other, it’s always changing…it’s, you know you meet people from…all ways of life…some die and some get better, and it’s young people old people…”. He highlights a particularly social environment of patients, families and a diversity of professionals: “you meet all kinds of specialists and researchers too so it’s not just you know…you get to meet…quite a few people that have experiences in, and expertise in fields that you, might not even know existed”. A day in intensive care is like an experience of discovery, where he engages enthusiastically with the unique social experiences and considers “complete disasters” an enjoyable challenge rather than something to be avoided: “I’d say the greatest thing is not knowing what your day is
going to be like, you can have it very, very quiet in the morning then after lunch it’s just a complete disaster, and I quite enjoy that”.

Keith (Intensive Care Specialist) also talks positively about his specialty while identifying uncertainty in terms of changes that challenge its traditional ideology. He details more structural changes than the day-to-day changes Andrew described:

It’s been interesting seeing, the development of intensive care and many of us were attracted to it because it was exciting and you keep people alive…but, gradually I’ve been more interested in the sometimes perverse…direction that we’ve taken in intensive care…where people are increasingly on this conveyor belt from home to the emergency department, to the ward, to the intensive care unit in the last few days of life.

Keith was attracted to intensive medicine through the excitement it provided when saving lives. But he also describes the changing structure of medicine where ICU becomes the end station of a “conveyor belt” to death and dying. Yet, despite initially being motivated by the excitement of keeping people alive, he finds the new, somewhat perverse direction of ICU more interesting. He identifies how the ICU physician must more frequently manage death and dying; where different (non-traditional) care goals need to be negotiated. Mutually exclusive goals of cure and palliation reflect a changing dynamic of intensive settings, but Keith experiences his dual role satisfyingly nonetheless: “I mean I like saving lives, you know, getting people who are otherwise going to die, getting them alive again, that’s very satisfying still. But I must say that I get increasingly more satisfaction out of managing death…well”. The increasing satisfaction Keith gains from managing death stands in contrast to the reports of physicians in the literature review and some of his non-palliative colleagues in the present study (chapters 7 and 9) who do not consider this their role and sometimes experience patient deaths aversively. He also talks about “managing death well” something that does not always occur in all settings (see chapter 7 for “good” and “bad” deaths”).
This major theme, “Doing what they Love”, captured some of the positive experiences of physicians engaged with treating dying and suffering patients. All were motivated by particularly enjoyable factors that prompted their entry into, and continued engagement with, end-of-life care. They described many pleasurable aspects which made practicing end-of-life care an attractive and rewarding profession for them.

Applying Goal Theory (Locke & Latham, 1990), physicians as much as anybody else pursue what they love doing. They are driven to satisfying immediate goals, which also sustain them in their pursuit of longer term or telic goals that are often characteristic of achievement through planning (Apter, 1982). Maggie was drawn to her profession and specialty through a longstanding ambition, she was goal directed. Maslow (1943, 1987) further identified esteem needs; to gain recognition by achieving and striving for competency and mastery. Indeed, Robert mentioned being recognised for his efforts and encouraged to continue, while others like Keith may have also satisfied esteem needs when pursuing personal interest goals. Self-Efficacy Theory is also underwritten by goal setting and proposes that physicians with self-efficacy beliefs are marked by similar qualities of achievement, competency and mastery (Bandura, 1997a). In pursuing a palliative care career, Jenny demonstrated self-efficacy by believing “she could do it”.

Physicians who spoke about “helping others and making a difference” highlighted the complexity of patient/physician relationships and the relationships physicians have with others. The work of Caprara (2002) and others (Caprara, et al., 1998; Caprara & Steca, 2005) suggests that physicians with emotional self-efficacy are motivated toward prosocial behaviour and providing holistically focused care simply because of the positive affect and wellbeing physicians gain from their interaction with patients and patient families. Research has shown how the physician/patient interaction can be mutually therapeutic (Adler, 2007; Suchman, 2006; Suchman & Matthews, 1988). Correspondingly, Maslow (1943, 1987) mentions the “connectedness” that Suchman and Matthews talk of in his hierarchical third level, describing needs of affiliation, acceptance and a sense of belonging. We saw this in the accounts of the palliative specialists who
spoke of “jumping in” and “being with” people, where they “walked beside” their patients as a “companion”.

Access to and expertise with technology was also a positive experience for physicians, particularly in critical/acute settings. Yet, despite the common perception of dedicated palliative care being technology free and comfort based, a number of palliative specialists also endorsed the use of technology. Technology could be seen fulfilling mastery goals (Apter, 1982; Bandura, 1989, 1997a) and further developing clinical self-efficacy for physicians treating complex conditions presented by patients (Bandura & Jourden, 1991). Technology provided physicians with greater diagnostic certainty and an ability to meet the challenges of complex illness.

Indeed, physicians found those challenges particularly enjoyable. Many physicians declared they were attracted to end-of-life care because of the challenges it presented. Further developing optimum care for patients and patient loved ones through research, and obtaining positive clinical outcomes, were experienced with pleasure by physicians. A challenging vocation provides a means for satisfying any cognitive needs physicians might have because, according to Maslow (1943), they can know, understand and explore (p. 384-385).

Through perceived self-efficacy, physicians persist in the face of difficulty. They have mastery and an achievement orientation, and exercise agency (Bandura, 1989, 1997a). This explains how some physicians will actively negotiate seemingly impossible positions where, although constrained within rigid social structures, they might assist a hastened death that is in their patient’s interests. They will overcome barriers inhibiting good end-of-life care (and good deaths), and experience their efforts positively.

8.3. Doing a Good Job: Providing the Good Death

When physicians could provide optimum care and assisted patients (and families) in what was considered a good death, all physicians regarded their experience in positive terms. For example, many commented that they “did a good job”, others simply classified
such deaths as “good”; but rewarding to be involved in. The memories left for families were also a consideration of some physicians. Physicians provided some very detailed examples of their experiences in these deaths.

Andrew (Intensive Care Specialist) describes his experience of a good death; talking of a collaborative decision process with the patient and her family. He recounts her awareness of impending death, and peace with that, and focuses on the quality of her last few hours. He “felt really good” implementing a treatment plan tailored specifically to her needs, where sedation was carefully titrated to allow balance between communication and comfort:

She knew we were going to sedate her…and so she just slowly…well…passed away, and the sedation was carefully titrated, along that process. But she had I’d say half an hour when she could say her last farewells…and then she had another half an hour, hour when she could…open her eyes and, smile and squeeze their hands, and then another couple of hours when she was sedated and not really responding but very comfortable and then she passed away yeah…and I felt really good because…it’s a good death in the way that, her wishes, the family’s wishes…the treatment was really…tailored to suit her, quite unique needs uhm…and, the way that she would be…perfectly alert on the ventilator and knowing this is the plan, knowing that “now I’m going to die in a few hours’ time”, and she…well she…you know…reconciled the fact that this is what’s going to happen.

Andrew shows that the way he managed her death was not only at a clinical level, but a personal one also: “we spoke with her and we could connect we, we were there…I liked that”. He enjoyed “connecting” with her and provided support by being there for her. This more palliative type of care contrasts somewhat with the biomedically focused and often de-humanising nature of intensive medicine. Furthermore, although positioned within such a curative setting, Andrew does not see this death as a medical failure: “I felt I did a great job, I didn’t cure her…I didn’t give her another few years to live, uhm…but I’m,
quite sure I did something that would make her…death, a memory for the family”.

Andrew feels he did a “great job” despite not being able to cure her or gain extra time. Memories are important and he suggests this death was regarded positively by the family. Similarly, Candice (Palliative Specialist) also talks positively about memories and doing a great job: “when I’ve been able to put everything together, all that I’ve learnt, and take away the suffering, and it’s a good death…then it’s a great feeling I get…I’ve done a great job. They’re really memorable experiences”. Applying her knowledge and skills to treat suffering and provide a good death gives Candice a great feeling, something she remembers well.

Thomas (General Practitioner) similarly identifies the social nature of end-of-life but also how experiences may be mixed. “It’s great when something…you’ve put a lot of work into turns out well…although it’s hard when it’s somebody you’ve spent a lot of time with and you know them well, at the same time though…it’s a job well done”. Thomas describes the time consuming nature of caring for dying patients and the attachment that goes with it. He regards some patient deaths as “hard” but, like Andrew, also experiences his efforts as a “job well done” saying: “it’s great when it turns out well”.

8.3.1. Personalising death and dying. Andrew spoke about his positive experience of a good death, one that was tailored to the patient’s unique needs. Many other physicians also described their rewarding experiences in providing a good death through personalising or individualising the care they provided, a care focus that also included patient families. Often another product or dynamic of particular settings, such care was more noticeably experienced by palliative specialists. These physicians recognised the person in the bed rather than prioritising the illness. Consistent with dignity-oriented patient care (Chochinov, 2002, 2007; Chochinov, et al., 2002), they were able to value and preserve (and repair) individual humanness and self-worth. They were able to “get it right”. Patients were given great autonomy in how they utilised services and were encouraged to make hospice their own place.
Jenny (Palliative Specialist) describes how personalising care, actually being able to “get it right” for dying patients, is a very fulfilling experience:

I learnt a lot from him because he was such a positive amazing man, so I went with him...and identified what his hopes were, so that I would be able to make them as real as possible, and support them, and it’s very fulfilling when you get it right for somebody and you feel that your partnering them and, providing them with the best care that you feel they deserve or they can get.

Jenny describes a patient where she “went with him” and “partnered” him, reflecting the palliative discourse where physicians journey or walk beside dying patients. Through empathy, she identifies and supports his hopes and needs and bestows the best care she feels she can provide. Jenny illustrates the interpersonal aspects of caring where she learnt a lot from him, regarding him an “amazing” and “positive” man. Empathy and compassion are important qualities of physicians who practice end-of-life care. Jenny mentions “partnering” where she regards her patient as more than his medical condition, as someone she has a personal investment with. Focusing care on the patient validates their importance and worth as an equal, and impacts the dying process (Chochinov, 2002).

By personalising care, the patient’s individuality is recognised. Marginalised humanity is sometimes re-instated. Indeed, Candice (Palliative Specialist) describes this: “sadly some people live out there completely alone...one elderly patient came here and we became family to her...it was lovely to see her brighten up in her last days, showing her how important she was for us”. Jeremy (Palliative Specialist) provides a similar example of such an experience, one he regarded as a good death, where the patient rather than her condition became his focus. He talks positively about “becoming part of the patient’s life”:

I remember a patient stuck in the back wards of a long-stay psychiatric institution…totally crippled to function in society, but coming into a palliative
care unit, she was treated with love and given some dignity…and this lost soul came alive…and the last three weeks of her life, she said were the best she ever had…that she was loved and valued…her track record and past psychosis didn’t matter a damn…and she was befriended and she rose radiant…and I remember that very, very clearly…that was a good death, one where I felt…really good being a part of her life.

Jeremy’s religiosity emerges when talking of lost souls and rising radiantly - as if resurrected. For him, a good death is also about reinstating dignity and humanity. This patient was loved and valued as a person, not medicalised, and her last weeks were the best of her life. Sometimes patients are “labelled” and subsequently positioned in a system where that label is largely directive of the care they receive. This patient was “stuck” for most of her life in a long-stay psychiatric institution, somewhat forgotten by the system and society. When Jeremy mentions “being befriended and loved” he illustrates intra and interpersonal aspects; the emotional and psychological relationship physicians have with some patients. But he also identifies unique characteristics of palliative settings that make these aspects of a good death possible.

Kerrie (Palliative Specialist) gives another example which emphasises rapport, where she also became part of a dying patient’s life. She individualised care for this particular patient and provided a unique understanding of what hospice and palliative care can be. Kerrie describes what she saw as an initially difficult patient who used the hospice as a “bed and breakfast”. He would come in when he needed care and then leave: “He was referred from another hospital, I thought this was one difficult dude [laughs], quite awkward to work with, but I developed rapport and gave him some freedom…and this guy…basically used the hospice as a bed and breakfast”. For Kerrie, the palliative setting had the capacity to provide such individualised care; care that was largely patient directed. She was able to provide end-of-life care without constraints:

we had the capacity to give him that freedom…and so he’d go home, but he’d…always come back, always come back and allow us to work with his
pain...we had a rapport with him, and I believe that probably was one of the best things I’ve done, to give this guy that much freedom…and a safe place...to die.

Kerrie talks of the patient “always coming back” and “allowing” her to work with his pain as if it was a privilege for her to do so. This was a formative or special moment in her career when she says developing rapport and providing such freedom and safety was one of the “best things she has done”.

As with Kerrie’s patient above, many dying patients wish to be at home for as long as possible (Abel, et al., 2011; Foreman, et al., 2006; Hudson, 2004; Kübler-Ross, 1969; Palliative Care Australia, 2004, 2011a). However, when home care can no longer be accommodated due to financial or care constraints, particularly as patient conditions deteriorate, a good death may be facilitated if a compromise can be made and the hospital room can be personalised to become home. Gary (Palliative Specialist) said: “I encourage patients to put up family photos and bring in small sentimental trinkets…it gives their space some flavour of home, and it’s nice to then talk with them about these things”.

Similarly, Maggie (Palliative Specialist) describes a patient who participated in art classes as part of a Diversional Therapy program and his paintings were hung on the wall:

It sort of just evolved that this was his base, and he personalised it and I think that was very helpful for his wife…she felt very guilty that…the cost of the ramp and modifications somehow, had been a decision not to allow him home and, she got herself into all sorts of twists about it…it’s very hard for someone who feels that their decision has somehow changed the course…of action…It was interesting how hospital spaces can become personal spaces very quickly…if you give them permission, people can make home, or their space…very much within any setting, if they’re given permission. I found it gratifying that I could arrange that sort of care and really work with them. It turned out this was the best outcome…it was very pleasing to see how relieved his wife was.
Initially, Maggie negotiated to have an expensive (non-standard) wheelchair ramp constructed at the patient’s home, but its benefit of extending home care was outweighed by the patient’s rapid deterioration and subsequently rejected as not cost effective. She empathised with the patient’s wife, and was “very pleased” for her relief when the patient was able to personalise his hospital room. Maggie found it interesting how his hospital room became his home base. She was “gratified” being able to arrange such care and really work with the patient and his wife. Maggie also particularly mentions the need for “permission” indicating that even in palliative settings where such efforts are perhaps more achievable they still need to be negotiated within administrative and institutional boundaries.

8.3.2. Affecting the timing of death. Correspondingly, just as physicians are motivated by individualised patient care goals that need to be negotiated, extraordinary suffering similarly motivates physicians to find ways of addressing it (de Jonge, et al., 2006; Kon & Ablin, 2010). Physicians often “affected the timing of death” where, generally in the interests of alleviating suffering, the process of death was also sometimes manipulated. Sometimes a hastened death was a good death. Although physicians previously discussed their understanding and position on practices that might hasten death when addressing patient suffering (Chapter 7), this subtheme details how, regardless of their stated position on such practices, all physicians experienced situations where their interventions either intentionally or inadvertently hastened death. Sometimes pressure was applied to physicians by patients who literally begged to end their lives, and a few physicians complied. Bearing witness to intolerable suffering might often be an aversive experience, particularly when treatment interventions are limited. Yet, physicians have measures at their disposal which can address such situations and culminate in a positive experience.

Indeed, Gary (Palliative Specialist) is really glad he can sedate with phenobarbitone to end a patient’s extraordinary suffering:
There are times when I’m really glad I can use sedation…I remember a guy about 10 years ago with mesothelioma…who I went to see one morning and his eyes were literally bulging, he was gripping the bedside table and really struggling with every muscle trying to breath, so, I mean you can’t do anything else in this situation, because there was nothing reversible, and ah…he was going to stay like that. And it was through his breathlessness he pleaded with me to do something…so I told him what I was going to do, and consulted the family...said ok…this is what we’re going to do, and once we start this over the next four hours he will get sleepy and he’s not going to wake up.

Gary highlights how he collaborated with the patient and his family on the treatment decision and provided them with clear information on what the outcome would be. Clearly, Gary knew that the consequence of the treatment was death. But he had little choice to address the level of suffering he was confronted with. The patient was literally begging him to do something, placing Gary under considerable psychological and emotional pressure. He remembers this well even after 10 years. Yet Gary considers the outcome positively. He “felt good” turning a difficult situation into a “good death”: “I’m glad I got to him when I did, because nobody should suffer like that. Within a few minutes he settled…and a few hours later passed away peacefully. I felt good…it ended up a good death considering his situation”. Earlier in Chapter 7, Gary declared he opposes deliberately hastening death, but when confronted by intractable suffering, he shows he will do whatever he needs to for the patient, even if it shortens life. Similarly, Aaron (Respiratory/Thoracic Specialist) is motivated to end suffering regardless of whether it hastens death: “look, I don’t believe in hastening death for just any reason. But there have been patients suffering so much that there’s little else I could do but treat it…and sometimes they died…but I’m happy with that…I’ve stopped the suffering”. Aaron feels “happy” hastening the deaths of patients because they no longer suffer. Like Gary, he has limited options to do otherwise.
Keith (Intensive Care Specialist) further illustrates how death hastening practices may be manipulated with sedation to satisfy legal and professional imperatives, and provide a satisfying outcome that addresses extraordinary suffering. He feels “really lucky” being able to do this:

You know I feel really lucky, because I’m in a position to stop suffering…there was a fellow drowning in his own…lung water because his heart was failing so badly, he was really suffering, so I put him to sleep, put a tube down him just to stop all of the secretions coming out, but I sedated him so much I had to take over his breathing otherwise it would have killed him, and I said “we’re just going to put you off to sleep now” knowing that they were the last words he’d ever hear…and then I sort of weaned him off the ventilator…he was deeply unconscious and 10 seconds later I pull the tube out and now I’m withdrawing treatment because it’s futile, but there’s only a minute between me giving the big dose of sedation and him actually dying…but you see, why did I intubate and then extubate? I did it because I didn’t want it to look like euthanasia…but that’s pretty close to euthanasia isn’t it?…I just couldn’t watch that suffering…nobody can watch a man drown, I mean in his own blood and sputum, he was in so much distress…but that’s pretty close isn’t it?

Keith indicates his intention to address what seems like extraordinary suffering for this patient in the best way he could, by ending life. However, he illustrates how highly procedural it needs to be to bring about an outcome that also protects him legally and professionally, where intent is assisted by the active/passive distinction. He regards the action almost in terms of euthanasia when he says “that’s pretty close to euthanasia isn’t it”. But he goes further into an almost involuntary euthanasia position when he declares “knowing they were the last words he’d ever hear” with the patient told he was only going off to sleep. This might have avoided further patient distress but it might also have been Keith acquiescing to an earlier request by the patient. Keith’s motivations to address suffering are quite clear when he talks about nobody being able to watch that amount of
suffering. This begs the question of whose suffering he was trying to alleviate. Keith stated when he can pro-actively address such suffering: “it’s a very satisfying experience, whereas 20 years ago I wouldn’t have thought that was satisfying. I wouldn’t have even thought about it perhaps”. Keith tends to think about these instances more than he once did, but recounts this experience as “very satisfying”. These excerpts identify important contextualised structures that uniquely influence in the moment, specifically, those of the patient, himself, and professional and legal ones, and which also situates his experience temporally. At the same time, those structures provide specific possibilities for identities and roles, where Keith identifies as an objective scientist dispensing end-of-life care, a legal practitioner negotiating a hastened death, and the feeling human who could not watch a man drown.

Robert (Palliative Specialist) also describes a hastened death performed in the interests of patient suffering, but one that was in collaboration with the express wishes of his patient. Robert felt “so honoured” to be involved and give his patient control over death:

My role as a palliative care doctor is, well if he’s stopping this treatment, how am I going to ease his passage, knowing he’s going to die soon after because he’s quite dependent on it for his breathing? So in that situation, obviously at his home, and by the time I left he died, he knew he was going to die, I knew he was going to die. Just putting aside the question of my intention for the moment, but certainly his intention, that he would die as a consequence of his decision, and ah…my role as the doctor then was that because the ventilator was coming off he would get low oxygen and need sedatives, and some morphine to take the edge off the air hunger, that he was going to experience. So I gave him a dose before taking the ventilator off, and then his respiration dropped, he turned a bit blue but he was getting agitated. I put the ventilator back on, gave him a bigger dose, then took the ventilator off, and, ah he died…wife holding one hand and his daughter the other.
I felt so honoured to be able to do this for my patient, give him the control over death that he wanted.

Robert describes a procedure where in-line with patient wishes, he withdraws life sustaining treatment. In order to do so he administers sedatives and opiate medication to alleviate his patient’s agitation from extreme breathlessness. He describes how the patient most likely died from suffocation, albeit peacefully and with his family members present to comfort and support him. Such a procedure was easier in the home setting where it might be less scrutinised, but Robert also talks about intentions (double effect). Both he and his patient knew the outcome of the chosen decision. Robert’s stated intention was to honour his patient’s wishes and withdraw treatment; his patient’s intention was to die. Robert mentions his role as a palliative care physician to provide comfort through treatment *titrated* to the patient’s needs. But he describes how this process was not so straight forward, leaving the actual cause of this particular death uncertain. Honouring a patient’s wish to die and providing assistance could also be understood as complicity.

Nonetheless, Robert’s emotional experience of this patient’s death highlights the intrapsychic when he reflects on the interpersonal aspects of care he provides. He is moved and considers himself privileged to be intimate with what he regards such a personal and important emotional occasion: “you’re privileged to be there…a very intimate, very important and emotional occasion…and when you reflect on it you think this is an incredible human drama that your professional life takes you into…it’s very emotional, very moving…great satisfaction”. Illustrating an interaction of meso and micro influences, Robert describes an experience of great satisfaction; “an incredible human drama” where feelings are inherent and is grateful that his professional life affords him this. At the same time, Robert acknowledges his “professional responsibility” suggesting he also needs to remain objective: “you’ve also got to be aware of your professional responsibility, but you can’t help but experience the human, feelings that are bound up in that situation”.

As treating physicians, both Robert and Keith had a direct obligation to secure the comfort of their dying patient and ease them into death (albeit with intention) in a legally and professionally congruent manner. Double effect appeared to flow throughout the accounts physicians provided of their experiences when death was hastened. But other physicians who do not have that direct level of agency may still accede to a suffering patient’s request for death by equipping them with knowledge, and experience those situations positively. For example, Peter (General Practitioner) deals with requests to die and supports patients who seek his advice: “I’m completely sympathetic to it”. As their GP he acts in a somewhat consulting role and advises patients on how they might obtain a hastened death from their treating physician:

I’ve been involved with a lot of people who have been dying difficult deaths with cancer…where as their GP I’ve suggested, that the best way in this situation to get what they want is to try the following strategy with their doctors…and ah…that’s sometimes been helpful in the sense that they’ve been able to talk their doctors into taking them through one of these uhm…double effect deaths…I feel good helping patients like these who have nowhere else to go.

Confronted by many patients suffering difficult deaths, Peter enjoys helping them by providing information and strategies on how they might approach their treating physician and encourage them to assist hastening their death. Asking their physician for a “double effect” death has been helpful to patients. The treating physician is protected legally and professionally, and the patient’s wish to die is accommodated. Peter suggests that some physicians might more readily consider a request to die if it is made by a patient informed with a practical strategy. Legal considerations are a necessary priority for Peter when he advises patients to seek a double effect death, and he shows how medico/legal constraints can be negotiated, but there are also times when he steps over that legal threshold:

Uhm…on occasions I’ve talked to them about how they ah, and I’ve got to be a little bit careful here, because this is illegal, uhm…but I’m aware of the fact that if they were to take certain drugs that they’re being prescribed, in certain ways, that
they would get the peaceful death that they want, so ah, and those situations are always coming up, and certainly I haven’t got the slightest moral qualm about my…involvement, I feel quite pleased about it. I think it was the right thing to do, but it isn’t the lawful thing to do. And…it’s one thing suggesting that they talk to their doctors about double effect…but it’s another thing entirely to suggest that they take this particular drug that they’re being prescribed by another source, in a certain way. And that’s obviously illegal.

Peter goes beyond double effect, and provides information to patients on how misusing the medication that another physician has prescribed can bring about the outcome they are seeking. Such situations are frequent and he certainly acknowledges the illegality of giving such advice, but, in complete support for his patients, he declares he does not have the slightest moral qualm. Peter makes his position clear indicating, that although illegal, “it was the right thing to do”; he identifies a personal moral and ethical structure that guides him. He also regards his involvement as “quite pleasing”. This is understandable when he can practice consistent with his beliefs, and also successfully negotiate medico/legal constraints. In a sense, Peter is positioned as a medical maverick who will champion the cause of dying and suffering patients who have nowhere else to turn.

In this theme, many physicians described “doing a good job”. Getting it right for patients and assisting a good death was experienced positively by physicians. These physicians demonstrated strong interpersonal efficacy by collaborating with patients and their loved ones and negotiating individualised care that culminated in good deaths. For many palliative physicians in particular, the patient/physician relationship was one of equals, where physicians “partnered” their patient. They drew satisfaction from recognising the patient’s humanity rather than only their illness, and enhancing their patient’s quality of life for as long as possible.

Again considering Maslow’s (1943, 1987) suggestions of satisfaction being derived from affiliation and a sense of belonging, some physicians like Andrew similarly spoke of “connecting” with their patient (see also Suchman, 2006). Andrew illustrated
empathy and the intrapsychic experience he has caring for patients. Yet, despite critical/acute physicians generally being characterised as (or obliged to be) objective and emotionally detached (Billings, et al., 2010; Halpern, 2007), Andrew displays emotional efficacy and enjoys rather than avoids the closeness he experiences with his patient.

Drawing on Self-efficacy Theory (Bandura, 1986, 1997a), physician expertise and mastery also became evident when titrating sedation and managing deaths well through applying the knowledge they had acquired. Many spoke of such deaths being memorable experiences. Achievement oriented physicians often exercised agency in negotiating institutional and administrative barriers to enhance their patient’s quality of living. But, sometimes a hastened death was a good death, with physicians negotiating medico/legal prescriptions and constraints to alleviate suffering and support their patient’s best interests and wishes. Further demonstrating the interpersonal and intrapsychic aspects of end-of-life care, many physicians were motivated by compassion for their patient and addressing the extreme suffering some patients endured.

8.4. Discussion

Consistent with the aims of this chapter, and a focus on the research question, the positive experiences of physicians providing end-of-life care in Australian palliative and critical/acute settings were examined. The supportive question seeking to elicit what motivated physicians to care for the dying was also addressed. Physicians reported on their experiences of negotiating many end-of-life care decisions, and the particular practices they engaged in. A critical realist perspective that considered the complexity inherent in end-of-life care was helpful for understanding and explaining those experiences.

Additionally, the theories and constructs drawn on throughout the chapter offered further clarification of the complex multileveled nature of experience. For example, Maslow’s need-based hierarchy encompasses biological factors at its lower levels and progressively more psychosocial factors oriented toward achievement and actualisation
(Maslow, 1943, 1987). Biopsychosocial elements in experience are similarly accounted for by Goal Theory where physiological and psychological energy mobilises action (Locke & Latham, 1990), while Self-efficacy theory considers a biological component, a learned component through direct and vicarious experience, and a cognitive component in motivated behaviour (Bandura, 1991a, 1991b; Bandura, Taylor, Williams, Mefford, & Barchas, 1985).

The positive experiences physicians described were also subject to specific and often interactive macro, meso and micro social influences which physicians negotiated to achieve a satisfying outcome. For example, some negotiated medico/legal constraints that allowed them to practice in ways consistent with their personal beliefs and bring about a hastened death. We saw Keith, Robert and Peter all demonstrate such agency in the care they provided to particular patients.

When discussing the “privileged relationships” they enjoyed with patients, patient loved ones, and with professional colleagues, many physicians displayed interpersonal and emotional efficacy (Bandura, et al., 2003; Caprara, 2002; Caprara, et al., 1998; Caprara & Steca, 2005; Guido, et al., 2009). Most palliative physicians actually sought relationships of a close and emotional nature while others, especially in critical/acute settings, often cherished professional relationships more. Good relationships were an integral component of their positive experiences, sometimes quite formatively and memorably, and often reflected an enhanced quality of care for dying patients and their families. Noticeably, the types of relationships physicians enjoyed were strongly delineated along professional and setting lines. Setting factors strongly determine the type of medicine physicians can practice (e.g. a biomedical curative approach vs. a biopsychosocial comfort-based approach) and how they will engage with patients.

Yet throughout this thesis, and also discussed by Keith above, critical/acute settings are strongly identified as increasingly taking on the end-of-life care role. Physicians in these settings manage death and become exposed to relationships that require an empathic and patient centred focus rather than an objective (and emotionally
distanced) illness oriented focus. Physicians in these settings frequently lack skills or motivation for dealing with relationships of an emotionally intimate nature and, without training or mentorship that assists them to develop emotional self-efficacy, may avoid such relationships or suffer adverse health consequences (Girgis, et al., 2009; Jackson, et al., 2008; Larson & Yao, 2005). If, as we have seen above, emotional self-efficacy fosters positive experiences at the bedside, then it makes sense to encourage physicians to develop and refine their capabilities for engaging in empathic and emotionally laden interactions.

It may be that some physicians have a capacity for empathy but find it difficult to communicate. Carl Rogers (1951, 1959) advocated a client-centred approach to therapy where emotions would be validated (rather than avoided) through an empathic relationship. Therapists could be taught techniques where they reflect the communicated feelings of clients, and gain an insight and understanding of their client’s world. Some researchers suggest that empathy can be learned by physicians. For example, Larson and Yau (2005) spoke of “surface” and “deep acting”, where physicians could promote a certain image of their profession, one characterised by empathy, through managing their experienced and displayed emotions. Recognising that empathic interactions can be of mutual benefit to the physician and patient (e.g. Adler, 2007; Suchman, 2006; Suchman & Matthews, 1988), they suggested physicians should utilise method acting techniques employed by screen and stage actors. Physicians, particularly those in non-specialised palliative settings, could thus develop emotional self-efficacy (Bandura, 1991a, 1997a) and derive greater meaning from their work (Shanafelt, West, Kolars, & Haberman, 2006).

However, some regard the capacity for empathy more an inherent than learned quality, and liken surface and deep acting to “faking sincerity” (Lipsitt, 2005). Lipsitt states that before admission to a medical course, students should be screened as much for their capacity to empathise as their expertise in biochemical and other sciences. Such sentiments are not isolated within the medical community. For example, one renowned
intensive care specialist told me he was “howled down” by his Canadian and US colleagues at the suggestion of “learned compassion” strategies being developed for critical/acute physicians.  

Nonetheless, some physicians in Australian critical/acute settings use acting techniques which they have refined through a lengthy career at the bedside. For example, Keith told me of a “spiel” he uses with families of dying patients confronted by difficult decisions like withdrawing life support: “over the years through experience, and watching superiors, I’ve developed a ‘spiel’ that’s almost automatic now. I offer profound and compassionate statements…you know measured…in a quiet tone, look downwards and drag my toe on the ground, things like that”. Keith describes a form of learned compassion that assists him in emotional interactions with others and illustrates the utility of observational learning (Bandura, 1997b). Of further benefit, such strategies may also have a protective effect for physicians in critical/acute settings that need to manage death and dying without the motivation or training to do so, and who might otherwise potentially avoid or disengage from such patients and patient families.

Something like learned compassion does not sit well with everybody. America or Australia might not be ready for such a shift in cultural and professional attitudes, where empathy increasingly becomes accepted as simply another accreditation bolstering a physician’s credentials. The societal expectation, supported by the Hippocratic Oath, is for physicians to work in the best interests of their patient, where empathy and compassion are regarded inherent physician qualities. Society positions the physician in a role of trust and guidance, as someone providing support and understanding in a time of great need (Cohen, 2007). Such learnt strategies may sometimes be helpful at the bedside for a physician (and others) but do not account for how compassion and empathy is also “felt”. There is an affective dimension that influences physicians also (Frankel, 2009; Kim et al., 2009) and, therefore, drawing on Bandura’s research (Bandura, 1991a, 1997a;  

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8 Gordon Rubenfeld (Chief of Trauma, Emergency and Critical Care Program Sunnybrook Health Sciences Centre Toronto Canada; Professor of Medicine University of Toronto). Personal communication with the author, July 16, 2010, Liverpool Hospital.
Bandura, et al., 2003), it might be particularly beneficial for physicians to learn how to effectively manage their felt as well as displayed, emotions.

In the key theme “doing what they love”, many palliative physicians demonstrated their emotional efficacy, being motivated to help others through empathic and holistically focused care. But regardless of specialty, all physicians were identified as achievement oriented and driven to pursue both proximal and distal goals. For example, many physicians entered their profession and particular specialty through long-held ambitions, while also enjoying the more spontaneous aspects of their work when describing challenges and complete disasters that needed to be dealt with in the moment. The challenges that complexity and uncertainty posed attracted these physicians and motivated them to persist even when faced by difficulties. Many could draw on technology, and research provided them with greater self-efficacy. Research and clinical practice were symbiotic with one informing the other. Physicians pursued the unique opportunities offered by their chosen specialty and loved coming to work each day.

I provided a theoretical discussion when summarising this theme earlier, but there is a major point that needs to be canvassed further. Keith spoke of critical/acute settings undergoing an ideological shift (something I also identified throughout the literature review) where, although he “still finds keeping people alive exciting”, he “increasingly enjoys managing death well”. But he also pointed out earlier (chapter 7) how many of his critical/acute colleagues find this type of work aversive and not part of their brief. Indeed, also in the previous chapter, Gina-Leanne said:

It’s not what people are trained in, not what people chose intensive care to do, we didn’t choose it to be palliative care doctors, it’s just that…you know, quite a lot of patients die when they’re with us and we have to do it.

Keith stands in contrast to many of his critical/acute colleagues by drawing satisfaction in managing death. If “managing death well” can be satisfying, it makes sense to encourage physicians in critical/acute settings to develop their capacity for providing this type of
care and resourcing them appropriately, especially when end-of-life care is now increasingly becoming their task.

But emerging professional and cultural norms may further condone pursuing futility and preserving life at all costs because of a greater ability, through technological advances, to save life than ever before (Day, 2009; DelVecchio Good, et al., 2004). It may also be that other critical/acute physicians armed with increasingly advanced technology and highly developed clinical techniques may not judge when it is appropriate to *stop* providing curatively oriented treatment. The satisfaction that technology and advanced clinical practices bring physicians may be short lived if they become a double-edged sword and actually inhibit the ability to assist “good deaths”.

Certainly, some physicians are motivated to pursue achievement oriented goals and advance the science of their specialty. However, such goals may provide conflict because not all physicians agree with them. As an example, Gina-Leanne told me of a ninety year old patient receiving heart surgery:

> I think the expectation, of what intensive care can deliver is very high… it’s totally unrealistic about what we can achieve, you know…there was a patient went to this private hospital and, you know this guy very proudly said “well we’ve just done open heart surgery on a 90 year old” and I went “you fucking stupid littlest person, why did you do that for!”? you know…it’s gonna take them months and months to recover, they’re never going to get back to where they were before and in a year’s time you can bet your bottom dollar they’ll be dead…what’s the point in that?

When surgeons are finished with their patient, the task of keeping the patient alive goes to intensive care where, as Gina-Leanne points out, expectations are high and often unrealistic. Unlike her palliatively specialised colleagues, she cannot just “allow” the patient to die; curative goals are still in place. But cases like this suggest a need for reviewing medical ethics at multiple levels, particularly as to what constitutes futility in
each case. The double-edged sword of advanced technology and clinical breakthroughs demands an ethical consideration of whether physicians *should* engage in certain practices just because they can.

Any multilevel review of medical ethics should consider how some physicians fearing litigation wish to be seen as doing everything possible (Cunningham & Dovey, 2006; Salem & Forster, 2009). Many are also influenced by their professional ideology and cultural expectations to pursue all measures and save life (Billings, et al., 2010; Curtis & Vincent, 2010; Meier & Beresford, 2006). Indeed, the miracles of intensive medicine are countenanced by the media which often implicitly promotes unrealistic expectations, and continued aversion towards death and dying (Regen de Bere & Petersen, 2006).

Importantly then, physicians outside of dedicated palliative settings may gain great satisfaction managing dying patients if they are familiar with the intricacies of each specialty, where each physician knows what the other can and cannot do (Hillman, 2011). In the previous chapter, palliative specialists often related a “bad death” to the lack of professional recognition they receive, with their specialty being undervalued by other medical colleagues and always “falling of the map”. Encouraging cross disciplinary collaboration among physicians may engender a supportive environment conducive to managing deaths across settings, and enhance their positive experiences.

In the final theme, physicians felt they “did a good job” when they could assist a good death and get things right for their patient and patient loved ones. Throughout this theme all physicians displayed strong interpersonal and emotional efficacy (Bandura, 1986, 1991a; Bandura, et al., 2003; Caprara, 2002; Caprara & Steca, 2005; Guido, et al., 2009). They illustrated intrapsychic aspects of the care they provided, often describing compassion and empathy for their dying patients and their families. Many physicians spoke of “connecting” and “partnering”, illustrating the strong biopsychosocial nature of end-of-life care and the inadequacy of biomedical approaches that marginalise patients and their families. Physicians demonstrated that when they had effective control over outcomes, their experiences were rewarding.
By taking a “complex” view of end-of-life care (Bhaskar, 2011; Byrne, 1998; Munday, et al., 2003; Williams, 2003; Williams, et al., 2003), we can understand that the opportunities for agency, and how physicians are willing to exercise it, will influence the outcomes they are responsible for, and how they subsequently experience those outcomes. The physician’s perceived self-efficacy in a given situation also influences their engagement with particular behaviours (Bandura, 1989, 1997a). The specificity of context means that outcomes and experiences cannot be predicted. Each interaction at the bedside will be unique with its own dynamics.

A number of palliative physicians described negotiating institutional constraints, where personalising care for their patient and patient loved ones culminated in a good death and positive experience for the physician. Physicians pursued goals of restoring patient dignity and humanity. Physicians could sometimes exercise agency and practice consistent with the personal and professional beliefs they held.

In the previous chapter I discussed the importance of Kohlberg’s (1969) work and that of others (Kohlberg, et al., 1983) on morals and personal ethics, showing how physicians could be motivated by personal ideals and clinical goals that do not necessarily conform to established norms. Many physicians previously identified their religiosity and identification with the sanctity of life position. Yet, a number of these physicians engaged in practices that could be considered death hastening; practices that intuitively contradicted their personal position and that of their profession, and potentially attracted legal and professional retribution. Clearly, these physicians needed to make sense of their practices in such a way that allowed them to experience their actions positively. Drawing on the critical realism of Bhaskar (2011), physicians could do this by negotiating and positioning themselves within various macro, meso and micro social structures.

To illustrate, many physicians considered themselves lucky that they could alleviate extraordinary suffering through their clinical expertise and efficacy with practices like sedation. They demonstrated compassion and empathy for their patient and reflected ideals of the Hippocratic Oath to address suffering. Further, when a patient
subsequently died, physicians could be supported by a position of double effect. Sometimes physicians manipulated particular practices to support ideals of patient autonomy and control to intentionally bring about a hastened death, but could still position themselves protectively within double effect. In all of these cases, physicians could practice true to their personal beliefs and, through agency and the way they chose to position themselves, achieve satisfying outcomes that still supported enshrined cultural and medico/legal prescriptions.

Physicians can be considered goal driven to achieve “good deaths” (Apter, 1982; Bandura, 1997a; Bandura & Cervone, 1983; Locke & Latham, 1990) and when bolstered with a sense of self-efficacy may negotiate multiple factors toward that outcome (Bandura, 1989). For many physicians, regardless of their particular specialty and setting from which they practiced, death was not so much the issue for them; instead, the way death was managed was the important focus. If we wish to gain an understanding on why physicians engage in practices that hasten death and why providing end-of-life care more generally is rewarding for them, we need to similarly consider interactive macro, meso and micro factors that play out uniquely at each bedside. The current research has demonstrated that it is important to adopt a systemic approach when multiple factors influence a physician’s capacity to exercise agency and negotiate good deaths, and then experience their efforts positively.

8.5. Summary

This chapter focused on the positive and rewarding experiences of physicians. All physicians detailed the factors that motivated them in their chosen specialty and illustrated how their experiences were often influenced by particular setting characteristics. The specificity of context emphasises how often, rather than being predictable, experience was emergent through interpersonal engagement within complex multileveled social structures. Physicians enjoyed relationships with patients, colleagues and others. They enjoyed the positive outcomes from their efforts when effectively negotiating care that considered their own beliefs and positions, those of others, and also
broader cultural and professional prescriptions. However, end-of-life care is not always experienced positively by physicians. Accordingly, the next chapter will examine the more negative or aversive experiences that physicians may have when negotiating and providing end-of-life care.
Chapter 9

Negative Experiences of Physicians in End-of-Life Care

Significant and meaningful experiences are remembered regardless of whether they were rewarding or aversive. Andrew (Intensive Care Specialist) makes this point: “yeah, there’s always a few cases that you for ever remember…you know; the success stories…and also the not so…successful…” The memories of some experiences can be quite enduring.

Throughout the literature review, and particularly in chapter 5, I identified how physicians frequently experienced their provision of end-of-life care aversively. For example, many experienced “medic fatigue” (Australian Medical Association, 2006c) and burnout (Dunwoodie & Auret, 2007; Girgis, et al., 2009). From the available research, multiple influences were recognised as interactively affecting the experiences of physicians. In order to completely address the main research question regarding how physicians understand, negotiate and experience end-of-life care decision-making and practices in Australian critical/acute and palliative settings, this chapter focuses on the negative experiences physicians report when providing end-of-life care. Particular consideration will again be given to the negotiated aspects of care affecting physician experiences. The opportunity to exercise agency becomes particularly important for physicians in mediating negative experiences. By examining end-of-life care from a critical realist perspective (Bhaskar, 2011; Harvey, 2002; Mingers, 2004), such opportunities can be regarded as subject to the particular dynamics of individual settings.
and social interactions, and the particular capacities of individual physicians.

Accordingly, some experiences are more negative than others. For example, some are felt more strongly and more enduringly than others. However, despite the aversive experiences physicians report, they remain engaged with their profession providing end-of-life care while negotiating ways of supporting their own welfare and that of patients and others.

Four major themes are considered in this chapter. In the first, all physicians identified “socio-cultural constraints and difficulties” which frequently culminated in negative experiences. They identified difficult cultural taboos around death and dying that placed particular, often unrealistic, expectations upon them when managing dying patients and patient loved ones. Managing younger patients was especially problematic for physicians, but family conflict and religious influences were also identified in the physician’s negative experiences.

The second major theme examined the negative experiences of physicians who found themselves “up against the system”. All identified various aspects of the “system” where constraints and conflicts inhibited the care they could provide. Physicians described demands of the job, resourcing challenges and collegial conflict. At the same time, they described their experiences of negotiating a seemingly authoritarian medical system.

The third key theme identified “the intrapsychic burden” physicians experience when providing end-of-life care. All described the emotional pressure they faced from numerous sources, and where they sometimes also identified with particular patients and patient families. Many described self-recrimination and particular dilemmas and conflicts which they experienced quite aversively.

To address the supportive research question enquiring “how physicians manage their experiences”, the final key theme explores how physicians “cope with aversive/negative experiences” in the process of engaging with end-of-life care.
Throughout this theme, the *negotiated* aspect of experience became prominent when, through a range of strategies, physicians could exercise agency and mediate their negative experiences with varying degrees of success.

### 9.1. Working with Socio-cultural Constraints and Difficulties

All physicians identified the problem of discussing death and dying. Such discussions are often regarded a taboo in many Western societies like Australia (Byock, 2002; Hillman, 2011; Mills, 2004). There is a societal expectation of medicine to cure, and an avoidance of death. However, physicians often need to discuss these issues at the bedside simply because this is where imminent death is confronted. Gary (Palliative Specialist) recognises the reluctance to discuss death and dying in the general community: “we’re all getting older but most of us haven’t had a close encounter with death, and no one likes talking about it…but we need to. We keep pushing it away as if it won’t happen to us.” He identifies an aging population that needs to come to terms with death and dying sooner or later. Yet, the cultural difficulty with dying is further compounded when “younger” patients are involved and, as illustrated below; many physicians also experience those deaths aversively.

In a multicultural society such as Australia, end-of-life care exposes many physicians to a diversity of beliefs and cultural norms. Particular “religious” beliefs held by some families create conflict over treatment decisions and inhibit the care a physician can provide. Some physicians also report sexism, which may foster further “conflict” at the bedside. Cultural taboos on death and dying are also reflected when unrealistic expectations are placed on physicians by families and others (Ahern, et al., 2012). Advancing technology and innovative clinical practices frequently promote such expectations; something Kerrie (Palliative Specialist) considers problematic: “everyone suffers; I think doctors suffer, I know I do…because there’s this big expectation on us. I think our technology has gone way ahead of our, our…ethics or, or our governance about this”. Physicians suffer because technology has been so successful in saving life and prolonging its quality that it almost becomes mandatory to use it, even when situations are
hopeless (and further treatment futile and burdensome). Kerrie talks about technology outpacing ethics on end-of-life practices. Cultural (macro) and professional (meso) influences strongly direct practices at the bedside, with some practices, particularly if burdensome or futile, being regarded as ethically dubious and contentious.

9.1.1. Young patients shouldn’t be dying. In the earlier literature review, I identified younger patients dying as something of a taboo and particularly problematic for many physicians in Western end-of-life care (Brown & Sourkes, 2010; Hurwitz, et al., 2004; Monterosso & De Graves, 2003; Orloff & Huff, 2010). With some similarity, many physicians in the present investigation related younger deaths to “bad deaths” (Chapter 7). Many also experienced discomfort and difficulty when providing end-of-life care for younger patients. Indeed, Thomas (General Practitioner) says: “although you accept that patients will die, you never get used to it when they’re young”. Similarly, Robert (Palliative Specialist) talks of the difficulty he has with younger patients dying: “you get the occasional you know, younger patients, and I’m sure we spend as a team, we struggle with it more, we spend more time talking about it with our social workers”. He reflects cultural taboos of younger deaths, where others around the dying person struggle. He indicates his team needs “more time” with social workers when young deaths occur. Like Thomas, Robert accepts deaths of older people but considers young deaths unfair. He is also affected when younger deaths occur:

You see people struggling with it more, ah, I feel like other people probably feel, that, you know there’s a sense of unfairness or, you know, life sucks sometimes, it’s a lottery and some people get a bad deal, uhm, so yeah, I guess I’m affected like other people are in that sense…and probably more accepting of people dying in old age.

If palliative specialists like Robert experience young deaths with difficulty, then such experiences may be compounded for curatively oriented physicians. Andrew (Intensive Care Specialist) highlights critical/acute dynamics and the types of patients he has. Patients arrive in emergency and acute situations, but the young ones are unexpected,
shouldn’t be there, and are particularly difficult for him when it comes to decisions that may end their life. He comments on decisions of treatment withdrawal:

yeah….I mean [withdrawing treatment] it’s, it’s, not as…stressful as with those…well particularly young patients, you know where, where there’s been…well, traumas or what have you…uhm…just, young people dying when they really shouldn’t be dying that, that’s very stressful…but it’s definitely, yeah driving home it’s something I would think about.

Andrew experiences younger patients dying as stressful and not something he can just leave at work or easily switch off from. Such instances have an enduring impact and are remembered. Similarly, and despite her extensive experience with patients dying in ICU, Gina-Leanne (Intensive care Specialist) finds the deaths of younger patients particularly upsetting: “when they’re young people dying, you’re going all out for them usually and that experience…is much more upsetting, you know, the influenza outbreak, last year…we had two young women die in one week; that was extraordinarily upsetting”. Gina-Leanne reflects cultural taboos of young deaths and imperatives of the medical profession, particularly intensive medicine, to cure. Young deaths are “extraordinarily upsetting” for her, especially when as she states she is “going all out for them”.

9.1.2. Family conflict. The socially engendered discomfort of discussing death and dying, and accepting its inevitability, often became problematic for most physicians at the bedside. Many of them needed to negotiate a clinical or medical reality that conflicted with beliefs and attitudes held by families of dying patients. Sometimes conflict with families and within families culminated in an aversive experience for these physicians when seeking to manage the care of a dying patient. Furthermore, physicians felt family conflict also often translated into less than optimal care for the patient (and the family).

Occasionally, the socially influenced expectations of intensive medicine to cure and prevent death (Curtis & Rubenfeld, 2001; Curtis & Vincent, 2010; Hillman, 2009b;
Robichaux & Clark, 2006; Stolick, 2003) were quite noticeable for physicians interacting with families of dying patients. Andrew (Intensive Care Specialist) highlights this with some families applying pressure to inappropriately exhaust all options: “some families push⁹ for everything to be done…and it’s, I mean it’s extremely distressing to see someone dying and knowing that there could be other ways of doing this”. Andrew experiences such pressure as “extremely distressing”. He describes how his hands are tied because he “knows there could be other ways” but must witness a less than optimal dying process. Similarly, Aaron (Respiratory/Thoracic Specialist) also experiences conflict with the family over decisions aversively. He feels helpless when constrained from providing care in the patient’s best interests and describes such situations as “very, very difficult”, particularly when patients suffer needlessly or undergo futile treatment: “I get a sense of helplessness…when families apply pressure…yeah, because you know what is the most appropriate way of managing the patient, uhm and to see someone suffering, or go through treatments, that’s not appropriate is very, very difficult”. Conflict with patient families over treatment decisions can therefore result in what is considered a bad death. Jenny (Palliative Specialist) points this out as something she also experiences as distressing:

The family… …didn’t accept that the father, a doctor, was dying, and his family were all doctors as well, and they wanted to keep him living, and I was asked to come in as the fifth practitioner because no one was dealing with it, to uhm, explain that he’s dying and this is how you keep him comfortable…and, until the day he died, there were barriers actually getting him comfort care, uhm…and that was distressing and inadequate, this person really didn’t have time to, for any issues to be discussed or…any last thoughts, so I found that very distressing…a bad death.

In this particular case, the patient and his family were all doctors, each with personal and medical opinions. Each did not accept the patient was dying and wished to prolong

⁹ Underlining added by author to denote physician’s emphasis.
treatment focused on survival. But Jenny found the conflict “very distressing” especially when opportunities for the patient to express his last thoughts or engage in important discussions were lost. Conflict inhibited the care she could provide and culminated in what she regarded as a “bad death”.

The cultural diversity in Australian society fosters multiple opinions and attitudes that may conflict over clinical end-of-life decisions at the bedside. Gina-Leanne (Intensive Care Specialist) talks of some unhelpful cultural norms where sexism is considered acceptable. Her ability to provide appropriate care for a dying patient was impeded and consequently a negative experience for her, something she described as “horrible”:

Yeah I have experienced that (sighs) uhm…yeah, where you lose, well I didn’t have their trust ever from the word go because I was a woman and of course, in this particular culture “that’s a fat waste of time really”, uhm, you know “we want to speak to the Director” “well tough luck mate, you know I am the Director”… and uhm… yeah we lost their trust, and it was horrible, in the end we just… basically we had to sit there, and wait until the person’s, you know…brain, just about rotted.

In this relationship of conflict, Gina-Leanne was unable to assist the dying patient by withdrawing life support and letting them die. Families often wait for a miracle, sometimes unrealistically and will not accept medical evidence or the expertise of the physician (Widera, Rosenfeld, Fromme, Sulmasy, & Arnold, 2011) and, in some cultures, particularly if the physician is a woman (Glick et al., 2000). Gina-Leanne found discriminatory dynamics in the relationship made developing trust difficult, something that is essential in end-of-life care (Heyland, et al., 2006; Mack et al., 2009): “I mean the worst thing you can do for a family is to lose their trust, once you’ve lost their trust…it’s just horrible…just horrible…”
Because of the potential for conflict, a physician’s role is frequently as a mediator. Peter (General Practitioner) talks about multiple influences at the bedside; where he tries to accommodate the family’s interests as well as his patient’s. But this is not without difficulty:

You try to accommodate them by at the same time, making it pretty clear one hopes, to the patient and to the family…that you have a responsibility and ultimately the decisions you will be taking are determined by what the patient wants. Now, it’s all pretty good when these things all come together but there have been plenty of situations where families who want treatment continued have disagreed strongly with what…the patient…wants, and they can be the messiest and most difficult of situations for me.

Peter prioritises the patient’s needs and is talking about patients who wanted to withdraw treatment and die, something the family can strongly oppose. He is caught in the middle and needs to negotiate situations that are messy and very difficult for him.

9.1.2.1. Religion. Many of the subtheme excerpts above identified negative experiences of physicians exposed to influential cultural norms and expectations of cure and saving life. However, sometimes physicians who are in a position to save life are constrained from doing so by the religious beliefs of some patients and their families. Many religions uphold the sanctity of life position (Chapter 3) yet sometimes particular religions may also support views that contradict that position and constrain curative practices. In some circumstances a physician might agree that allowing a patient to die is the appropriate course of action but this can be difficult for a physician who believes a patient could be saved. A few physicians spoke of some patients refusing treatment due to cultural norms of stoicism, and others due to religious beliefs of redemptive suffering. These individual beliefs are generally respected by physicians because patients have the right to refuse treatment. However, it is more difficult when the patient cannot speak for themselves. Andrew (Intensive Care Specialist) made this point when talking of religious beliefs that he needs to respect but which essentially tie his hands. Patients are brought in
as an emergency and request care but do not want blood. Andrew is compelled to stand by
and do nothing to prevent an unnecessary death:

Another thing that I’ve struggled with is with Jehovah’s Witnesses…who would
say…“we don’t want blood whatsoever”. As a young doctor, I was involved in a
case. She was 25 years old. She had a uterine rupture and she was bleeding to
death…and, then the father arrived in hospital and said “she’s a Jehovah’s
Witness, you can’t give her blood”…and she bled to death on the table…and, I
was the junior doctor…there were two senior consultants involved and they didn’t
transfuse her and, and I told them “I, I just can’t understand why you did this,
because I would have”\(^{10}\) …and, they told me “why would you, why would your
decision be more valuable or more important than her own and, and that of her
father?” and I was saying “well you don’t know what her decision was really, you
don’t know the context, it was an authoritative father saying “you will never
receive blood”.

Constrained by professional authority (senior colleagues) and the religious beliefs of
family, Andrew indicates that if he had the authority he may have exercised agency and
given blood despite the families’ wishes. These decisions are dilemmas that are difficult
to resolve and are memorable. He identifies the importance of context and illustrates how
he argued against his senior colleagues who were influenced by the father. This case
highlights how macro influences of religion affect meso level practices of physicians and
subsequently influence personal experience in the process.

This key theme identified socio-cultural constraints and difficulties for physicians. Certain taboos within Australian society toward younger deaths, and the expectations of
medicine to cure, were evident in the accounts provided by physicians. Sometimes
conflict would ensue because of differences over treatment decisions between physicians
and patient families. Multicultural and religious influences also emerged at the bedside,
which further constrained physicians in the care they could provide. Although palliative

\(^{10}\) Andrew spoke very softly and appeared pained when recounting this part of the excerpt.
physicians were certainly not immune to negative socio-cultural influences, they were especially noted by critical/acute physicians.

However, when considering the conflict physicians experienced when engaging with patient loved ones and other colleagues, an important issue of “control” emerges. For example, many physicians identified how treatment decisions were not entirely theirs. Patient loved ones and others involved with the dying patient also exerted influence. Although physicians are in a position of authority and charged with a clinical and ethical responsibility for their patient, even in critical/acute settings where decisional control is generally accepted as being with the physician (Clarke, 2010; Curtis & Vincent, 2010; Hancock, et al., 2007; Prendergast & Luce, 1997; Seymour, 2001, 2003) it did not always play out that way at the bedside.

Accordingly, the aversive experiences physicians reported may be explained as cognitive dissonance (Festinger, 1957, 1964); where the beliefs and positions physicians hold contradict the practices they are compelled to engage in. Festinger argued that cognitive dissonance is an aversive state which prompts a remedial action. However, other than some physicians (particularly palliative specialists) “accepting” that young deaths will occur - an emotion-focused response (Lazarus, 1991); the conflicts physicians reported were not addressed by any mediating strategy. A critical realist view of end-of-life care proposes that the contextualised social structures physicians engage with provide the possibilities for agency where physicians might take appropriate remedial action (Bhaskar, 2011; Giddens, 1984; Lewis, 2000; Mingers, 2004). Bandura (1989, 1997a) further argued, however, that a physician’s perceived self-efficacy influences whether or not they will exercise agency.

9.2. Up against the “System”: Professional Constraints to Care

The “system” refers to institutional/administrative, professional/medical and legal structures which physicians must negotiate differentially when providing end-of-life care. Such efforts are subject to the level of agency that may be exercised in individual
contexts. Frequently, physicians are pitted against a system that restricts practices and resources and “constrains” the care they can provide. All physicians provided accounts of professional, institutional and legal constraints that they experienced aversively.

9.2.1. Self-sacrifice: Meeting demands of the job/setting. The system contains various end-of-life settings, each of which place particular demands on the physicians practicing within them. Regardless of specialty, all physicians described aversive experiences that were reflective of their settings and the associated roles they adopted when providing end-of-life care. All settings placed a significant physical and psycho-social burden on physicians that often extended beyond the immediate work place, and frequently with an enduring effect. For example, Kerrie (Palliative Specialist), experiences emotional exhaustion where, after “giving” of herself all day at work, she has nothing left when she gets home and needs time to herself: “you know…you’re always giving…and you come home emotionally drained…and I withdraw sometimes…I need to be alone for a while”. Likewise, Jeremy (Palliative Specialist) describes how he feels at the end of the day: “it’s certainly energy demanding doing this sort of work, uhm and I go home quite fatigued at the end of the day now…” End-of-life care is fatiguing for Jeremy, requiring much of his energy, but a demanding palliative setting also carries wider impacts: “Uhm, certainly…if things are grim, and onerous at work, then how the hell do I deal with the conflict at home with my spouse or, or with family and, and the answer is well I don’t”. He indicates how his career is all consuming, where conflict at work, especially if unresolved, leaves domestic conflicts unattended. He puts the needs of others ahead of his family’s needs; there is an element of self-sacrifice which is “hard” for him and his family: “it’s hard for me because it’s hard for them…they, often bear the consequences of my, ah…my altruism to others”.

Similarly, Keith (Intensive Care Specialist) describes long working hours as difficult demands of his job: “Uhm…being on call of a night. I’m here seven days now, and I’m on during the day, eight till five or something, but then I’m on call all night, and a bit of me is half awake…” He does not get a day off and is continually on call; it is
difficult to sleep always being “half awake”. The enduring nature of unremitted long hours has a detrimental effect on his health: “and I think it’s caused permanent sleep disturbance because I’m always, thinking the phone call is, you know I’ve got to wake up, get dressed and get to the hospital”. He suffers permanent sleep disturbance, unable to completely switch off because of waiting for the phone to ring. Like her colleague Keith, Gina-Leanne (Intensive Care Specialist) describes similar dynamics of the ICU setting and how they affect her: “the hours and the call, I think…its uhm, it’s an exhausting specialty; all our patients are sick… the hours are long…in ICU”. She finds it exhausting to maintain continued long hours in the ICU, where the condition of patients is critical, placing great demands on her. She also identifies the roster system and how being on call is difficult: “I’m probably…on call, a third of my life…so every third night, every third weekend I’m on call, and after a while that really gets you; that’s the hardest part of this work”. The effects of being on call build up over time and “really get to her”. Moreover, work life inhibits her social life, where she is unable to do things “ordinary people” can: “you can’t do things ordinary people do like join a tennis club because every third weekend you can’t play, I think at some stage you’d like to have a normal life which you just can’t on a specialty”. Gina-Leanne further identifies how with advancing age the specialty of intensive care becomes more demanding and difficult physically: “as you get older you find it more difficult…I mean I’m at the start of a ten day stint, and I know that at the end of ten days I’m going to be absolutely written off…uhm, and that’s hard”. Shift work is hard for her, particularly as she gets older. The fact that she still needs to keep such a work-load suggests that resources might not be available that could share the load with others. This problem may be compounded when physicians were identified as leaving the profession in large numbers due to dangerous levels of fatigue from working long hours (Australian Medical Association, 2003; Coyne, 2011).

9.2.2. Resourcing challenges. Funding for staffing, capabilities to handle increased patient loads, access to expertise and training, and simply having the “time” to provide optimal care were things all physicians needed to factor into their practice.
Regardless of specialty, they all spoke about inadequate resourcing as one of the major impediments to providing good end-of-life care at the bedside. Many physicians also spoke about resourcing problems as something that pre-occupies them, often beyond the workplace. For example, Jenny (Palliative Specialist) talks of resourcing problems and the effect they have on her: “there’s not enough time, not enough of us to look after everyone who needs us…you can always do more, and in ideal circumstances we would be doing an awful lot more…it’s impossible not to take…some aspects of this home”. She laments that she is constrained in doing more, which is something that also occupies her thoughts at home. Jenny’s colleague Candice (Palliative Specialist), experiences similar effects of an under-resourced workplace: “yeah I do take it home sometimes, knowing that if resources were better, so much more could have been done. I really, really struggle with that sometimes”. Candice talks of “really struggling” with the knowledge that much more could have been done for patients if resources were available. She implies that the deaths of some patients could have been managed better. Like many of her colleagues, she needs to make do with what she has at hand. Gary (Palliative Specialist) identifies a system where demand and expectations sometimes exceed what is actually possible: “if we had more hands and more time we could always provide the best care. I feel sad that’s not the reality”. It saddens him to be limited sometimes in what he can do for dying patients.

As another obstacle, physicians who were already under-resourced often needed to divide their time managing administrative and institutional barriers rather than focusing time and effort exclusively on their patient and loved ones. Some physicians saw this as a necessary component of the care they provided where the quality of patient care would decline further without negotiating administrative support. For example, Maggie (Palliative Specialist) adopts multiple roles where she must negotiate administrative and institutional structures to secure resources. She talks of “difficult challenges” she faces in providing good bedside care:
I think the difficult challenge is delivering adequate bedside care but you’re also very much involved in strategy, policy…keeping palliative care on the map…and it seems to fall off the map on a regular basis…and that I think is the big challenge of this role…that you can’t be delivering quality at the bedside if you completely ignore the policies. Delivering good bedside care is not only contingent on good medical expertise, but is reliant on resources for support.

Maggie talks about how her specialty “falls off the map”, implying a lack of recognition and understanding of its benefits. Funding is prioritised elsewhere: “it’s very much an underfunded and less prioritised specialty by comparison with others”. Without funding and adequate resources, it is challenging for Maggie to provide good end-of-life care. However, while she is spending time negotiating administrative and policy matters she is not at the bedside, but she indicates she cannot do one without the other.

9.2.2.1. Juggling patients. Under-resourcing requires physicians to make difficult ethical decisions based on what they regard as priority, but which influence patient outcomes. In a metaphorical sense, patients are juggled within a system constrained by resources, where some patients will miss out on essential care. With similarities to Gary in the palliative setting, Aaron (Respiratory/Thoracic Specialist) discusses critical/acute settings and demand, and the difficulty that resourcing sometimes is for him. He needs to juggle patients according to available resources:

There are times when it’s difficult. It’s not a problem that’s particularly solvable I think, you’ve got full beds, you’ve got a 26 year old involved in a car accident, you’ve got someone with metastatic cancer and you’re not sure whether you should ventilate or not, you take the cancer patient off and put the 26 year old car accident patient on, and all the intensive care beds are full. A classic example was during the swine flu when we had all these young people on cardiac by-pass…you know…when do you take someone off so someone else can go on…you know, they’re ethical decisions that have to be made which there is no real answer for. I find that tough…really hard.
Aaron talks about critical medicine in terms of ethics, where he is reluctantly positioned as the one to determine who lives or dies. He talks of a system that prioritises on resources and need, which means some people will die despite his best efforts. Difficult ethical decisions are “tough and really hard” for Aaron. Such decisions are sometimes referred to as “tragic choices” (Enck, 2011) but, from a governance or institutional perspective, it might be acceptable to lose some patients rather than many, and still provide an acceptable standard of care for most (American Thoracic Society, 1997; Curtis & Vincent, 2010). Physicians, in-line with neoliberal forces in health care (Alston, 2007; Rumbold, 2006), are expected to practice a harm minimisation strategy by extracting the maximum benefit from limited resources, and saving as many patients as they can.

Andrew (Intensive Care Specialist) also illustrates how ICU is not a place to practice end-of-life care. Like Aaron, he is forced to prioritise care on those he can save, and those recognised as dying miss out: “it’s so easy to have twenty other patients who are not meant for comfort measures only, who require your full attention and…I must, confess…that if it’s really busy we might neglect those patients for palliation…that’s obviously a very sad thing”. He considers it “very sad” that setting dynamics and resources direct the care he can provide. Andrew seemingly describes an experience of intrapsychic unease, or cognitive dissonance, because from an ethical standpoint, Andrew may uphold Hippocratic ideals of beneficence and non-maleficence (Isaacs, 2011; McNeill & Dowton, 2002; Veatch & Macpherson, 2010), yet is constrained from providing palliative care to those who are dying.

9.2.2. Time is the enemy. For many physicians, time often represented a particularly scarce resource. Maggie (Palliative Specialist) identified above how she needed to divide her time between clinical and administrative duties. Similarly, physicians in the critical/acute setting found institutional factors that regulated patient loads, and a professional ideology focused toward curative efforts, limited the time they could spend with dying patients. End-of-life oriented care was subsequently inhibited. Andrew (Intensive Care Specialist) experiences this unhelpful dynamic of the ICU:
Even if I can spend only half an hour with someone that’s still better than nothing…but it’s tough sometimes because half an hour is not anywhere near enough time for most people and, and the families of those patients who are dying, for palliation and comfort only need, need as much time to have discussions...maybe more...as, as the families of, patients who are being actively treated in ICU, but...our focus...at least in this place is...more or less forced, onto the patients we can cure...and that’s the very sad part sometimes.

He tries to compromise, some time is better than none. But he experiences this as tough and with sadness. Time is a valuable resource that is prioritised elsewhere. Yet he considers time for discussion equally if not more important for dying patients than those who are not dying. He is essentially “forced” to abandon patients he cannot cure and focus on those he can.

Time is also considered a helpful resource for dealing with uncertainty. Results are not always instant and medication and treatments take time to evaluate their efficacy and determine the next move, (particularly in crucial decisions of withdrawing treatment that might hasten death). This is a point Aaron (Respiratory/Thoracic Specialist) makes:

It’s more the institutional things like lack of resources and time...because there are times when you don’t know what’s going to happen, you need an indication of what’s going to happen with the progress of someone medically, and sometimes 48 hours is not enough, sometimes you need 72 hours to make a decision, but there might not be the resources for you to do that...and that’s really tough...

Like Andrew, he also identifies how time as a resource is often determined by setting influences. In essence, crucial clinical decisions are determined by institutional (meso) factors regulating the time Aaron can spend with patients, which are often further reflective of macro or political level influences in terms of health spending (Cookson, McCabe, & Tsuchya, 2008; Rogers, 2004). He experiences resourcing constraints as “pressure” which he must deal with for the patient and family. He suggests exercising
agency and becoming a patient advocate against the “system” as something he needs to do quite often:

…then you have to deal with that pressure while giving the patient’s family or relatives your honest opinion…and what you’re trying to do is become an advocate for the patient against the system, and that’s not infrequent either. I don’t know if that’s been mentioned in your other interviews. That to me is difficult.

Aaron experiences this dynamic of critical/acute settings with difficulty, wondering if other physicians also confront these challenges. Indeed, all physicians discussed resourcing difficulties of one type or another, where they found themselves pitted against a constraining system of care. When Aaron talks about advocating against the “system”, there are particular similarities with Maggie above (and below) who, like many of her palliative colleagues, also needs to negotiate institutional factors on behalf of her patients.

9.2.2.3. Inadequate training and expertise. Training and expertise in end-of-life care is not widespread outside specialised palliative settings (Australasian Chapter of Palliative Medicine, 2011; Le & Watt, 2010; Palliative Care Australia, 2011b). Critical/acute physicians emphasised earlier (Chapter 7) how they were not motivated or trained in palliation but find it a task which they increasingly needed to take on. This was also reflected in the literature review (Curtis & Vincent, 2010; Fitzsimons et al., 2007; McKeown, et al., 2011; Pattison, 2006). All physicians regardless of specialty, acknowledged the lack of access to specialist palliative expertise either through training or consultation, and how some patients (and their families) suffered needlessly as a result. Physicians experienced such situations with difficulty.

Indeed, Maggie (Palliative Specialist) talks about being in “damage control” because of colleagues who lack expertise and clinical experience. Contrasting critical/acute with palliative care and the importance of her specialty, Maggie highlights how non-specialised physicians without adequate knowledge or skill need to provide end-
of-life care. Patients are sometimes “dumped” and she needs to repair that damage before working to further improve patient outcomes:

I think it’s lack of knowledge and…attitudes…and just seeing what people without the clinical experience are doing…you know hearing NFR\textsuperscript{11} conversations in the corridor…being dumped, but…half the time it’s through no fault of…the clinician…it’s just their lack of experience, or not having access to…experience and mentorship…but a lot of damage gets done and…we’re often in damage control…when we see someone in acute care, because they’ve had five or six bad experiences…not only do we have to try and work for the future we’ve got to undo…have conversations about their…misinformation and…their bad experience…and repair that before you can sort of improve.

Maggie clearly identifies a lack of adequate training and access to expertise and mentoring. But she also talks of “attitudes”, implying a lack of recognition for her specialty. It is “terrible” for her to see patients missing out on the care they deserve. Feeling somewhat helpless, these are difficult challenges Maggie continually negotiates to provide bedside care: “fixing needless damage is a difficult challenge we face every day, yeah…and it’s terrible watching helplessly knowing that many patients will miss out on care they deserve”.

In end-of-life care, there will always be patients who present with challenging problems and, regardless of specialty, not all physicians will deal effectively with every situation. For example, Candice (Palliative Specialist) says: “patients have multiple needs-physical, spiritual and psychological, and it’s not easy getting everything right for everyone…and often heartbreaking when you don’t”. Similarly, although expertly managing complex pain is acknowledged as reflective of specialised palliative training (Palliative Care Australia, 2011a, 2011b), Aaron (Respiratory/Thoracic Specialist) recognises that not all physicians develop such specific expertise without training: “you do your best but some of us are more skilled at titrating meds than others”. Aaron also

\textsuperscript{11} Not for resuscitation
talks of how he struggles with some patients to strike a balance between adequate pain relief and maintaining cognition and a capacity for communication:

There’s times with breakthrough pain where you feel helpless, you know, we’ve all got patients with severe, intractable pain where, you know, they get refractory to the medication, and in that situation you generally sedate them a bit, which basically…helps with the pain but also takes away the consciousness, and that’s something their relatives in particular find difficult…when except for the medications they could still be communicating with the patient. That’s a difficult thing for me.

Although Aaron works in critical/acute settings and expert palliation is sometimes available, there are times he needs to manage intractable pain and when sedation is the only effective remedy. But Aaron illustrates the divisive nature of sedation, not in terms of shortening life, but as an impediment to a capacity for patients and family to communicate together. He considers communication important and, when it cannot be achieved, experiences such situations as difficult and with a sense of helplessness.

Aaron emphasised communication between patients and their loved ones as an important goal potentially facilitated through greater physician expertise, while Maggie further identified how ineffective physician communication skills often translate into poor patient outcomes that physicians also experience negatively. Communication difficulties for physicians engaged with dying patients appeared with ubiquity throughout the reviewed literature (Back, 2004; Clayton, et al., 2005; Moreno-Jiménez, et al., 2008). This area of training was poorly resourced where, particularly for non-palliatively specialised physicians, skills might only be acquired on the job and develop with experience. Accordingly, many of these physicians found themselves out of their depth when communicating end-of-life issues with patients and their families. For example, Gina-Leanne (Intensive Care Specialist) reflects the problematic nature of dying in ICU where efforts are curative and communicating the fact that patients are dying is difficult: “the hardest thing in ICU is to tell the patient that they’re dying, that there’s nothing else
that you can do for them”. Telling patients that they are dying is hard for Gina-Leanne but this may be due to both a lack of communication training and expertise (Clayton, et al., 2007), but also an ideological focus on cure where the expectations of her specialty and those of patients regard death and dying with great difficulty (Curtis & Vincent, 2010; Hillman, 2011). Gina-Leanne still finds communication an obstacle sometimes, even after many years in ICU.

Physicians also need to factor ethical considerations into their decision-making and communicate these to patients and others, and physicians are encouraged to adopt an ethical platform like the Hippocratic Oath early in their education (McNeill & Dowton, 2002; Veatch & Macpherson, 2010). Training necessarily includes ethical aspects when clinical interventions may sometimes be aggressive and painful, potentially futile, and also shorten life. Ethical end-of-life issues that include death hastening measures are more frequently becoming the domain of critical/acute physicians. Knowledgeable physicians may, therefore, be a valuable resource in an educational context and I asked Keith (Intensive Care Specialist) if he has the opportunity to impart his experience to new students, particularly when the dynamic of ICU is increasingly taking on the capacity for managing death and dying. Keith has offered to do this but it appears that ethics around end-of-life care practices are taught by an ethicist rather than someone with end-of-life care experience at the bedside: “I don’t talk about end of life…it’s talked about at university by, by an ethicist…”. Furthermore, Keith points out that the claim to teaching bedside ethics is zealously guarded: “I rang that person up and said ‘look I don’t mind giving a talk on this, about the realities we’ve got’, and he said ‘oh no, I can handle it, I’ve got a much bigger picture than you have’”. Keith mentions “realities”, alluding to ethics taught in the classroom not necessarily reflecting those at the bedside. As if some sort of a turf war, Keith believes his expertise is not respected or wanted, even in a voluntary capacity: “so it spun off that I’m a volunteer, and I was happy to volunteer, but they said ‘oh no, they were…they were doing fine’”. Keith is disillusioned by the

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12 Keith’s voice and demeanour became subdued when telling me this.
structures that regulate the training and education of physicians in the specialty, particularly in end-of-life issues that frequently carry divisive moral and ethical implications.

9.2.3. Collegial (Professional) conflict. Conflict is sometimes related to institutional and administrative structures that regulate where patients can be sent and how care may be provided. Care goal transition has been identified as problematic throughout the literature review (Beckstrand, et al., 2006; Curtis & Rubenfeld, 2005; Le & Watt, 2010; Seymour, 2003; St-Laurent-Gagnon, et al., 2008) and by most physicians in the present study (see “Bad Deaths”; Chapter 7). Patients need to be transferred into appropriate care as their condition develops, however this is also contingent upon others in the system accepting patients into their care. Other physicians may also be constrained by resources limiting their capacity to accept and care for dying patients. For example, Aaron (Respiratory/Thoracic Specialist) experiences professional conflict over patient transfer:

The major source of conflict that I have is basically intensive care. That’s the major problem I have. A patient in intensive care…someone decides look it’s useless, it’s hopeless, we need the bed for someone else, can we ship them up to your ward, and if you disagree with that, that’s where the conflict can occur…where most of my conflict, most of my difficulty is.

Aaron’s collegial difficulties are related to limited resources and receiving dying patients. He particularly identifies intensive care where there is little interest, or capacity for palliative efforts. Patients are subsequently forced elsewhere, to physicians like Aaron who might meet similar constraints for providing suitable care.

Yet many palliative specialists identified above, and earlier when discussing “Bad Deaths” (Chapter 7), the lack of recognition their specialty receives from colleagues and how their expertise is frequently undervalued. Many identified how they often have capacity to take on critical patients transitioning to palliative goals despite the common
perception among colleagues that palliative care is synonymous with cancer patients only (O’Leary & Tiernan, 2008). Candice (Palliative Specialist) makes this point: “we have many cancer patients but can handle most critical patients too, you know...hepatic, renal and cardiac patients...respiratory failures...end-of-life is all about multimorbidity...and it’s so frustrating and sad not being asked and seeing patients suffer who don’t have to”.

Professional etiquette also directs that physicians need to be asked. Candice is somewhat helpless and cannot just take over a patient who could benefit from her care. Similarly, Jenny (Palliative Specialist) said: “it’s so devastating watching people die bad deaths that could benefit from our help...we’re seldom given the chance...except by oncologists”.

Difficult clinical decisions with disagreement over treatment goals also frequently underpin professional conflict between physicians. Gina-Leanne (Intensive Care Specialist) talks of treatment withdrawal, describing how it is particularly problematic for her in the critical/acute setting:

Withdrawing is much more a setting, much more an issue at [hospital de-identified] with the cardiothoracic...patients; we would like to withdraw because we see it as futile, but the surgeons were very attached to their patients, the issue is that my colleagues will promise intensive care when it’s unwarranted...so they’ll have one of their patients they’ve looked after for a long time who’s slowly getting sicker and they’ll say “oh you know intensivists will do blah-blah” and, and invite us to go see them, the patient already has the expectation that we’re going to do blah and blah, and blah and blah is totally unwarranted. That really is a difficult problem for me!

Physicians in critical and acute care will make unrealistic promises to patients and their loved ones. She recognises the problem as specific to particular settings and to specific physicians. Some surgeons have a considerable emotional investment in their patients and are reluctant to acknowledge that they are dying. Death may still be a medical failure for them. She identifies how the societal expectation of intensive medicine to cure is further, but unhelpfully, promoted by colleagues. However, it places Gina-Leanne in a very
difficult position between the reality of what her specialty can do and the unrealistic expectations of the patient and her colleagues. Keith (Intensive Care Specialist) similarly points out how some physicians engender unrealistic expectations in their patients and loved ones, and then hand them over to ICU. He experiences such instances with relatives of dying patients as “confrontational”: “mostly relatives, usually because they’ve been handled in the wrong way up until the point they have come in to us here, but expectations have been unreal, and, sometimes that can be confrontational”. Unrealistic expectations are promoted by an influential professional ideology that supports exhausting all resources in the hope of cure (Hillman, 2009b). Understandably, relatives will cling to hope especially if it comes from the authority of a physician (Curtis et al., 2008).

But some physicians have problems confronting a diagnosis of dying. Keith identifies medical peer pressure to save lives as a difficulty he experiences among colleagues: “the constraints are medical peer pressure to cure…that’s the most difficult part”. Again in curative settings, sometimes also through emotional investment where physicians might have developed a close relationship with patients, interventions are still aimed at patient survival and not comfort, as if death is a failure.

9.2.3.1. Professional paternalism. A seemingly authoritarian medical system further promotes views supporting the sanctity of life both to the community and its physicians, which influence (and constrain) practices (Gielen, et al., 2009; Nitschke & Stewart, 2005). Frequently those views are contrary to those held by the mainstream community and many individual physicians (Allen, 1998; Ashby, 2003; Neil, et al., 2007). Yet the entrenched ideology of the medical system is supported by others in power, and reserves the capacity to censure physicians that hold contrary views. Death and dying remains under professional control and some physicians who sought to support patients in controlling their deaths were made to suffer.

I noted in the literature review that some physicians and their institutions with the support of religious and political structures often played God (Davis & Slater, 1989).
According to Peter (General Practitioner), this may still be the case. He discusses the patronising position of the Australian Medical Association (AMA) in relation to practices that hasten death, particularly at the request of patients and others: “That upset me…it annoyed me, aggravated me a little because of the way they tried to, to suggest that if people think this is a good idea it’s because they don’t fully understand the implications…the AMA’s line was quite patronising”. He supports patients having control and choice over the timing and manner of their deaths and feels very strongly about this. However, control over death rests with the medical institution which precludes any support for a hastened death and further positions itself as expert in these matters:

The idea that you could come along as an expert and tell people that they’ve got the wrong idea, you know, what’s right and what’s wrong, was, annoying me and upset me…that my profession would have taken such, first of all this paternalistic and rather arrogant role, suggesting that they were the experts in the field of death and dying.¹³

Peter speaks out against what he perceives as the authority of the established medical institution and their paternalistic and arrogant role. It annoys and upsets him, considering it wrong that they should control death and dying by medicalising it when it is such a personal matter:

They want to be the bloody experts in death and dying, and that kind of irks me because it’s such a personal process…and it’s not as if…the medical profession has any unique reason for being the experts in that field, I mean maybe with the administration of drugs etcetera, but the idea of death and dying and to medicalise it, to turn the whole process into some form of…almost disease, that this particular profession claims the controlling ground over is wrong.

The established medical institution vigorously resists any challenge to its position and physicians like Robert (Palliative Specialist) have been made to suffer by those in

¹³ Peter said this quite venomously yet with heartfelt emotion.
authority for speaking out against the entrenched views of his profession. He talks about the position of the specialist palliative care community, which denies any validity for hastening death:

I’ve been working in a palliative care community…and held views that the community has not approached end-of-life issues…in a forthright, honest way…and I’ve come into conflict with the community, and it’s been quite stressful for me at times…uhm “I seem to be out of step” and, you know…(sighs) uhm…I’ve been criticised and people have tried to muzzle me if I, and I’ve made some quite public comments, and yeah its challenged the palliative care community, and they haven’t liked it. Because there’s been a…a party line that palliative care has been expected to follow. 

Suffering significant institutional efforts to discredit and silence him, Robert has been pressured to toe the line. Expressing contrary views to those of his specialty are a stressful experience for him, but he stays with his convictions: “I’ve spoken them whenever I’ve been asked about them, uhm…but it has affected my working life uhm, uhm…because…some people have made life difficult for me. That’s been one of the biggest stresses for me”. Like Peter, Robert is somewhat pitted against a powerful system of authority holding influential but minority views. Consistent with the academic literature (Ashby, 2003; Kuhse & Singer, 1988, 1993; Neil, et al., 2007), he shows how out of step his specialty is with other areas of the medical profession, and particularly with public views:

Public opinion on euthanasia shows 75%-80% in favour, and my comments were always well received by the public, uhm, and the medical profession fifty-fifty, but then you get down to palliative care, and this is the interesting phenomenon, the closer people get to the situation the more they’re, sort of, resisting any reform, or…any notion of voluntary euthanasia. So I being a member of that palliative care group, and holding views contrary to theirs, uhm…and one of their own sort of defecting if you like…has been difficult for me. I’ve really copped
some flak yeah.

Holding contrary views to that of his profession has been difficult and he has been targeted for it by those in authority. Like Peter who contends that the medical profession wishes to retain control over death and dying, Robert makes this claim more specific to his specialty. This is something of a contradiction for the palliative community who advocate patient collaboration and control yet deny any choice over the timing of death (Palliative Care Australia, 2011c).

9.2.4. Negotiating an authoritarian system. Many physicians often field requests by patients and loved ones to hasten death. Although these are made for a variety of reasons, usually it is to end suffering. At other times, physicians might autonomously bring about a hastened death to address suffering. However, physicians are legally and professionally constrained from doing so and must manage the care of their patient in a manner that balances patient wishes with legal and professional imperatives. Each situation and opportunity is unique and sometimes physicians have little capacity for agency within institutionalised structures. At such times they can experience their provision of care aversively. For example, Aaron (Respiratory/Thoracic Specialist) says: “it’s really difficult when some patients suffer intractably and nothing you give works. Sedation isn’t perfect but sometimes it’s all you have...you can’t euthanase even if that seems the most appropriate thing”. Similarly, Keith (Intensive Care Specialist) says: “I know some patients suffer terribly...it’s tough watching that but there isn’t always opportunity to give them what they want and so I manage them as best as I can”.

Correspondingly, Peter (General Practitioner) provides an example of a patient suffering end-stage stomach cancer that wanted to end his life, but was institutionalised and essentially “trapped”. As his GP, Peter had limited options at that stage and witnessed the steady decline of his suffering patient, describing it as “macabre misery”:

I was there for a long period with him while we went through that stage and I watched it in all of its rather...ah macabre misery...you could see that there wasn’t anyone out there trying to harm or hurt him or prolong his suffering, in fact
the doctors and the medical services were doing what they could. But I think in a sense you saw the best the system could offer someone, who was effectively by that stage trapped.

Peter doesn’t blame the available medical services but considers them manifestly inadequate for some patients. He illustrates the relationship where he spent much time with his patient—not abandoning him to the “system”. Peter regards the care his patient was receiving as only prolonging a grim dying process but the system was not in a position to provide the peaceful death he wanted: “he didn’t want them to prolong what was a pretty grim period in his life, he wanted a peaceful death and that wasn’t on offer”. The “peaceful death” Peter refers to is one hastened at the patient’s direction.

Like a number of his colleagues, Peter described the lack of options, of patients being trapped within institutional structures, where performing a hastened death at a patient’s request was fraught with difficulty. However, sometimes the system can be negotiated to bring about a hastened death, albeit within a very limited range of options. Although successfully accomplishing a hastened death requested by his patient, he described the required process as “disgusting” and “obscene”:

I described it as pretty…obscene, I mean she woke up at one stage there, after some 24 hours in what is it, in almost an induced coma that we were administering using increasing levels of narcotics and Midazolam…she woke up at one stage when the infusion stopped, in the middle of the night…and asked her best friend who was a nurse who was helping us with the whole process…because what we were trying to do was bring about her death, ah...“Am I dead”? It was just bizarre that...“Kathy am I dead”? I remember it, because I was asleep in the next room, and there’s this scream from Kathy who comes in and wakes me up and said she’s woken up the drip’s stopped. They got the drip started then she lapsed back into unconsciousness again and, it’s an obscenity, I mean we’re not seeing good medicine here, we’re seeing an obscene practice under the guise of medical process and ah nothing, nothing I suppose…I think it’s a, pretty disgusting
situation now that doesn’t mean that I think that doctors who take this path…should be criticised, it’s the only option that the current legislation allows them, I mean no one’s suggesting doctors should go and throw themselves on some sacrificial pile, if they want to help you, and they have to do it in a way that they stay safe themselves, this really is the only option.

Peter is describing a death brought about by sedation, a legal practice manipulated to achieve an outcome suitable for the patient. He highlights the problematic (and potentially traumatic) nature of such a divisive intervention with the patient waking up during the process of her death. Again supporting his medical colleagues, Peter levels blame for such obscene deaths at the medical system, which constrains options for hastening death. He acknowledges legal and professional concerns of physicians who elect to take this path without legislative support.

9.2.4.1. Double effect: An ambiguous scaffold. Physicians, who sometimes negotiate hastened deaths, often regard being compelled to find protection within ambiguous legal structures as inadequate and inappropriate. Double effect is divisive within the medical community (MacIntyre, 2006; White, et al., 2011) (discussed extensively earlier, see particularly Chapters 3-4), indeed Jenny (Palliative Specialist) said: “the old term ‘double effect’ shouldn’t be used anymore…I think if opioids are used appropriately it should never happen; that’s the reason why palliative care is so extremely important in Australian end-of-life care and worldwide end-of-life care”. She promotes the value of her specialty and the expertise of its practitioners, denying that double effect is still required. Although some physicians like Peter above will actively manipulate practices to hasten a death and subsequently draw on double effect; others will only use it reluctantly or of necessity. For example, when his intractably suffering patient died shortly after being treated, Jeremy (Palliative Specialist) acknowledged how he could be compelled to use double effect despite finding it distasteful:

I don’t like invoking the Principle of Double Effect as justification for what I did with that patient…at all. But, uhm……I know that I could. I know if someone
attacks me in law I would have to use that argument to say that, that I was not responsible for his death…but I feel responsible.

Using double effect does not sit well with Jeremy. He has no other option, however, if attacked in law. Although he might find legal and professional protection, the situation remains difficult for him. He acknowledges the protection he has but also identifies how double effect does not assuage his sense of responsibility for a patient’s death. This is something he is left to deal with.

Furthermore, Robert (Palliative Specialist) identifies how the law only considers the doctor’s “intent” when a death is deemed to be hastened. He suggests patients implore their physician to be compassionate and assist a hastened death. There is significant emotional and psychological pressure brought to bear on the physician by the patient and also by the system or context the physician is immersed in. Robert suggests that there is little capacity in the law to recognise the motivations of physicians when a death is hastened. Nonetheless, the physician is forced to negotiate the needs of patients within legal and professional structures but in a way that is also consistent with their own position on particular practices:

Not just a petty crime, the worst of all crimes, all hinging on this concept of intention which, I think, is where there should be some reform, to the ethical and legal framework, because…the person’s autonomy, what they’re looking to the doctor to do, the doctor’s motive of compassion and understanding and professional responsibility to help people who are suffering and struggling…all of those things are morally relevant and they should be legally relevant…I shouldn’t be made to feel like a criminal if I’m helping my patient!

Robert talks about other issues beyond a simplistic evaluation of intent that are also important moral considerations in a hastened death. He mentions compassion, understanding, a respect for patient autonomy and a responsibility to address suffering.
As morally relevant they should also be legally relevant. He proposes a review of current narrow and simplistic laws:

Yeah the law hinges on just one thing: was it in the doctor’s mind to intend bringing about this guy’s death? And…that’s a very simplistic and crude way of framing it, and why I think there should be a review of that law. It’s really hard focusing on the patient when I have to always worry about what might trip me up. And I do worry about that.

He explains how the focus he needs to keep on his patient is distracted by “always worrying” about potential legal ramifications of the practices he engages in. But there is little or no recognition in double effect of the emotional pressure physicians are placed under by patients and others to accede to a hastened death.

This major theme identified how physicians across settings sometimes found themselves pitted against a system which placed considerable physical and psycho-emotional demands on them. Physician efforts were often one of self-sacrifice; indeed, we saw Jeremy and Kerrie experiencing “compassion fatigue”, something quite common for end-of-life work (Keidel, 2002; Najjar, et al., 2009; Sabo, 2008; Sprang, et al., 2007), while Keith and Gina-Leanne experienced long term effects of aversive organisational factors commonly related to burnout (Dunwoodie & Auret, 2007; Girgis, et al., 2009; Keidel, 2002). Also, frequently limited by time and training, physicians needed to negotiate multiple resourcing challenges in the interests of their patients. Cognitive dissonance was expressed by all physicians throughout this subtheme, where constraints inhibited the care they wished to provide, forcing them to compromise and do the best they could. Physicians needed to continually negotiate the system to mediate the effects of resource limitations, and the relative efficacy with which they could do this (Bandura, 1989; Bandura & Jourden, 1991) impacted their experiences. Physicians also experienced collegial conflict over treatment decisions and professional paternalism from their institutional structure that issued retribution to physicians holding a contrary position. A seemingly authoritarian system forced physicians like Peter, Jeremy and Robert to
negotiate or manipulate certain practices, especially when hastening death, and then seek protection behind ambiguous legal structures. Throughout this key theme, physicians were compelled to provide care in ways they considered inadequate.

9.3. The Intrapsychic Burden

Although the socio-cultural and professional influences discussed above carried emotional and psychological effects for physicians, these effects were often quite explicit and subject to an identifiable external source. However, physicians also experienced psychological and emotional effects that were more implicit, and sourced from within the physician. Frequently these were in the context of personal relationships. For example, all physicians mentioned experiencing “emotional pressure” applied by dying patients and their families. Many physicians also experienced unpleasant intrapsychic effects from “identifying” with these people. Most physicians also experienced “self-recrimination” after particular decisions and outcomes, and often when confronted by particular dilemmas and uncertainty.

9.3.1. Feeling emotional pressure. Most physicians experienced emotional pressure from patients and their families requesting a hastened death. Often they would beg or plead with the physician to be compassionate and bring about a hastened death to end suffering. One physician, Robert (Palliative Specialist), talks of emotional pressure applied by patients to hasten their death: “it’s much harder legally to…ah accede to a patient’s…you know, request…but it’s more than a request, it’s not a demand because they can’t demand uhm…but it’s a plea really”. Robert identifies requests more as a “plea”, where patients and others place themselves at the mercy of the physician but also bring significant emotional pressure to bear. Robert mentions “harder to accede”, suggesting that because such a decision is collaborative rather than autonomous by the physician it may be more professionally or legally risky. But it may also be “harder” for Robert because the decision comes with added emotional pressure. His colleague Gary (Palliative Specialist) discussed this also: “you know some patients and their families are literally begging you to end it…it’s really tough sometimes but you can understand their
suffering”. Gary empathises with patient and family suffering and it is “tough” on him when they “beg” for death.

In contrast, a number of physicians also experienced similar emotional pressure, usually applied by family members of a dying loved one, to exhaust all avenues and save life. Not unexpectedly, this was something all critical/acute physicians experienced. For example, Andrew (Intensive Care Specialist) said: “families often expect miracles; they beg you to do something…that’s terrible sometimes…how do you tell them the brain-dead patient lying there will never come back to them”? Similarly, Gina-Leanne (Intensive Care Specialist) talks of emotional pressure applied by loved ones who “bargain” with her to continue treating when withdrawing treatment is the more appropriate option:

One of the awful things that often comes up, is the issue of…uhm…say for example bad head injury following trauma, we know there’s nothing more we can do for the patient, so ideally the best thing to do…would be to withdraw and let the patient die…and the families say “just one more day, just one more day, just one more day”…that does make it incredibly difficult when you’ve got a patient sitting there, you know it’s useless, futile, it’s a waste of time, but the family just want to hang on to them for another 24, 48 and they bargain with you, they’re not bargaining with you about, you know…a bag of groceries or something, their bargaining with you about somebody’s life!

Gina-Leanne is positioned as the one controlling life and death. It is “incredibly difficult” for her when loved ones “bargain” for the life of the dying patient. The constraints of culture and setting, which create expectations to save life, become a difficult obstacle that Gina-Leanne needs to negotiate. She acknowledges the dying person as not just a “bag of groceries” and highlights multileveled influences where socio-cultural engendered expectations of cure, and similar professional aspects, affect her experience of the physician/patient relationship.
9.3.2. Identifying with patients. The physician/patient relationship is expected to be professional and objective (Lee & Dupree, 2008; Shapiro, 2011). Even when physicians express empathy for dying patients and their families, they are generally able to maintain a personal emotional and psychological distance and still provide personalised care. However, sometimes the boundary that separates physicians emotionally and psychologically from patients and others is breached, and a number of physicians experienced unpleasant emotional effects from “identification”. For example, Keith (Intensive Care Specialist) finds that even for the most seasoned and experienced veterans of intensive care, a physician can be deeply affected, particularly when they have formed an attachment or identified with their patient: “Sometimes you get knocked for six quite unexpectedly; especially when you might identify strongly with a patient… sometimes… sometimes even for the most hardened of us a patient will touch a raw nerve”. In specialised palliative settings, this is not uncommon, in fact it is often expected, and there are usually recognised strategies in place in terms of support and debriefing (Blomberg & Sahlberg-Blom, 2007; Rumbold, 1998; Vachon, 2003). But, in the intensive setting where patients are not expected to die, physicians are less prepared for dealing with death, and access to such supportive strategies may be limited. Unlike the dynamic of palliative settings that encourages physician/patient relationships, curative settings have been described as busy, impersonal and transient so physicians may not have much experience dealing with identification issues that can lead to burnout (Sprang, et al., 2007) and disengagement (Keidel, 2002).

Gina-Leanne (Intensive Care Specialist) similarly talks of being affected when least expecting it. Like many of her colleagues, identifying with particular patients and their family can be upsetting when they die:

Some people will…get you and some people won’t, some people you can be very cool, calm and collected, and some people for some reason maybe they look like someone you know, or…they’ve got a condition that someone you know died
from, or you got very close to the patient, or close to the family…that can be uhm, yeah it can be upsetting.

Gina-Leanne talks of trying to stay objective and clinically focused, yet that professional expectation is difficult for her to sustain sometimes. Likewise, Jenny (Palliative Specialist) relates her emotional experience when identifying with dying patients and their loved ones: “lots of sadness…the people that had the most impact on me, its people who you just think, why…it’s so tragic, young mother with young kids…it’s tragic, and maybe the…same age kids, and thinking why and this is so unfair”. It is difficult for Jenny when she has children the same age as those have who are dying. She identifies closely and experiences a “lot of sadness” in such tragic and unfair circumstances. These are cases which she finds hard to understand and significantly impact her emotionally.

Correspondingly, Andrew (Intensive Care Specialist) empathises with young children when one of their parents dies. He finds it difficult that they will really never know their parent or understand the circumstances of the death: “it’s really difficult, if you’re young with a young family, if you’ve got small kids and knowing that they will never really know who their mother or father was, or remember actually what was happening, that is difficult”. Like Jenny, Andrew positions himself as somewhat kindred to young families with a dying loved one. He identifies with them:

It’s also very difficult when they’re, obviously when you’ve got kids yourself and they’re about the same age, it’s so easy to relate to what’s going through their minds and, and it is difficult when you know that they realise what is happening but they just can’t comprehend what is happening…and in those cases, being young patients, I have to say “I don’t understand either…why your mum had to develop leukaemia, why there’s nothing more we can do”.

It is very difficult for Andrew to see children who are confused and struggle to understand why their mother has died. He understands what is going through their minds. He positions himself as a surviving parent and tries to explain with honesty and at a level
comprehensible to children of that age, how he has not been able to save their mother.

9.3.3. Self-recrimination. End-of-life care exhibits great specificity, with uncertainty in treatment decisions or outcomes common. Most physicians spoke of the uncertainty they experienced at times with individual patients, where things might not have gone as expected or hoped for and leaving the physician with a sense of self-recrimination. They would often question themselves over whether they could or should have done things differently. For example, Thomas (General Practitioner) talks of an acute situation and, although these are often difficult to predict and adequately prepare for, hindsight leaves him wondering if he could have done better: “I wondered if there was something I could have done better, differently, maybe more prepared…” Similarly, Andrew (Intensive Care Specialist) provides an example of a girl with severe mental impairment. He asks himself if it was best for her quality of life to allow her to die - an onerous responsibility:

One of the most difficult cases I’ve been involved with was a, young girl…thirteen from memory, who had severe mental retardation, and she aspirated in the…facility she was in and had a cardiac arrest, and she was resuscitated by the nurses and resuscitated by the ambulance crew all the way to the hospital. The parents arrived in the emergency room as we were still resuscitating and they, they asked us “stop resuscitating”…and obviously in that situation you don’t know too much about the patient, uhm, you know, that she’s from a nursing facility, that, that an acute event happened, and if you stop resuscitation she will die…and, then again everyone involved agreed, including myself, ah that we should stop, and as we did I was just thinking, “did I really know that much about her quality of life”…was it more, I, I remember this quite well because I stopped to think was it more the parents…who didn’t want to see her in that state anymore?

Andrew recognises how he is in no position to understand and make difficult decisions on behalf of another person’s quality of life. He questions himself over whether he was working in his patient’s interests or her family’s who could not bear witnessing their
child’s suffering any longer. Andrew does not forget such incidents: “I don’t know what her life was like, I quite a few times thought about that girl”. He makes the point that end-of-life decisions are sometimes made on a *perceived* quality of life. But this excerpt also highlights how a structured procedure (even if regarded as inadequate) directs many end-of-life decisions. For example, unless an Advance Care Directive is in place, professional and legal imperatives *require* patients to be kept alive until handed over in emergency (Hillman, 2011) and then in the wards (Chan & Berg, 2010; Chen, et al., 2008). This patient was only young and under parental guardianship, but she was constantly resuscitated.

Sometimes physicians are confronted by extraordinary suffering, where actively administering narcotics is the only remedial choice but dramatically shortens life. For example, Gary (Palliative Specialist) said: “when you treat intractable suffering like that and the patient dies…sometimes you struggle…you go over it and over it in your head and ask yourself if there was another way”. Similarly, Jeremy (Palliative Specialist) describes such a case where he hastened death, and experiences ongoing self-recrimination:

Now that’s not to say that I haven’t killed people. I remember very clearly…a well-known figure, who was in the terminal stages of a terminal illness…extraordinarily distressed with unrelieved pain and breathing difficulties and thrashing around on the bed, and nothing that had been given was working. And I drew up a syringe full of Midazolam, and I popped it into a vein, and I just pushed it in and pushed it in and pushed it in until his breathing settled down and he relaxed, and he stopped thrashing around, and found ah, an induced peace if you like. Now a quarter of an hour later he died. I cannot tell you whether my intention was solely to relieve his suffering, or to address my suffering, or to address the suffering of the staff and others who knew this man. I can’t unpack that in all honesty…I know that in all probability the medication I gave him did hasten his death…I still struggle to unpack that for myself.
This was an incident that occurred over 20 years ago but still troubles Jeremy. Like Andrew above, Jeremy questions whose suffering he was trying to alleviate. He struggles to unpack and come to terms with the experience. Physicians like Jeremy find themselves in a difficult position. They mustn’t hasten death according to religious doctrines (which some like Jeremy strongly support) or professional and legal requirements, yet they cannot witness extraordinary suffering and do nothing either. They have an obligation to their patient.

Many physicians were frequently confronted by particular dilemmas, where they needed to make a choice that would impact the survival or quality of life for a patient. Physicians experienced dilemmas from uncertainty related to institutional factors, sedation, treatment futility, goal transition, and internal conflict. For example, Aaron (Respiratory/Thoracic Specialist) spoke earlier of institutional factors where decisions that might suggest withdrawing seemingly futile treatment are out of his control. Results are not always instant but he is caught between institutional constraints limiting time and the welfare of his patient: “you don’t know if you made the right decision, you don’t know if it’s going to be the right decision for maybe another one or two days, whether the treatment you’ve given has made a difference or not”. Aaron questions his decision making which is inhibited or constrained by higher influences and experiences self-recrimination: “these are dilemmas I really agonise over…because if I had more time things might have been different for the patient”. He “agonises” over dilemmas that are essentially out of his control.

Although physicians do have some control over clinical interventions, therapeutic outcomes may still be uncertain and experienced with dilemma. Complexity Theory emphasises non-predictability (Byrne, 1998, 2005) and this applies strongly to the timing of death. Jenny (Palliative Specialist) talks of the divisive practice of sedation, something she uses only in exceptional circumstances. Confronted with enormous symptomatic complexity and suffering, she finds herself in a “difficult” position and questions herself over whether sedating the patient actually shortened his life:
A youngish man with a dreadful, dreadful disease\textsuperscript{14}…severe pain, and loss of dignity was overwhelming for him, he had frequent incontinence, couldn’t do anything…he, found living with his disease so distressing…of such overwhelming anxiety…whatever he ate was actually passing straight through. So…he wanted sedation, and nutrition was, uhm…was not going to prolong his life because there was no way of him absorbing it…we tried various ways until he said “there’s no point, I don’t need to eat, I don’t want to eat, I don’t feel hungry, the more I eat the more it comes out”…uhm…and…in that stage of sedation I had a difficult, I felt, the dilemma of…sedating, am I hastening his death because he will be less likely to eat and drink, versus his distress and anguish and the dreadful state of his disease?

Nutrition and hydration are normally withdrawn when instituting sedation, and it is normally an intervention provided only at the very end-of-life. As a palliative specialist, Jenny thoroughly understands the implications of sedation but still “felt the dilemma” of providing a treatment intended to address suffering (and maintain dignity) while potentially hastening the patient’s death at the same time. The problematic nature of sedation was noted by most physicians and like Jenny, Gina-Leanne (Intensive Care Specialist) experienced similar dilemma and self-reproach: “if you’re sedating they’re close to the end anyway but the dilemma is finding the balance…you know, stop suffering without completely ablating consciousness…deaths are more distressing when goodbyes can’t be said…you know; have I taken that opportunity away”? Gina-Leanne identifies the importance of communication at end-of-life and the influence titrated sedation has for the quality of death.

Sometimes, goal transition from an investigative and curative phase to one that is more comfort-based poses a particular dilemma for physicians. For example, in her current case with a young man suffering advanced lung cancer and suspected spinal cord

\textsuperscript{14} Jenny spoke of a fistula where “his rectum had invaded his bladder”.
compression, Kerrie (Palliative Specialist) does not know whether further treatment would be futile and worries about such decisions:

The correct management, in some situations would be to send him for an MRI, start some medication, and get him transferred for some radio therapy very quickly…I made the decision not to do those things, because I believed his life expectancy wouldn’t warrant it. Now in fact he has compressed his cord and he’s now, essentially a paraplegic…but he probably still has longer to live than I expected, uhm and those, those dilemmas I find myself, you know…I worry if I did the wrong thing not investigating further…you know…would it have made any difference? Have I detracted from his quality of life in the last weeks of his life because he can no longer walk now?

Kerrie experiences a dilemma of whether she should have provided potentially futile and burdensome treatment that could have adversely impacted his quality of life. She wonders if it would have made any difference. The patient’s life expectancy was longer than she thought, but not prescribing treatment potentially affected the quality of life he had by preventing him from walking again. Kerrie’s negative experience may be all the more intense because she also identifies a gatekeeper role over treatment access (Davis & Slater, 1989) and decisional responsibility is hers alone (Grönlund, Dahlqvist, & Söderberg, 2011). Similarly, Candice (Palliative Specialist) also “agonises” over difficult decisions that are context specific and never clear-cut:

It’s not clear-cut, it can never be, and…that’s a dilemma, where I agonise a lot, would this person actually be more comfortable on antibiotics, that’s a common one, a chest infection at the very end of life. Should I put in a drip or not, would I change outcomes or, or not? Yeah, would I want that drip?

Candice considers a personal position on whether she would want treatment, agonising over whether she would change outcomes and make a positive difference for the patient.
But she illustrates the complexity of end-of-life decision-making and the subjectivity involved that she must take into consideration in each case.

The dilemmas Kerrie and Candice experience over care goal transition to a comfort-based focus may be particularly problematic for curatively-oriented physicians. Uncertainty and intrapsychic unease at the prospect of patients dying are experienced by some physicians when influenced by mainstream societal expectations and the ideology of critical medicine to cure (Hillman, 2011; McDermid & Bagshaw, 2009). The realisation of impending death is difficult to accept and influences decision making at end-of-life. The physician’s decisions are sometimes based on “hope” rather than any evidenced-based science. They cannot make decisions with any degree of confidence. Indeed, Keith (Intensive Care Specialist) identifies with the uncertainty of some physicians when treating the dying and their motivation to incrementally increase treatment to cure and prevent death:

The other difficult part is ourselves in that your instinct tells you to stop…but we’re incrementally providing more and more treatment…they’re slipping away from us and we incrementally provide a bit more of this and a bit more of that and keep them…stable, so they, so they don’t slip away from us in the hope that they’ll turn around and get better. So it’s our uncertainty that’s another blocker.

This key theme examined the intrapsychic burden that physicians experienced in their interaction with dying patients and patient loved ones. Many experienced emotional pressure both to assist a hastened death and, sometimes, to inappropriately exhaust all avenues and prevent death. Patients and their families often “begged” or “pleaded” with physicians. Physicians responded to a complex interaction of influences, where their decisions needed to be clinically and ethically astute, and also compassionate. A number of physicians also identified with patients and patient families and often regarded those experiences as difficult. The consequences of identification can be quite detrimental, being linked to compassion fatigue and burnout (Figley, 1995; Huggard, 2003; Kearney, et al., 2009; Sprang, et al., 2007). Physicians sometimes experience vicarious
traumatisation in situations where they relate strongly to a patient or patient loved ones (Figley, 1995; Najjar, et al., 2009; Sabo, 2008; Sinclair & Hamill, 2007) and, in the earlier literature review; corresponding issues of transference and countertransference were reported to adversely affect physician (and patient) well-being (Kissane, 2000; Vachon, 2003). Indeed, Keith reported being “knocked for six” when least expecting it. Although spirituality and a belief in life-after-death is claimed to mediate the effects of identification (Pearlman & Saakvitne, 1995), physicians like Keith, a self-pronounced atheist, might not draw any such benefit. Many physicians also experienced self-recrimination over treatment decisions and practices which, often shrouded in uncertainty, also presented difficult moral and ethical dilemmas. Physicians frequently demonstrated cognitive dissonance (Festinger, 1957, 1964) as a factor in these experiences.

9.4. Coping with Aversive Experience

End-of-life care is associated with many potentially aversive consequences for physician experiences (Dunwoodie & Auret, 2007; Girgis, et al., 2009; Keidel, 2002; Sabo, 2008). To continue practicing, physicians sought ways of managing experiences that could threaten their physical and psychological health and their relationships with friends and family. For most physicians, coping was not always successful. Some strategies worked and others did not. They were also context specific requiring physicians to accommodate different situations, although previous strategies, effective or not, were a resource for physicians to draw on. If unsuccessful they generally avoided them and found another way, and successful ones were adapted and implemented again. All physicians described common strategies they used with varying degrees of efficacy to cope with aversive experiences.

Lazarus’s transactional model represents one of the most widely utilised conceptualisations of coping (Lazarus, 1993a, 1993b; Lazarus & Folkman, 1984). In essence, the model suggests a coping response is required to reduce the psycho-emotional stress resulting from a perceived or actual discrepancy between demands and resources; to address incongruence between the person and environment (Lazarus & Folkman,
Accordingly, psychological and physical energy is directed toward reducing negative emotions, or directly at the stressor (Lazarus, 1991). A transactional approach emphasises cognitive appraisal and considers biological and social aspects of stress (Folkman & Lazarus, 1988; Lazarus, 1999). The model is therefore multidimensional, advocating roles of stimulus, emotional and behavioural responses, individual differences, and of the environment (Lazarus, 1999). Further, consistent with the current research epistemology, this model recognises the importance of situation specific coping strategies where the dynamic and multidimensional nature of individual situations and experiences requires an adaptive response (Kyngeas et al., 2001).

According to Lazarus (1991) and others (Folkman & Lazarus, 1985; Lazarus & Folkman, 1984), coping may be cognitive or behavioural, and also active or passive (Roth & Cohen, 1986; Suls & Fletcher, 1985). For example, adaptive coping generally occurs through problem-focused and emotion-focused strategies which may be used together or independently according to the specific situation (Lazarus, 1991, 1993a). Problem-focused strategies are instrumental coping efforts (cognitive and/or behavioural) to reduce stressor demands or increase personal resources. For example, physicians might seek information and debriefing, negotiate constraints, or develop particular skills to deal with negative experiences. Emotion-focused strategies may employ cognitive efforts such as positive re-appraisal, acceptance, seeking emotional support and expressing emotions, or engaging in prayer. An active approach attends directly to the source of stress, seeking ways to manage it; while a passive or blunting approach sometimes through acceptance, avoidance or distraction, is more concerned with minimising the threat of a particular situation (Roth & Cohen, 1986; Suls & Fletcher, 1985). Through the subthemes below, the physicians’ accounts illustrated strategies they use to try and cope with their negative experiences in end-of-life care.

9.4.1. Self-reflection. For most physicians, self-reflection was a strategy that helped them cope with aversive experiences; where they could process psycho-emotional material at a suitable time and place. By reflecting on their experience, physicians could
consider ways of dealing with similar events occurring in the future, and sometimes assist others. In a cathartic process, physicians could think things through, ask themselves questions, take responsibility where appropriate and learn from their experience. They also better understood and came to accept how some things were not always in their control. For example, Maggie (Palliative Specialist) regards self-reflection as helpful for working through particular issues that might not have been completely dealt with otherwise: “sometimes when it’s quiet you…reflect…but you process it… yeah…it’s just something you tend to deal with, in the job”. Maggie identifies quiet times that allow for self-reflection, where she can think through and “process” difficulties in the job.

Similarly, Gina-Leanne (Intensive Care Specialist) finds self-reflection helpful for working through troublesome experiences. She reflects on whether she could have done anything differently: “you always reflect and ask yourself…‘could I have done anything better…to have, made that better’? And once you’ve thought about it…if something’s there, put it somewhere and think about it for next time, otherwise draw a line under it”. She considers her experience as a lesson for “next time” and, if out of her control, moves on; she “draws a line under it”.

Likewise, Robert (Palliative Specialist) talks about reflecting and “owning” responsibility, apologising where appropriate, and moving on; something which is not always easy to do:

If you feel you’ve made a mistake or…should have done something that could have made things better, or you feel like you’re being criticised by the team members or the family, you have to, reflect on it yourself, and the best thing you can do is own it, and say “look I apologise, I’ve made a mistake” or “I could have done things better” or, and, that is not always easy to do, and different people handle things differently.

The process of self-reflection is also illustrated by Andrew (Intensive Care Specialist) who talks about decisions and practices that have accelerated death, particularly those where treatment was withheld. He points out how complex end-of-life care is when it
“triggers lots of questions”:

I can’t say I regret the decision…I think she would have died in the hospital within a few weeks’ time…but, but it’s just that….and that’s important, I think that, that a few of these cases really triggers a lot of questions…that you keep reminding yourself “yeah that’s the question I need to have the answer for”.

Through self-reflection, Andrew asks himself questions (some of which may not always be answered) that ultimately allows him to experience a difficult situation without regret. He can acknowledge that the patient would have most likely died in hospital later anyway rather than as a direct consequence of his decision. Similar decisional difficulties were also experienced by Jeremy (Palliative Specialist) who reflects on an incident in which a patient with intractable suffering died shortly after receiving the medication he administered: “I acted, uhm…as a decision making thing which is what I’ve been trained to do, and it was only subsequently that I needed to think about it and reflect on it, and unpack it”. Jeremy suggests he acted reactively - almost by instinct, a product of his training, and that only upon self-reflection did the implications of his action become apparent. He could then “unpack” and work through his problem. Jeremy also identifies a particular identity as a “decision-making thing”.

9.4.2. Rationalising decisions and actions. As a strategy for mediating potentially aversive experiences like cognitive dissonance, physicians frequently rationalised their decisions and practices. For example, a particular action or decision that physicians might regard as unpalatable or conflicting with their personal and professional values and beliefs, or with legal prescriptions, could be rationalised as serving a greater good. In essence, they could cognitively “reframe” or “reappraise” a negative event or experience to one more positive. This was illustrated by all physicians, some of whom also received requests to hasten death. A small minority said they had acceded to such a request in very particular circumstances, mostly to address extraordinary suffering. For example, Peter (General Practitioner) often gets requests to die: “people ask all the time, and if they’re suffering I’ll try to find a way to help them with what they want…that has
to override anything the law might say”. Peter rationalises his decision to assist a hastened
death in the interests of addressing suffering and upholding patient autonomy. Keith
(Intensive Care Specialist) also said: “I support patients with extraordinary suffering who
make a rational choice to die…and I work in their interest…that’s what I would want”.
Like Peter, the patient takes priority for Keith but he also considers his own position.
Potential psychological unease can be mitigated if practices are consistent with personal
beliefs (Festinger, 1957, 1964) and Robert (Palliative Specialist) similarly upholds patient
autonomy by giving patients control over dying while further rationalising practices as
addressing their suffering: “look if it’s appropriate and a patient says ‘don’t hold back -
bomb me out’ then I’m ok with that…I won’t let them suffer. Patients should have control
over their death…that’s very important to me”.

Similarly, but after acting independently, Jeremy (Palliative Specialist)
rationalises hastening death as the only course available to him when confronted by
intractable suffering:

I feel I was responsible for his death, uhm, that’s how it feels to me. But I also feel
that his anguish was so great that it was appropriate to relieve that anguish for him
and…perhaps it might have been for me a little bit. I’m troubled by how much my
own distress was relieved by that.

Earlier (Chapter 7), Jeremy stated his active involvement in the Church. We can
understand, therefore, why he is so troubled by this experience when he feels responsible
for the patient’s death. Clearly, even for someone of Jeremy’s experience, some things are
never completely (or adequately) dealt with. He still wonders whether he was also
motivated by his own distress.

However, most physicians also mentioned that they had been involved in
situations where death ensued shortly after providing measured and more generally
accepted remedial interventions. A number of physicians referred to practices of sedation,
something earlier identified as divisive in the medical community (Chapters 4-5) because
it frequently hastened death. Physicians rationalised engaging in those practices through having no alternative when confronted by intractable suffering. Indeed, Gary (Palliative Specialist) talks of sedation being his “only option”: “I mean when their breathing is so distressed, you have no other option than to treat them by sedation”. Sedation is a practice Gary is comfortable with when he has no other choice. He talks about an extraordinarily distressed patient struggling to breathe who “pleads” with him to do something: “…and it was through his breathlessness he pleaded with me to do something. I don’t have a problem with it, because again, I know that’s what I’ve got to do”. Gary is further confronted by the emotional pressure of a patient “pleading” with him and again rationalises his actions as “knowing that’s what he has to do”. His colleague Kerrie (Palliative Specialist) also said: “I’ll use it only as a last resort when nothing else works”; while Jenny (Palliative Specialist) also rationalises her reluctant use of sedation:

   I rationalise it in my practice, it’s not a treatment I use very often…when somebody is suffering so extremely from their symptoms, and sedatives are required, then the balance of that compared to the suffering, knowing that death might be hastened but that there is no adequate or possible cure or life prolonging measure that can be instigated, uh, sort of outweighs it and there tends to be a balance.

Jenny finds that using sedation to alleviate suffering is “balanced” by the alternative of not using it. She rationalises that, even if death is hastened, no cure or life preserving measure is available.

   As identified, physicians may cope with psycho-emotional demands in end-of-life care by practicing in ways consistent with the beliefs they hold. Such beliefs provide ways of rationalising decisions and practices, and Keith (Intensive Care specialist) identifies a professional framework that guides him: “I have a very strong professional framework, and I stay within those bounds… …as long as I’ve got my professional framework really tight, then I think I can live with most other things”. Keith “can live with most things” if he can rationalise them within the professional structure he holds.
Similarly, the medico/legal doctrine of *double effect* is helpful to physicians who believe they could face allegations of hastening death and Thomas (General Practitioner) rationalises these deaths accordingly: “if they’re dying and they’re suffering then I’ll relieve the suffering…and if they die slightly quicker, ok”. Most physicians drew comfort from such legal and professional support being available if needed. Indeed, Aaron (Respiratory/Thoracic Specialist) also rationalises a hastened death this way: “provided it’s been thought through, and there’s been proper consultation and communication, then if measures I use to help alleviate pain hasten…ah, hasten death for whatever reason, I’m very comfortable with that”. Aaron talks about double effect, where being motivated to alleviating pain hastens death, and he draws comfort from that. He also indicates how such decisions are not without thoughtful consideration and, where possible, professional collaboration. This is a strategy that diffuses responsibility and provides reassurance.

**9.4.3. Doing the best you can: Working with what you have.** Sometimes, coping entails an *acceptance* of limitations, particularly a lack of resources that inhibit the care which may be provided. Limitations, sometimes multiple, are often reflective of particular settings and many physicians were compelled at times to make do with what they had. Constraints to patient care can be rationalised this way. For example, Aaron (Respiratory/Thoracic Specialist) highlights setting differences, where all critical/acute settings are not the same: “at some places you don’t have to worry…juggling resources to manage patients…you make good clinical decisions, whereas other places you just have to deal with the limitations and factor them in your decision making…and do the best you can”. Aaron particularly refers to resourcing constraints, being compelled to just do the “best he can” and work with what is available. Importantly, he acknowledges how such constraints are influential in his decision making. He takes a problem-focused approach when “juggling” limited resources and “factoring” them into his decisions.

Understandably though, not every situation will have a perfect outcome. Much is beyond the control of physicians, and accepting that is a realistic approach to coping with situations that are difficult (Lowe, Norman, & Bennet, 2000; Shapiro, et al., 2011).
Acceptance was a coping response illustrated by a number of physicians. For example, Jeremy (Palliative Specialist) accepts, albeit sadly, that sometimes giving his best is all he can do: “well sadly, you can’t win them all… you can only give it your best shot”. Kerrie (Palliative Specialist) understands this also: “I have to have my professional boundaries and, and… you know, you’re not going to get every single thing right. Yeah, and sometimes you just have to walk away”. Kerrie’s professional boundaries help her accept that she cannot get everything right and signal when she should move on. Similarly, Candice (Palliative Specialist) accepts that not all deaths will be the best: “sometimes you need to accept that this is the best death you can get for some people” while, philosophically, Robert (Palliative Specialist) also accepts that “bad things will happen to people”:

You kind of accept that death is going to happen to people…and you kind of accept that bad things are going to happen to people, uhm…I like to think of the serenity…what’s that little prayer…? “Have the courage to change the things you can change, have the serenity to accept the things you can’t change [the fact that some people are going to die], and the wisdom to know the difference”.

Most physicians often just accepted and worked with particular limitations and difficulties they encountered providing end-of-life care. When situations were beyond their control, they did the best they could. However, there were also contrasting situations where a number of physicians took a proactive approach, seizing any opportunity they could to exercise agency and negotiate better outcomes for their patients. Accordingly, the negative experience of resource limitations and other constraints could be somewhat offset or balanced by not taking a passive role. For example, Maggie (Palliative Specialist) illustrates her use of agency, as a way of coping with things like resource problems: “it’s about having a voice…you can’t just sit quietly and just whinge (laughs) you’ve got to advocate…so, again…by choice I’m on a huge number of committees that might have a role in advocating…and getting things for patients…”. She takes a proactive approach to end-of-life care issues, being able to exert influence with her involvement in
many committees. Similarly, Peter (General Practitioner) said: “if people are suffering and want help dying their way, I’ll support them…I’ll badger the politicians, be a pain to the AMA…I’ll help them find some way through the system”. He will not just accept anything the system offers his patients. Just as importantly, Jenny (Palliative Specialist) talks of raising the profile of her profession, and negotiating better outcomes through exercising agency and drawing support from research evidence:

It’s really important to raise our profile...that we’re highly qualified palliative care specialists who educate and do research. It’s making sure you’ve got the language of evidence at your fingertips to support what we do is effective...people get better symptom control, they’re less anxious, they’re more likely to die where they would like to, they stay out of hospital and those sort of things, “I promise you that I can help keep your patient out of hospital... this is cost effective for you”, uhm, and that’s the sort of language that clinicians understand.

Jenny works to negotiate institutional and professional constraints that inhibit end-of-life care for her patients. She recognises that strategically using the correct language of scientific evidence and fiscal responsibility, she is in a strong position to overcome professional barriers, and gain recognition and respect for her profession (and enhance patient outcomes).

9.4.4. Learning from experience: Developing communication skills. Coping strategies are generally learnt, develop with experience, and are exercised according to context (Lazarus, 1993a, 1999). As an action-oriented or problem focused strategy, communication skills are a particular acquisition that assists physicians to cope with problematic interactions with patients and families (Back et al., 2007; Gordon, 2003), although some research indicates that physician burnout and stress levels, due to their multifactorial nature, do not always improve (Butow et al., 2008). Throughout the present research, ineffective communication skills and communication difficulties have been identified in the negative experiences physicians report. Yet, most physicians developed communication skills on the job rather than as part of formal training. They also did not
believe they were born with such skills. For example, Thomas (General Practitioner) regards discussing end-of-life issues a learnt rather than natural skill: “People think because I’m a GP and see lots of people that I’m a natural communicator. But really…especially with difficult conversations of dying, it’s taken me many years to get comfortable with it”. Similarly, Andrew’s (Intensive Care Specialist) communication skills have developed with experience. He once found it difficult to be forthright, saying: “as a young doctor it was difficult…being as frank, as open about stopping treatment…and…with more experience now it’s very difficult not being frank and open…it makes my work…and life, so much easier…knowing I won’t hide any facts…there are no agendas”. Andrew points out, particularly in relation to withdrawing life sustaining treatment, how over time he has learnt to become more frank with patients who are dying and their loved ones. Unlike many of his colleagues who fear distressing patients further and thus distort the truth (Blackhall, Frank, Murphy, & Michel, 2001; Blackhall, Murphy, Frank, Michel, & Azen, 1995; Samarel, 1995), Andrew does not hide anything and this makes his job (and life) much easier.

Likewise, Andrew’s colleague Keith (Intensive Care Specialist) finds that experience at the bedside helps him “pick up tricks” for communicating decisions with those who are dying and their loved ones: “I’ve developed tricks, like I say ‘I’d like to be able to say something else’ or ‘working in intensive care, I’ve got to be honest with you’. So I’ve picked up these tricks”. Keith has learnt that particular phrases are helpful to him, especially in diffusing potential conflict. He puts loved ones in the patient’s position to make them feel guilty: “‘are you sure that, you know, is this something that you would like, to be in this bed surrounded by strangers, having painful procedures’? So I don’t mind laying on that guilt if I feel it’s warranted”. Correspondingly, other physicians like Aaron (Respiratory/Thoracic Specialist) spoke about a lack of communication training and needing to learn such skills on the job:

These issues [hastening death] were never brought up in our training. As medical students we just learnt the science of medicine without learning about the art of
medicine, and I think, that communication, you know, is better taught these days, but when I went through it was like, you know, you just got thrown straight in at the deep end as an intern, there’s lots of issues that you never talked about, that you never learnt, so you learnt on the job.

Despite some research showing otherwise (Forbes, et al., 2008), Aaron believes communication training is now more accessible than it was for him. He talks about being “thrown in at the deep end”. He indicates how proficiency and expertise in negotiating matters like death hastening practices are something that develops with experience. He also makes the distinction between “medicine as science” and “medicine as art”, something that assumedly also develops for the practitioner, bringing skill through experience rather than by teaching.

**9.4.5. Everybody needs a distraction.** Sometimes physicians cope with difficult or aversive experiences through distraction, by engaging in pleasurable pursuits beyond the workplace. Distraction can sometimes be seen as an avoidant (Roth & Cohen, 1986; Suls & Fletcher, 1985) and emotion focused response (Lazarus, 1991), where physicians can disengage from negative experiences that preoccupy their thinking and potentially lead to detrimental health effects such as those symptomatic of burnout. But distraction could also be seen as problem focused when physicians took up activities like research that assisted their clinical practice. All physicians identified particular ways in which they unwind. For example, Jeremy (Palliative Specialist) recognises the pressure that physicians are continually under and the need to find an appropriate release: “Looking after the dying, you need to find a way of dealing with all the shit that comes up in the medical world…where, you’re under the gun the whole time…you need to find what’s right for you”. Jeremy points out that everyone needs to do something, preferably something that is most suitable for each individual. He finds music a particularly effective strategy for dealing with difficult experiences: “fortunately I’m able to play a musical instrument…I find a huge amount of sustenance being able to perform at a reasonable level…I get to play regularly…and for me, that’s a way I can deal with some of these
things”. Similarly, Candice (Palliative Specialist) listens to music on the drive home as a way of unwinding: “I’ve got an hour drive between work and home…and I’ve found that…the music on the CD, and just the rhythm of driving that you…actually process, so when you get home you’re calm…and it’s gone”. For Candice, driving and music are a soothing influence where she can relax and process the day’s events.

Utilising a different activity, Thomas (General Practitioner) finds exercise helps him unwind: “I try and swim everyday…it’s a great way to unwind when you’ve had a tough day…especially with terminal patients who are really struggling…I can calm down and think of other things”. Similarly, Kerrie (Palliative Specialist) loves to exercise with friends: “we love to exercise with…we have very, very good friends who are doctors”. But Kerrie also finds travel and socialising with close friends a particularly beneficial release and a sustaining influence:

We travel, we drink good red wine (laughs), we eat out, we have, I believe a lovely life outside of work, and I cherish that and enjoy it. We have a very good group of friends and we’ve been doing this for years, we’re all a bunch of silly, you know in our late forties but we exercise together every week and we’ve been doing it for years and years and years, and after every, it’s actually a just a…. deal so we can go back to each other’s homes, (laughs) and we get pizzas, and it’s like a stream of consciousness that’s like been going on for about twenty years.

In contrast to Kerrie, Gary (Palliative Specialist) prefers television and some quiet time with a glass of wine as his way to release the pressure of end-of-life care: “You know, my wife would be so amazed seeing how much I talk all day long…I come home and I’m quiet, all I want is a glass of wine sometimes…and just to veg in front of the TV”. This distractive strategy works for Gary. He notes how his wife sees a different person than the one he is at work.

Many physicians also had an academic interest as part of their clinical career. Some found this particularly pleasurable in balancing their work life and informing
clinical practice, but also very helpful in bolstering the physician’s argument when negotiating administratively or among colleagues. For example, Jenny (Palliative Specialist) finds research a pleasant distraction which “balances” her work: “I’ve been a full-time palliative clinician for many years, which has been fantastic…to, develop and keep improving my clinical skills, but also intervening that with teaching and my research…it’s, a lovely balance and lets me focus on other things”. Like Jenny, Maggie (Palliative Specialist) also places value in her research interests: “I come with both clinical and research interests…and since starting as a consultant I’ve been doing both simultaneously…I think that’s been…very helpful. It gives you a feedback loop and stops you getting preoccupied in one area”. As identified by the physicians’ accounts in chapter 8, research often has a symbiotic relationship with clinical practice. As a proactive and problem-focused coping strategy, an evidence-based argument carries some “considerable weight” for Maggie who finds negotiating difficult end-of-life issues with colleagues and administrators an enjoyable distraction:

You try reaching consensus with everyone, sometimes it’s easier than others…but you have scientific research you can fall back on…and that carries a lot of weight…negotiating administrative matters is a distraction, but one I like because it’s important for providing good end-of-life care.

Maggie does not just passively accept consensus as elusive, but also points out that evidence-based argument does not always work because there are other (e.g. financial) arguments that take precedence. And that is still “trying” for her: “it can still be difficult even when you have good evidence…like securing funding for some services…or rationalising and cutting back on other things, staffing…prioritising services on criteria other than just medical…yeah that can be trying sometimes”.

9.4.6. Managing emotions. All physicians adopted emotion-focused strategies at various times to cope with aversive experiences of continued exposure to death and dying. For some physicians, distancing themselves emotionally was effective in countering difficult experiences at the bedside. Positive and negative emotions are
recognised as mutually exclusive (Colombetti, 2005) and sometimes humour was the mechanism that assisted physicians to maintain emotional distance. For example, Kerrie (Palliative Specialist) said: “mixing with a good bunch of friends who make you laugh is a good way of keeping you sane and separating the sadness you get from work sometimes”. Similarly, Gary (Palliative Specialist) said: “those times when I just need to shut off from work and watch TV…I enjoy something light-hearted…you know, a comedy’s good”. As a way of distancing emotionally, Keith (Intensive Care Specialist) describes how humour among colleagues, at the bedside, can be helpful to lighten the pressure of caring for dying patients. It is a strategy that he and his colleagues have found effective in some situations:

We support each other when we feel it getting to us…like black humour can be a, a good way of distancing yourself, you know, making light hearted jokes between us of some situations, but obviously without humiliating patients or their relatives…sometimes we might talk about someone’s latest holiday…or what someone did the night before…and I think relatives intuitively see these frivolous comments for what they are, especially when they themselves have had to sit by the bedside with a dying patient for days or weeks.

Keith talks about relatives being at the bedside for days or weeks, suggesting they understand why physicians who continually engage with dying patients would use humour as a release.

For other physicians, another way of distancing themselves emotionally was to maintain professional objectivity. Where appropriate, such a strategy could be helpful for a physician who might identify with a particular patient. With the added influence of a curative ideology, remaining objective was a strategy particularly noted for critical/acute physicians For example, Andrew (Intensive Care Specialist) says: “it’s hard not to empathise with those that have a limited prognosis but this is not the place for end-of-life care. We’re forced to focus on those we can save…often it’s easier because it’s less personal with those patients”. Andrew identifies a dynamic of his setting that helps him
stay clinically focused, while Gina-Leanne (Intensive Care Specialist) more actively maintains professional objectivity to distance herself from emotional situations. She does not allow herself to get too close with patients, recognising that her relationship is a very transient one: “you also have to know, that even if they’re dying you’ve only met them for this incredibly small part of their life…your job is to do ‘x’ for this very short period of time for them”.

Although distancing emotionally can be an effective strategy to diffuse aversive situations, sometimes expressing emotion can be a cathartic experience (Konrad, 2011; Martin & Doka, 2000). Yet despite the emotional engagement many physicians have in the end-of-life care they provide to dying patients and patient families, only a small number identified this strategy as a useful coping mechanism. For example, Candice (Palliative Specialist) says: “you know, I often cry…sometimes here and sometimes later at home…sometimes the sadness gets to you…but I’m human and I feel much better not bottling it up. It helps me continue”. Similarly, Jeremy (Palliative Specialist) identifies the personally emotional aspect in end-of-life care and how he deals with it:

I own my own engagement emotionally with these situations. And that happens every day with dying patients in the ward…I’m…used to it, so I’m immune from some of the distress but I do still weep on occasions…and sometimes it’s appropriate for the younger doctors to see that I, I do experience some of those things…that I am touched and I do feel the sadness, and sometimes I have to show that.

Jeremy talks about his emotional engagement with the dying; as something that happens every day, as something he is used to. He acknowledges how it affects him, he weeps, but he accepts that he is not immune; he “owns” his emotional engagement. Rather than being ashamed to weep or show emotion, something often expected of males (Martin & Doka, 2000; Ross & Mirowsky, 1984), Jeremy regards this as an effective strategy that younger doctors could benefit from. Clinical training further emphasises objectivity and emotional distancing (Shapiro, 2011), and younger, more inexperienced doctors who might
experience some end-of-life events as distressing or aversive might be reluctant to overtly express their emotions. Still, those physicians may achieve emotional expression through reflective writing or telling stories in a supportive environment; not only through weeping (Ahern, et al., 2012).

**9.4.7. Gathering support: Debriefing from burden.** End-of-life care is responsible for many aversive effects to physicians like burnout (Dunwoodie & Auret, 2007; Girgis, et al., 2009; Keidel, 2002; Sabo, 2008), and sometimes the personal capacity of physicians to deal with such effects is inadequate. All physicians provided examples of particular instances and issues that were experienced negatively; however, a large number of them also indicated that access to some form of debriefing has been particularly helpful. For example, Kerrie (Palliative Specialist) regularly seeks professional debriefing: “things can build up in my work and I actually personally debrief, yeah a couple of times a year I go and talk to someone professionally, and that’s as much about protecting [my husband] as it is me”. Kerrie recognises the importance of debriefing; her emotional and psychological well-being is crucial in also protecting her own loved ones. She understands the implications of suffering emotional exhaustion or other burnout symptoms like disengagement as more than a localised problem, as one also affecting her life away from work. Another physician, Jenny (Palliative Specialist) also said: “sometimes there’s just so much sadness doing this work…and if I feel it getting to me, I’ll chat with the social workers”. Similarly, Jeremy (Palliative Specialist) also seeks professional support to debrief: “I sometimes use the social workers to, debrief myself. And I have for a long time worked with a personal spiritual supervisor off site”. Although a number of physicians mentioned their religiosity during their interviews, Jeremy identified spirituality as a particularly effective mechanism he uses to cope with emotionally burdensome situations: “I have a regular prayer life so I spend time every morning finding solace and spending some quiet time. Sometimes it’s good to just go out and walk and argue with God”. Quiet time and solitude where Jeremy can engage in prayer is helpful. An internal dialogue through prayer and also sometimes “arguing
with God” helps Jeremy work through particular issues and sustains his continued engagement with end-of-life care. High rates of professional burnout are recognised in end-of-life care but, despite access to spiritual outlets, some physicians who unlike Jeremy do not “own” or acknowledge the consequences of their emotional engagement (Shapiro, 2011), might deny any emotional burden and not seek help.

This is a significant consideration because most physicians, regardless of specialty, identified the importance of collegial support assisting them to continue functioning effectively in end-of-life care. Such support helped address difficulties experienced by physicians that potentially affected their wellbeing, but also helped with difficult decision-making. For example, Maggie (Palliative Specialist) talks about supporting others: “it’s also looking after the staff who provide that care…because their ability to…stand alongside the next person, depends on how well supported they are….I think in acute care that’s the major difficulty…it’s very task orientated…very professional and clinically focused”. She contrasts the more personal nature of palliative settings with the professional emphasis of critical/acute settings, implying that colleagues are more supported in her specialty. She makes an important point (see Chapter 5 and burnout), however, that physicians cannot continue to “stand alongside” those who are dying if unsupported themselves. Maggie identifies a particular culture in palliative care where staff looks out for each other: “sometimes it’s unspoken, and someone will just come in the room and just check…or if they’ve noticed that was a particularly difficult conversation, a cup of tea will just appear while you’re writing your notes”. For Aaron (Respiratory/Thoracic Specialist), collegial support is also crucial in decision-making: “Yeah we often support each other and often, cross-consult each other, and I think that’s the key”. Similarly, Gina-Leanne (Intensive Care Specialist) talks of a supportive “team environment” where she can find back up when she needs to and consultation with difficult clinical situations:

If you need to go and do something people are always happy to back you up on the roster…or you can always ring up and say you know “hey Michael what do
you think about blah, I’m just not sure that I’ve got hold of the right end of the stick here”, yeah, it’s a team environment.

The key theme of coping has been important in providing insight to the research question that asked: “how do physicians manage their experiences”? All physicians reported strategies they implemented to deal with their aversive experiences in end-of-life care. Certainly these were not always effective, however, for many physicians, self-reflection allowed them to process experiences. Rationalising particular decisions and actions was another strategy that physicians frequently found helpful to attenuate their experience of cognitive dissonance when their beliefs and practices were incompatible. Time on the job also helped skills develop with experience, particularly where difficult communication issues were concerned. Furthermore, all physicians identified distractions that helped them disengage. Others emotionally distanced themselves from aversive experiences while some found emotional expression cathartic. Many also identified professional debriefing and collegial support that sometimes helped.

9.5. Discussion

The social structures that physicians engage with at the bedside provide varying opportunities for physicians to exercise agency (Bhaskar, 2011; Giddens, 1979, p. 55; 1984, p. 25; Lewis, 2000; Mingers, 2004). The key theme of “Socio-cultural Constraints and Difficulties” illustrated how macro influences at the bedside, such as religion and cultural expectations of saving life, can affect the control physicians have over certain decisions and practices, and how they will experience these. Multiculturalism provides diversity of beliefs and positions which physicians negotiate and attempt to accommodate. Although, physicians have much control over the process of death and dying, they cannot prevent it and, particularly in the case of young deaths, feel the unfairness and sadness that families and others involved with the patient do. For example, Thomas and Robert both accepted older deaths but had difficulty with the young ones. Gina-Leanne says she “goes all out for them”, seemingly influenced by cultural taboos of young deaths and a critical/acute ideology of saving life. Andrew also points out it is
easier withdrawing treatment from older dying patients than the young ones. When physicians are further influenced by family and parents of dying children to save life, then physicians may sometimes be compelled to administer futile and arguably stressful interventions for longer than they normally might for older patients.

It was also interesting to note despite only one physician, Gina-Leanne, describing such an experience, that sexism was an especially powerful influence at the bedside which, for the family of the patient concerned, seemed to trump any physician efforts for appropriate care. This dynamic is not considered in the end-of-life literature, but is a constraint to care that can emerge in multicultural societies like Australia, particularly in hospital catchments where local ethnicity may reflect a strong paternalist heritage. Accordingly, there may be scope for physician training that considers cultural sensitivity and empowers physicians in situations where cultural difference becomes problematic (Mitchell & Mitchell, 2009; Weissman, 2001).

Research has indeed shown that, although educational programs are helpful for things like developing communication skills and assisting difficult bedside family conflicts, without power and autonomy to effect change, feelings of helplessness, reduced self-efficacy and cognitive dissonance can increase (Wilson, 2007). Notably, physicians did not address their negative experiences captured in this theme by any explicit remedial strategy. Although Cognitive Dissonance Theory emphasises that psychological discomfort and heightened physiological arousal prompts such an action (Elkin & Leippe, 1986; Festinger, 1957, 1964), it became clear that physicians were often powerless or lacked control over some situations they experienced negatively. Certainly, if the literature were instructive, physicians could have just referred the patient or walked away and avoided the experience (Back, 2004; Fine, 2010; Granek, Tozer, Mazzotta, Ramjaun, & Krzyzanowska, 2012; Moreno-Jiménez, et al., 2008). Yet, this was clearly not the case with all of them persisting at the bedside despite enduring psychological discomfort. As Fine suggests, they may suppress their cognitive dissonance, but it may also be that the
rewards physicians gain from providing end-of-life care (see Chapter 8) balance the more negative experiences they encounter.

Indeed, the rewarding factors in end-of-life care may also explain why physicians who suffered what appeared to be compassion fatigue and aversive organisational influences related to burnout continue to provide care to the dying. The second key theme illustrated how physicians, often through “self-sacrifice”, negotiated multiple constraints to care in the best way they could despite being “Up against the System”. The demands of their particular settings were often experienced with enduring effects that also impacted their wider social circle. For example, Jeremy described his “altruism to others” impacting his family life but, supporting the contention that the rewards physicians draw from end-of-life care balances their more negative experiences, altruism has been reported a sustaining influence linked strongly to positive affect (Dulin & Dominy, 2008; Dulin & Hill, 2003; Yang & Chen, 2011). Some research also identifies altruism as a personality trait (Conway, Rogelberg, & Pitts, 2009), which might further explain why some physicians are attracted to end-of-life care and persist despite the demands and challenges they meet. With implications for mediating potential burnout risk, prospective physicians pursuing a career in end-of-life care could be screened for their capacity for altruism (Burks, Youll, & Durtschi, 2012).

Nonetheless, limited and ineffective resources were particularly challenging for all physicians and a major influence in their negative experiences. Physicians often described resourcing issues as inhibiting the end-of-life care they could provide to patients and patient families. Although doing the best they could, physicians experienced their practices and decisions with some cognitive dissonance. Physicians were often placed in the difficult moral position of deciding who dies and lives based on prioritising resources. Regardless of specialty, all physicians acknowledged that end-of-life care should not be performed in critical/acute settings yet, as identified in the literature (Hillman, 2009b, 2011; McGrath & Henderson, 2008), this is where a major proportion of Australians will die. Somewhat counterintuitively, specialised palliative services as particularly cost
effective by comparison to curatively oriented settings (Education and Health Standing Committee, 2010, p. 431) remain scarce and difficult to access.

Yet, a consistent point made by palliative specialists was that they could handle many critical/acute patients, but that their specialty continually “falls off the map” being under-recognised and under-valued by non-palliative colleagues. Palliative specialists are often not consulted, compelling many critical/acute specialists to provide end-of-life care despite not being motivated or trained to do so. Indeed, the expertise with end-of-life measures is not consistent among physicians across specialties. For example, although Keith said in Chapter 7 that he can sometimes sedate patients to a “nice level where they’re just under” he also acknowledged that “in ICU we sedate really well; we often use industrial strength doses”. This was a point made by Aaron who said that “some physicians are better than others at titrating meds”.

After also considering the position statement of Palliative Care Australia (2011b) and their proposal that generic end-of-life skills should become more common across specialities and settings, I canvassed the idea of enhanced physician training at undergraduate but also specialty level further with some critical/acute physicians. In light of the difficulty accessing palliative expertise in those settings and the increasing requirement to care for dying patients, I discussed the potential development and establishment of a subspecialty in intensive care as something also tailored to patients that have different requirements to those in dedicated palliative settings, trauma for example. Andrew responded positively: “I think that would be very, very helpful-yeah maybe a subspecialty of palliative-intensivist”. If mainstreaming specialised palliative care does not progressively abandon the social context of dying through a focus on physical aspects (Rosenberg, 2011), such a capacity may particularly assist with difficult decisions of care goal transition which are sometimes a source of collegial and family conflict.

With more specialist expertise available across settings, a mentoring capacity might be enhanced where currently, as pointed out by Maggie: “very junior specialists become senior very quickly”. Indeed, Aaron mentioned being “thrown in at the deep
end”, needing to learn on the job through experience. For most physicians, communication skills were often problematic, even for very experienced physicians. This problem has appeared with ubiquity throughout the current research despite significant efforts being marshalled toward relevant educational goals, both here in Australia and abroad. For example, in Australia over the past decade or so, an invigorated approach to educating physicians in communication skills and ethical end-of-life issues is occurring (Cameron, Dalziel, & Dalziel, 2008; Dalziel, 2007; Kissane, Bultz, Butow, & Finlay, 2010; Phillips, 2008) although, as Keith pointed out above, not always by the most appropriate educators and with classroom instruction not always translating to the bedside dynamic. Another consideration is that not all medical curricula in Australian universities are the same, which suggests specific educational efforts cannot be generalised, or easily assessed as to their relative efficacy. For example, cultural sensitivity has been pointed out earlier as an issue at some bedsides, while the curative expectations of critical/acute settings strongly influences the end-of-life communication that takes place there. Similarly, any classroom “roleplaying” strategies, where implemented, need considered evaluation if they are to help address the limited bedside mentoring capacity that physicians of all specialties report.

Nonetheless, the specificity of death and dying means that classroom instruction can only ever be adapted to the bedside, particularly in cases where death is hastened. As so strongly pointed out by Peter and Robert, the current medico/legal framework requires a multilevel review, where in-line with bedside realities and public opinion on death hastening practices, political and professional positions might be reconsidered. Many physicians pointed out how patients plead and beg to end their suffering and how double effect, that only recognises the physician’s intent, is inadequate as a defensive strategy that protects physicians in cases where death is hastened. Indeed, Jeremy acknowledged he could use double effect for protection but still felt responsible for his patient’s death. Current legislative and professional guidelines do not consider the emotional pressure brought to bear by patients (and others) suffering at end-of-life. Physicians who are
compassionate, and respect patient autonomy and dignity often suffer and are compelled to manipulate practices to assist their patient when hastening death is considered the most appropriate action. Therefore openness and transparency can be elusive, and a physician’s experience of cognitive dissonance remains unmediated. These issues were not as problematic in The Netherlands and Belgium where, before euthanasia and assisted suicide were legalised, Force Majeure or “superior force” was a recognised defence for physicians who inadvertently or otherwise hastened a patient’s death (Pollard, 2008; Van Der Weyden, 1997). Physicians were considered to be acting under necessity, where the moral and emotional pressures they face in providing end-of-life care were regarded a “superior force”, and of similar relevance as fundamental and generalised legal prescriptions (Leenen & Ciesielski-Carlucci, 1993; van der Wal & Dillmann, 1994). Any proposed multileveled review of current Australian end-of-life practices may benefit by similarly considering multitudinal aspects of emotional and moral influences in the physician’s intentions.

Yet, little is known of these influences and the impact they have on physicians. For example, the paucity of research applicable to Australian end-of-life contexts, especially in terms of the intrapsychic burden that physicians experience when providing care to dying patients and others, is particularly noteworthy. Although some research has been conducted with physicians elsewhere in this regard (Keidel, 2002; Meier, et al., 2001; Sprang, et al., 2007), and some research into mostly organisational factors of burnout for oncologists and palliative specialists in Australia (Dunwoodie & Auret, 2007; Girgis, et al., 2009), research has generally centred on the experiences of nurses (Byrne & McMurray, 1997; Rose & Glass, 2010; White, et al., 2004; Zander, Hutton, & King, 2010). The third key theme identified the “intrapsychic burden” experienced by physicians in Australian critical/acute and palliative settings, thereby generating new knowledge and exposing potential new paths of inquiry.

All of the physicians in the present research experienced intrapsychic burden in some situations. They faced emotional pressure applied by patients and others to hasten
death and also sometimes to save life despite evidence of futility. Physicians in all specialties described difficult treatment decisions they experienced with dilemma and frequently with great self-recrimination. For example, decisions that arguably hastened deaths were experienced aversively by Jeremy, Candice, Kerrie and Jenny, while Aaron spoke of moral dilemmas he faced when compelled to prioritise resources. Cognitive dissonance was commonly illustrated by these and other physicians especially when agonising over particular decisions. Although Festinger (1957, 1964) argues cognitive dissonance prompts a moderating response, this was not the case for these physicians who needed to choose the least objectionable treatment from a limited range of options. Often enduringly stamped into memory, these negative experiences lingered for physicians.

Additionally, almost all physicians detailed interactions where they identified strongly with patients and others. Although not necessarily the overriding goal of all physicians, it is clear that despite their best efforts and influential societal and professional expectations (Billings, et al., 2010; Halpern, 2007; Peteet, Ross, Medeiros, & Walsh-Burke, 1992; Rousseau, 2004), physicians cannot always remain objective or resist bonding or attaching emotionally with some patients and their families. Although some may avoid aversive emotionally laden interactions, physicians might not always be able to delegate patient care to others. Problematically though, such interactions are difficult to predict particularly when each end-of-life situation is unique with complex dynamics (Kirschling, 1990; Munday, et al., 2003). Indeed, Keith said: “it’s often when you least expect it…” and Gina-Leanne declared: “some will get you and some won’t”.

Identification also raises further concerns of transference and countertransference that potentially influence patient care and physician wellbeing (Kissane, 2000; Vachon, 2003). For example, physicians who correspondingly experience vicarious traumatisation when relating strongly to a patient or patient loved ones (Figley, 1995; Najjar, et al., 2009; Sabo, 2008; Sinclair & Hamill, 2007), may also experience compassion fatigue and burnout (Figley, 1995; Huggard, 2003; Kearney, et al., 2009; Sprang, et al., 2007). This
may be particularly so for those physicians with limited emotional self-efficacy (Bandura, et al., 2003; Caprara, Di Giunta, Pastorelli, & Eisenberg, 2012).

Nevertheless, and of benefit for some physicians, spirituality and a belief in life-after-death are acknowledged as mediating aversive effects of identification (Pearlman & Saakvitne, 1995) and the fear of death and dying (Greyson, 2009; Pevey, Jones, & Yarber, 2009). Although all palliative physicians reported instances where they identified strongly with patients, the Christian underpinnings of their specialty (Saunders & Baines, 1983) may mediate their aversive experiences. For example, religions like Christianity offer the promise of salvation and a heavenly existence beyond mortal life (Davies, 2009; Morgan & Laungani, 2005). This may be comforting or sustaining to those holding such a belief (Laungani, 2005) and in the literature review it was identified that religion and spirituality often attract physicians to a career in end-of-life care (Flannelly, et al., 2004; Mickley, et al., 1998; Saunders & Baines, 1983). For those not holding such beliefs, however, death may be denied and avoided (Becker, 1973; Kübler-Ross, 1969), sometimes leading to physician disengagement and further impacting patient care and physician wellbeing (Halpern, 2001). Certainly, many critical/acute physicians hold spiritual beliefs but these physicians also spoke of not being trained or motivated to provide end-of-life care, despite the responsibility for such care becoming increasingly common for them. It makes sense that the training and personal resources of individual physicians are compatible with the care requirements of their settings.

Although the intrapsychic burden suffered by physicians has been identified in the present research, the prevalence of these negative experiences needs to be elucidated across settings in Australian end-of-life care. When all physicians detailed such experiences, clearly a strong possibility exists that these experiences are not uncommon elsewhere for other physicians. Further investigation may provide a greater understanding of the impacts to patient care and physician health, and the multi-level factors behind them, and identify supportive strategies that could be developed to mediate aversive effects. For example, although it may seem counterintuitive by encouraging emotional
engagement, increasing emotional self-efficacy through learning and developing empathy (Ahern, et al., 2012; Kearney, et al., 2009; Larson & Yao, 2005) may give physicians better emotional control in situations where identification occurs. Similarly, developing greater physician self-awareness may both enhance self-care (Kearney, et al., 2009; Novack, Epstein, & Paulsen, 1999) and improve patient care and satisfaction (Meier, et al., 2001; Novack et al., 1997).

Going some way toward this effort, in the final key theme physicians identified various ways of coping with their aversive experiences in end-of-life care. Certainly, not all coping strategies were as effective as others and were dependent on the context of each situation. Physicians adapted problem-focused and emotion-focused responses (Lazarus, 1991, 1993a, 1993b, 1999; Lazarus & Folkman, 1984), and avoidant strategies (Roth & Cohen, 1986; Suls & Fletcher, 1985) to manage their experiences. There were times that particular strategies were used to the exclusion of others and sometimes in combination but, as evidenced by the preceding themes that illustrated their actual negative experiences, some physician experiences were not successfully resolved. For example, although Jeremy rationalised a hastened death through a motivation to alleviate suffering, he still feels responsible for the death. Similarly, Maggie conducts research and negotiates constraints to enhance patient care through evidence-based argument but finds that other arguments such as fiscal ones sometimes override her efforts.

It is important to understand, therefore, that physicians may adapt a coping response to a particular situation from a range of strategies. One strategy is not always better than any other, nor is any particular strategy equally effective for all physicians. By understanding what works and what does not, physicians may potentially be provided with better institutional support and a capacity to develop personal strengths that allows them to draw on as many coping resources as possible.

It is equally important to remember that physicians need to cope with aversive experiences influenced at multiple, often interactive levels that produce a unique bedside dynamic. For example, the key themes and their subthemes captured macro influences of
socio-cultural constraints, meso level influences often related to organisational, institutional and professional factors, as well as micro factors influenced at the interpersonal level and often culminating in intrapsychic burden. Any coping strategies physicians engage, therefore, need to be effective at addressing multi-level influences in their negative experiences, but also their multilevel “effects”. For example, physicians might experience emotional burden, as well as physiological effects of sleeplessness (as Keith did), and also social effects where their experiences may affect others (something Jeremy and Kerrie reported). In some situations, physicians might disengage from patients or withdraw from family, colleagues and others in their social circle. To also stem the reported numbers of physicians leaving their profession (Australian Medical Association, 2003; Coyne, 2011), which ultimately places greater strain on those remaining, creating an end-of-life environment conducive to maintaining physician engagement may go some way to enhancing physician wellbeing and patient care, but will need to consider a multileveled approach.

9.6. Summary

Contrasting with the previous chapter’s focus on positive physician experiences, this chapter examined the negative experiences physicians encountered providing end-of-life care in critical/acute and specialised palliative settings, and further addressed the primary research question. The way physicians negotiate and experience end-of-life decision-making and practices in Australia is now better understood. Similarly, the secondary research question asking how physicians manage their experiences was addressed by considering the various coping strategies that physicians use with varying efficacy. As with the previous chapter that examined the physicians’ rewarding experiences in end-of-life care, the specificity of context again emphasised how often, rather than being predictable, experience was emergent through interpersonal engagement within complex multileveled social structures. Physicians articulated that complexity through a range of descriptive themes, where analysis and discussion further reviewed the current state of play, and offered suggestions to enhance patient care and physician
The purpose of the next and final chapter is to reflect on the findings of the present research and suggest where end-of-life care in Australia might go from here.
Chapter 10

Conclusion

It is intended that the research contained in this thesis will advance discussion on death and dying in Australia, particularly in terms of institutionalised end-of-life care. To date, the voices of physicians in Australia who provide care to the dying, and the loved ones of dying patients, have not been heard. Addressing the aims of the study, this thesis, through its contextualised focus, has documented the experiences of physicians providing end-of-life care in Australia and how they understand and negotiate the practices they engage in, allowing for examination and dissemination.

Prior to this research, specific knowledge of the physician’s experiential world and their role in Australian end-of-life care was almost non-existent due to limited research in Australia. This research now provides a current account of the beliefs, understandings and positions physicians have on end-of-life care in Australian critical/acute and palliative settings. By uniquely contrasting these settings and focusing on the physicians’ experiences, both positive and negative, it has been possible to gain a deep understanding of Australian end-of-life care and offer sound suggestions that may enhance patient care and physician wellbeing into the future.

The depth of understanding has been achieved primarily through adopting a critical realist epistemology (Bhaskar, 2011; Harvey, 2002; Mingers, 2004) and a theoretical position that emphasises complexity (Byrne, 1998; Munday, et al., 2003; Urry,
through multitudinal and non-linear influences within nested social structures. Accordingly, the complexity in physician understandings and experiences, and their decision-making, could best be examined this way. Through thematic analysis and an explanatory lens focused with additional theoretical constructs, this research has been able to provide insights into the ambiguity and inconsistency in practices and decisions identified in the extant, mostly international literature and report on physician experiences that have previously remained unexplored.

To illustrate, although physicians were identified in the literature review as engaging in practices that hasten death, we now have some understanding of why and how they do it. Furthermore, this research provides knowledge to physicians like Gary who said: “euthanasia and sedation come up a lot; it would be good to see what other physicians are saying and doing about this - like how aggressive they are”. Similarly, Aaron said: “I don’t know if other physicians feel that pressure too, and advocate against the system to deal with resource problems”. Indeed Maggie, Jenny and others frequently negotiated decisions of resourcing and practices that may hasten death, and physicians like Peter and Robert, often at great personal cost, regularly pitted themselves against the “system” to give their patients autonomy and choice over how they wished to die. Researching the physicians’ experiences with particular practices enables these questions posed by their colleagues to be answered. An important purpose of this thesis, certainly, was to provide specific knowledge to physicians in Australian end-of-life care, but its additional aim was to advance academic knowledge of the topic more generally, and expose potential new paths of inquiry that can build on the current research.

Throughout the three analysis chapters I have undertaken discussion of the findings and evaluated them with reference to theory and literature. This concluding section will discuss the broad findings, reflect on the significance of the analyses for understanding the physicians’ experiences in Australian end-of-life care, and consider some of the implications at multiple levels for governance and policy, physician well-

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15 These epistemological and theoretical considerations were detailed in Chapter 2.
being, and education and clinical work. The primary research question driving this research asked:

*How do physicians understand, negotiate and experience end-of-life care decision-making and practices in the context of Australian critical/acute and palliative settings?*

This research question and its supportive questions were addressed through a multilevel systemic approach (chapter 2) which, like the preceding literature review, considered macro, meso and micro influences to the individual beliefs, attitudes and moral/ethical positions physicians hold for providing end-of-life care. This was the focus of the first analysis (chapter 7). Understanding the complexity of physician experiences was examined by applying the same approach, with chapters 8 and 9 respectively focused on their positive and negative experiences. The various coping strategies physicians employed, including their relative efficacy in mediating negative experiences, were also investigated.

The conclusions drawn from the findings in Chapter 7 suggest that the understandings, beliefs and attitudes physicians have on end-of-life care and particular end-of-life practices, stem from multitudinal influences encountered throughout their professional and personal lives (Bronfenbrenner, 1989, 1995; Vygotsky, 1978, 1987). The differential influences of family, friends and colleagues within their social and peer networks, religious (or secular) beliefs, and legal prescriptions, also influence the moral and ethical positions held by individual physicians and the decisions they make (Kohlberg, 1969; Kohlberg, et al., 1983). These influences play out at the bedside with great complexity because of the uniqueness of each bedside interaction with patients, patient families and other professional colleagues who also hold various understandings and positions on end-of-life care. Accordingly, due to the specificity of context, and corresponding with the ambiguity and inconsistency in end-of-life care understandings and practices identified when reviewing the literature, physicians will sometimes act contrary to the particular beliefs and positions they hold, and to prevailing social norms and imperatives. Not unexpectedly, such instances reflective of cognitive dissonance
(Festinger, 1957, 1964) sometimes culminated in a negative experience for almost all physicians.

Likewise, conclusions drawn from the findings of Chapters 8 and 9 suggest that the experiences of physicians were often intimately linked with how they understood and positioned themselves in relation to caring for dying patients and patient families. Experiences were just as multitudinally influenced where, consistent with a critical realist approach, the complex social structures that physicians engage with provided varying opportunities for them to exercise agency (Bhaskar, 2011; Giddens, 1979, p. 55; 1984, p. 25; Lewis, 2000; Mingers, 2004). Their ability to negotiate these structures subsequently influenced the outcomes achieved at the bedside and how they experienced these. Such findings provide an explanatory mechanism for why some physicians in Australian end-of-life care experience burnout and other adverse effects to their health, and patient care is sometimes compromised. Contrastingly however, many physicians also identified strategies they employ to cope with their aversive experiences, and how their positive experiences at the bedside are a sustaining influence that allows them to continue providing end-of-life care and remain motivated in their careers. These broad conclusions, drawn from more extensive discussions throughout the analysis chapters, have important implications for how end-of-life care is practiced in Australia and subsequently experienced by physicians.

10.1. Implications of Findings

The physicians in this study provided detailed accounts of how they understood and experienced end-of-life care decision making and the practices they engaged in within Australian critical/acute and palliative settings. The research findings identified implications for policy and presented challenges that the professional medical community, legal community, legislators, and Australian society in general could consider. For example, all physicians detailed resourcing constraints that impacted the patient care they provided and their subsequent experiences. Their experiences were also influenced by their level of personal skill when encountering difficult interpersonal and
clinical situations, while ambiguous medico-legal prescriptions that physicians regarded inadequate for guiding end-of-life practices or providing them support further impacted their experiences and patient care.

In contrast, physicians also identified many rewarding aspects in their work caring for dying patients and others, and strategies that sometimes helped them cope with the aversive experiences they encountered. It is exactly these positive aspects that need to be recognised so that physician engagement can be maintained, their wellbeing preserved and the best possible care provided to those dying and associated others. Maintaining an end-of-life care environment conducive to rewarding experiences, across settings, is one way of stemming the numbers of physicians leaving their profession and the detrimental health effects they report experiencing (Australian Medical Association, 2003, 2005, 2006b; Coyne, 2011). Indeed, the findings in Chapter 9 suggested strongly that a powerful reason why physicians persist in the face of sometimes seemingly insurmountable difficulties is because the rewards they gain offset their more negative experiences.

10.2. Building on the Current Research

The implications of the research findings and the particular challenges they present could be taken up at multiple levels. This is an important consideration when end-of-life care is recognised as dynamic and complex. Accordingly, sound proposals can be made that address these challenges and guide future directions for research and clinical practice from macro, meso and micro perspectives.

At the macro level, persisting culturally phobic attitudes toward discussing and confronting death and dying often provides an unhelpful bedside dynamic that physicians need to negotiate but sometimes culminates in compromised patient care and difficult decision making experiences for physicians. There is an expectation that physicians save life and avoid death. Indeed, Gary said: “people keep pushing it away as if it won’t happen to us”. Yet, there is some recognition that the burden of death should not be
passed onto following generations and initiatives like funeral plans providing a financial buffer for loved ones are now regularly promoted in the mainstream media. Many people also seek to protect loved ones through a will that further assists difficult post-mortem decisions, and there are some efforts, although limited in scope, toward organ donation with a national register through Medicare and consent also recorded in driver’s licences. However, as we have seen, end-of-life decision making is a continual source of conflict physicians meet at the bedside due to the multifactorial considerations involved. Accordingly, the issues of Advance Care Directives (ACDs) and Organ Donation are important topics for future research that may mediate the social discomfort with death and dying, and related bedside conflicts, and assist “good deaths”.

Despite the support given to ACDs by physicians in the present study, and their potential benefits in terms of patient autonomy and conflict resolution, the use of ACDs in Australia remains very limited. Future research can assist government promotional efforts and further investigate the benefit of ACDs in the end-of-life setting in terms of patient (and family) care and physician experiences, but also with a particular view as to how effectively they can be implemented. Certainly, this can better inform hospital crash teams and paramedics who are currently compelled to resuscitate those patients without documented directives, and where family discussion has not taken place (Chan & Berg, 2010; Chen, et al., 2008; Hillman, 2011). If unawareness and unhelpful social attitudes towards death and dying influence the currently limited use of ACDs in Australia, it is important to ascertain which sections of the community are reluctant to discuss death and dying and ACDs and the reasons why. Australia’s multicultural community may hold diverse beliefs on end-of-life issues but are there also barriers of knowledge or language that apply? Rhee, Zwar, and Kemp (2011) identified conflict and confusion with ACDs as problematic for health professionals and carers but this may also apply elsewhere across the population.

Accordingly, a stratified sampling strategy could utilise semi-structured telephone interviews that elicits information on population characteristics and social networks, and
how ACDs are understood and whether they are discussed and with whom. Personal experience with death and dying within the network are areas for consideration. Interviewees can become key informants and refer (snowball) others in their social network. By understanding the families and other social networks where end-of-life matters may or may not be discussed, targeted interventions may be designed to enhance ACD uptake.

Government and professional (e.g. AMA) efforts are similarly informed, but a national media strategy tapping into existing majority social attitudes supporting autonomy and control over the dying process (as with funeral plans) may also utilise experiential testimonials from health professionals (e.g. physicians, paramedics, nurses etc.) and carers that explains ACDs, their benefits and ways of accomplishing them. Accessibility may be further enhanced by engaging General Practitioners and legal professionals in the discussion and development process. Physicians across medical settings can engage patients and others in discussion on ACDs, especially in situations of prognostic uncertainty (Barnes, Gott, Chady, Seamark, & Halpin, 2012). Moreover, problematic State based inconsistencies for ACD implementation, recognised in the proposed “National Framework on ACDs” (Australian Health Ministers’ Advisory Council, 2011; Palliative Care Australia, 2010a), may be overcome through a “national” initiative.

The above macro/meso directed research strategy may also include organ donation, which could be similarly considered during physician/patient consultation, and enshrined legally when reviewing a will and ACD. Andrew (Intensive Care Specialist) showed how organ donation may be a vehicle for “good deaths”, and I discussed this as being an enduring altruistic legacy (Healy, 2006) but one which also provides a means of closure and sense of purpose or meaning for the dying patient’s family and physicians and others involved. If we acknowledge Australia as a secular and multicultural society, we can assume that there is a diversity of beliefs regarding the issue of organ donation.
Australia enjoys some of the highest success rates of organ transplantation when it can be effected (Australian Government, 2011). However, it was discussed earlier that Australia’s current “opt in” system may be one important barrier responsible for the small rates of donation compared with some other developed countries that utilise an “opt out” system. This means that a cultural (macro) level revision may be indicated, but also the current legal and medical guidelines (meso), which some physicians consider generalised and arbitrary (Chapter 3), may need further review so that organ donation might occur more seamlessly at the bedside and better facilitate the wishes of patients and their families, as well as the physicians involved with the dying and those in transplantation teams. An investigation into the opt out systems for organ donation in other countries that display high donation rates could evaluate benefits (and barriers) in terms of good deaths as well as reduced population death rates (which makes economic sense) where people waiting for organs have a greater chance of receiving them. Although not the primary focus, organ donation was an emergent but important issue within the current investigation. Accordingly, when considering its potential benefits, there is a good rationale behind examining the issue of organ donation further. This may be achieved through a mixed-method design that qualitatively investigates physicians’ experiences and positions on the issue while at the same time informing the construction of a piloted survey-based strategy with physicians more broadly. Prevalence is elicited through closed responses while an open-ended capacity allows physicians to explain responses and potentially identify new data. A similar research approach may also target terminal patients and their loved ones, and further assist efforts for governance and social debate. Patients could thus have greater choice and control over their deaths.

Although the euthanasia/assisted suicide issue is never far from social thought and periodically occupies parliamentary debate (Raphael, 2010; Rimod, 2009; Vaughan, 2009; Wheeler, 2009), death hastening practices both intended and as a consequence of care are an inescapable fact of Australian end-of-life care. Yet, the professional/legal structures scaffolding physicians when death is hastened, such as double effect, were
identified by many physicians in the present study and throughout the literature review as inadequate. Self-recrimination frequently illustrated the physician’s negative experiences when deaths were regarded as hastened, or when they were inhibited from doing so, because of narrow but overriding medico-legal imperatives. Certainly, recent organisational position statements on euthanasia indicate a developing stance toward “studied neutrality”, but the position remains professionally contentious (Johnstone, 2012) and is of little benefit to physicians who actually engage in death hastening practices. Future policy research may, therefore, investigate the current legal machinery and how the concept of Force Majeure, considered useful in Belgian and Dutch end-of-life law prior to legalisation of euthanasia (Pollard, 2008; Van Der Weyden, 1997), might work in the Australian context. For example, a retrospective case study approach examining when force majeure was drawn on in the international context may provide insights. Despite majority public support for euthanasia and physician assisted suicide (Ashby, 2003; Kuhse & Singer, 1988, 1993; Neil, et al., 2007), there also needs to be some consideration that a Sanctity of Life position is not always supported by physicians either, regardless of any religious or secularist position they may hold. Complex bedside dynamics do not always play out in a simple “either-or” way.

Moreover, the way medicine is prioritised at the government (macro) level influences funding and resource considerations. Consequently, these influences are expressed at the (meso) bedside where all physicians often need to “juggle patients” and compromise or make do just to provide some level of care to dying patients. The aversion of death and dying is perpetuated by the expectation to save life, with technology and specialised ICU beds further funded disproportionately by comparison with specialised and more cost effective palliative beds (Education and Health Standing Committee, 2010, p. 431). Australia’s aging population will increasingly need specialised palliative care (National Institute on Aging, 2009; Palliative Care Australia, 2011a; The Victorian State Government, 2004) but specialised end-of-life expertise is identified as lacking anywhere outside specialised palliative settings, and specialised training requirements are not met.
Although macro end-of-life strategies (Palliative Care Australia, 2010b; UK Department of Health, 2012) are developing to address these issues they still appear limited in their application, and present a major area for continued research. Indeed, as advocated by Palliative Care Australia (2011b), and reflecting the concerns of nearly all physicians in the present study, generic palliative skills should become part of every physician’s professional repertoire to enhance the capacity of appropriate end-of-life care provision across settings, but the most effective ways of achieving this remain elusive.

Further compounding the problem, it is especially difficult to access limited palliative care resources through the specialty being under-recognised and undervalued by non-palliative colleagues. At the same time, many physicians are also unaware of what Intensive Care can and cannot do, and refer or admit and retain patients there inappropriately. Meso level end-of-life considerations stress the particular importance of professional awareness and education so that multidisciplinary approaches to care and collegial support can be enhanced, and the best care can be provided by the most specialised physicians. If managing dying patients continues to be an increasing role for critical/acute settings then measures need to be in place accommodating this requirement. For example, besides training all physicians in generic end-of-life skills, developing a subspecialty within intensive care (suggested earlier in Chapter 9) was also recognised as an attractive option by critical/acute physicians to enhance end-of-life care for dying patients and to foster more positive experiences for the physician and others. Such an enhanced end-of-life care capacity was similarly suggested by palliative specialists like Kerrie who said: “we need to niche gentle subacute care across settings so that those missing out or receiving inappropriate… aggressively oriented care, and their families, can be better looked after”. A “middle ground” option like this may supplement currently limited palliative resources, enhance greater multidisciplinary collegiality and, as a presently unexplored area, could be well supported by focused research efforts.

This applies equally in the context of younger deaths which all physicians in the present study experienced aversively. Particularly in critical and acute settings, physicians
often felt compelled through societal and professional pressure, and sometimes their own discomfort, to pursue all treatment options even when they considered them futile. Palliation, if implemented, was often very late in the illness trajectory and performed in the critical/acute setting by default. Another investigation with similar characteristics to the present study may further explore the potential for specialised palliation in these settings focused on how “good deaths” may be achieved for younger patients. That research may target multidisciplinary collaboration for enhancing timely goal transition to comfort models of care, but also look further to establishing supportive networks which include an expanded and specialised outreach capacity that allows dying children to be managed in the home setting. The preference for dying at home is equally applicable for young patients whose parents wish to accommodate a dominant caring role for their children (Monterosso & Kristjanson, 2008; Monterosso, et al., 2009). Currently, most studies of this nature are with older terminal patients suffering cancer (Abel, et al., 2011; Horsfall, Noonan, & Leonard, 2011) and non-institutionalised care for young terminal patients remains relatively unexplored, particularly in Australia.

Regardless of where death and dying is managed, however, physicians can only make the best clinical decisions if they are appropriately informed. Earlier in Chapter 4 and in Chapter 7, I gave attention to the implementation of integrated care pathways in critical/acute and other non-palliatively specialised settings for guidance that could assist physicians experiencing difficult end-of-life decision-making. It was pointed out, however, that such generalised protocols often miss the specificity of each patient particularly as symptomatic expression may not always be reflective of the patient’s condition. For example, sometimes observed patient behaviour “masks” the underlying condition of the dying patient, where they might actually be improving but these signs are missed and the patient’s death is hastened (Spooner, 2010). As a supplemental measure that might be developed further to better account for patient specifics, such guided pathways for end-of-life care may become especially useful in some end-of-life settings if used judiciously, principally when specialised palliative expertise is difficult to obtain. It
must also be remembered though, that such a strategy is only one part of a complex biopsychosocial requirement at end-of-life, where strong interpersonal communication is also needed.

Equally, future research could look at physician concerns that little mentoring exists, especially in specialised palliative settings, with new specialists attaining senior status very quickly. As in other settings, decisional dilemmas experienced by physicians are often left unsupported. If very experienced physicians are sometimes further excluded as such a potentially important resource from classroom instruction, as Keith pointed out in regard to bioethical issues, understandably new physicians encountering bedside dilemmas have nowhere to turn. Currently, physicians upon graduation are deemed competent to engage with patients but, other than a brief residency or registrar requirement, there seems little to ensure ongoing competency and support, or measures in place that can help them deal effectively with every situation that might arise. We are fortunate in Australia to have physicians with great expertise and experience which could translate to the bedside and classroom, for example, Keith also said in reference to difficult bedside conversations: “I’ve developed some tricks over the years that help”. The extensive experience at the bedside of particular physicians is a resource that should be harnessed rather than squandered. Professional mentoring is available for General Practitioners (Royal Australian College of General Practitioners, 2011), but new research could develop and evaluate the effectiveness of a peer mentoring program across end-of-life settings where difficult decisions and clinical interventions can be supportively considered. Open-ended surveys which expand data from the current study could be completed by other willing physicians who may then be further engaged to develop a clinical and academic interface, and mentoring network, that brings mutual benefit to student and practitioner alike.

Correspondingly, strong reference was made throughout the thesis that despite especially invigorated efforts to address the problem (Cameron, et al., 2008; Dalziel, 2007; Kissane, et al., 2010; Phillips, 2008), communication difficulties still persist at the
bedside and often culminate in negative experiences for physicians. For non-palliatively specialised physicians in particular, competently addressing difficult bedside discussions like conveying bad news to patients and loved ones, negotiating ethical issues such as requests to hasten death, and diffusing interpersonal conflicts including with professional colleagues was not a generalised skill. Certainly, a mentoring capacity could help physicians who encounter these situations with difficulty, but the ongoing need for educating physicians in effective communication skills is strongly indicated. Physicians cannot always rely on assistance and are expected to make decisions and communicate them effectively. When educational programs are not consistent across Australian universities (Dalziel, 2007), and while the problematic nature of physician communication in end-of-life settings endures, it can be suggested that some measure needs to be developed or put in place that can assess the efficacy of such programs and advise where refinement could occur.

Indeed a future body of research may focus strongly on “individual differences” (micro) and emotional intelligence (EI), as characteristic of affect regulation and interpersonal self-efficacy, may be one important area to examine (Grewal & Davidson, 2008). Assumedly, prospective physicians are ranked for admission into limited undergraduate positions by correlates of intelligence such as GPA. Certainly, much physician skill also develops with experience, but how is EI implicated? For example, is EI a factor for why some physicians burnout and leave their profession while others remain? We saw identification as an aversive experience for many physicians, but is it particular coping strategies and personal qualities that include factors like EI and/or the positive experiences physicians have (as I have suggested) that support them when experiencing emotional difficulties? Accepting that some physicians might have more or less EI, how can communication skills and expertise with bedside ethical issues be taught most effectively? The earlier discussion (Chapter 8) considered “learnt empathy” as potentially helpful for physicians in graduate training for a career in end-of-life care, but empathy is also something that is “felt” and may be reflective of EI (Weng, Chen, Chen,
Lu, & Hung, 2008). In end-of-life care, empathy and EI have been identified as important physician qualities that influence the care dying patients and their loved ones receive and how physicians experience this, yet are also acknowledged as being particularly under-researched (Weng et al., 2011). Currently, limited research into EI has been conducted with physicians internationally (Deshpande, 2009; Hariharan & Padhy, 2011; Weng, et al., 2011), but none in Australia. An approach that utilises standardised self-assessment scales for emotional intelligence (Hariharan & Padhy, 2011; Mayer, Salovey, Caruso, & Sitarenios, 2003) may be helpful for evaluating the efficacy of end-of-life communication training programs where emotional factors are integral. Self-assessment can be administered pre and post-test. However, some research suggests current measures of EI may partially overlap personality measures (Grewal & Davidson, 2008; Taylor, Farver, & Stoller, 2011) and, since physician communication skills are sometimes also regarded as inherent qualities (Grewal & Davidson, 2008), further work with EI to parse out personality factors from more changeable aspects of behaviour could assist in designing effective training programs.

Consistent with previous research (Bandura, et al., 2003; Caprara, 2002; Caprara, et al., 1998; Caprara & Steca, 2005; Guido, et al., 2009), the findings discussed in Chapter 8 strongly suggest that emotional self-efficacy, reflected through strong interpersonal skills, underpins the positive experiences physicians draw from end-of-life care and their ability to work with experiences that are more difficult or aversive. This is an important consideration for the wellbeing of physicians and their continued engagement at the bedside, and especially for the care they provide to patients and others. The research and training efforts suggested above could strengthen the physician’s emotional self-efficacy and capacity to negotiate the challenging, often uncertain, contextual dynamics end-of-life care presents.

The systemic approach to research contained in this thesis highlights how the experiences of physicians are contingent upon complex multitudinal factors that interact non-predictively. Certainly, all of the issues flagged above for future research have micro
level considerations. It is a fact of life that everybody will die and it is clear from the present research that some will die better than others. This research has provided knowledge that can help more people have “good deaths”. Physicians who provide end-of-life care in Australia are invested in those deaths and, as we have seen, negotiate many influences in a unique bedside context to achieve them. The institutional and administrative structures that regulate Australian end-of-life care may be informed by the positive experiences physicians have reported and also by how effectively they cope with aversive situations. This knowledge can well be enhanced with further research, but already lays a solid groundwork that identifies what does and does not work and where efforts that can support physicians caring for dying patients and patient loved ones could be directed.

10.3. Limitations of the Current Research

When concluding a consuming research project that has fulfilled a particular personal passion and absorbed a number of years, I embrace its limitations rather than consider the research to be finishing on a negative note. I recognise that all research and the conclusions that may be drawn are limited in one aspect or another, but the research questions which are asked largely direct the procedure required to obtain answers. It is also through the particular epistemological and theoretical positioning of the research that such specific questions are raised and subsequently answered. Research limitations are balanced by their benefits and I acknowledge that the purposive sampling strategy suffers a self-selection bias; yet it was crucial for recruiting appropriate physicians. Similarly, the focused scope of this research effectively addressed the research questions but excluded the voices of physicians who are no longer practicing end-of-life care. The stories of those who may have left through burnout, or for many other reasons, are also relevant. This research has conducted one important investigation into Australian end-of-life care and, in doing so, exposed further research and clinical opportunities for the future that could be informed by and extend this research.
As a very specific example, all physicians in the present research experienced intrapsychic burden of some kind\textsuperscript{16} suggesting that such negative experiences may be more widespread. The purposive sample of physicians in this study was certainly adequate in addressing the research question. However, repeating these characteristics with a larger survey-based strategy that utilises the findings of this study in its construction may further uncover the extent of aversive physician experiences in Australian end-of-life care and their impacts to patient care and physician well-being. This would also provide a further opportunity to explore the views of physicians toward divisive constructs like hastening death vs. allowing patients to die. Such a strategy could similarly target the different settings where end-of-life care is practiced and capture responses from physicians across relevant specialties with the aim of informing broad-based efforts that may enhance end-of-life practices and experiences, and counter those more negative.

The qualitative approach utilised in this research had certain advantages in that it was able to focus on specificity, explore and explain phenomena in Australian end-of-life care that had not previously been investigated, and suggest future investigative directions. In so doing, this research has served a valuable purpose. At the same time, it needs to be acknowledged that the interview dynamic, the rapport (or not) between the participants and myself, was influential in how accounts were portrayed especially in terms of what was given by physicians and what I as researcher considered interesting to pursue further. Accordingly, meaning and knowledge is “located” and a partly co-constructed effort, where no two interviews (even if repeated with the same interviewee) could ever be the same. Consistent with a critical realist position, there is more than one truth (Bhaskar, 2011). It is for this reason that a more generalised research approach suggested above could complement rather than diminish the present research. Throughout this research I have maintained scientific rigor and, therefore, as with the multiple influences affecting how physicians understand and practice end-of-life care and what motivates them, I

\textsuperscript{16} This was evident throughout analysis and extensively discussed in Chapter 9.
reiterate that I am also subject to similarly complex influences that have guided my engagement with the research.

**10.4. Parting Comments**

Earlier I declared my position on Australian end-of-life care, a position that has further developed after also becoming a “consumer”. The findings of the present research reflect the current situation in Australia where, according to Palliative Care Australia (2011a) and Robert, one of its specialists: “not everybody will be lucky enough to get specialised palliative care”. Frequently, access is at the discretion of a referring physician who will evaluate a range of factors, often the most pressing of which is available resources. As identified throughout the thesis many dying people will be managed in critical/acute facilities, albeit professionally and compassionately, but also subject to the expertise and resourcing that is available. I consider myself fortunate that my recently deceased loved one received specialised palliative care through the progression of her terminal illness. This was a combination of institutionalised care and also assistance where the broader family could provide a high level of care in the home environment. Palliative Care Australia (2011b) talks of “needs-based care” where its goal for specialised end-of-life care to develop a capacity to adapt to each situation is something I consider a beacon in modern medicine, and something that should be fostered through any possible means.

As a macro/meso policy incentive, the palliative/hospice network could well be expanded beyond the currently limited institutional capacity that prevails. By integrating a social model of palliative care (Rosenberg & Yates, 2010), researchers at the University of Western Sydney (Horsfall, et al., 2011) and others (Abel, et al., 2011) have shown the cost effectiveness, and the positive patient/family experiences, that supported dying at home can provide. That research is working towards developing supportive carer networks through friends and neighbours which also lessens the burden on institutionalised care. Certainly, research suggests that many patients wish to die at home (Foreman, et al., 2006) but, as earlier pointed out by Candice, this is difficult to
accommodate when patients dying in the home setting frequently require professional assistance through a particularly strained outreach capacity. Indeed, Jeremy also said: “palliative care takes on this role by default...we send staff out into the field, and we’ve got a big catchment, but that often leaves us struggling here”. Further developing and supporting an expanded outreach capacity could effectively maximise resources by caring for patients in the home setting longer, where palliative specialists who act in a consultancy role to nurses and others in the field might not feel that the care they provide for institutionalised patients is subsequently diminished. Kerrie spoke of “preventative medicine”, while Jenny, Gary, and Maggie also spoke about the cost effectiveness of keeping patients out of hospital for as long as possible, and where helping them to “live life” helped prepare for a “good death”. In times of fiscal restraint and economic rationalism, this might be the type of language that appeals to government and other funding bodies.
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Appendix A: Interview Schedule

Research Question: *How do physicians understand, negotiate and experience end-of-life care decision-making and practices in the context of Australian critical/acute and palliative settings?*

Could you please tell me a little about your role in end-of-life (EOL) care?
- What is your background?
- What EOL settings do you have experience with (e.g. GP, palliative, critical, oncology, gerontology)?
- How long have you been providing EOL care in Australia?

Could I ask you, what do you see as a “good death”?
- Can you give me an example from your experience when a patient had a “good death”?
  - What happened?
  - What was that like for you? *(Explore deeper and seek a potential contrary)*
    - What did you think about that?
    - How did you feel about it?
  - When are you not able to assist a good death? *(Setting/other constraints?)*
    - Why?
    - An example?

What do you see as a “bad death”?
- Could you describe an example from your experience in which a patient had a “bad death”?
  - What happened?
  - What was that like for you? *(Explore deeper)*
    - What did you think about that?
    - How did you feel about that?

There may be times in end of life care when an intervention to alleviate suffering has the foreseeable but unintended consequence of hastening death. *(Increased analgesia—sometimes non-titrated due to restlessness; withholding antibiotics for pneumonia, withdrawing nutrition/hydration in PS etc.)*

- Could you give me an example from your experience when this occurred?
  - What happened (in terms of a good or bad death)?
-What was that like for you?
  -What were your thoughts about that at the time?
  -How did you feel on that occasion?
-What other experiences have you had when using such end-of-life interventions?
  -How have those experiences been different?

OR

-When would you consider such interventions appropriate?
-What has been your experience with patients making a “specific” request for you to alleviate their suffering through death-hastening means?
  -Could you describe a time when you received a patient request for assisted death?
    -What happened?
      -What did you do?
    -What was that like for you?
      -What were your thoughts about that?
      -How did you feel on that occasion?

Research shows that suffering is often much more than physical, for example existential suffering, anxiety or fear over the progression of illness, loss of functional integrity and dignity, and loss of autonomy and independence, have been linked more strongly than physical pain to patient requests for hastened death.

-What has been your experience in receiving patient requests (for death) to end that kind of suffering?
  -What happened?
    -What did you do?
  -What was that like for you?
    -What were your thoughts about that?
    -How did you feel on that occasion?

Have you had some experience with dying patients who, perhaps considering themselves a burden on others, felt it was their “duty to die”?

-Could you describe a time when you received a request to hasten death from a patient who considered it their “duty to die”?
  -What happened?
  -What was your response?
  -How did you feel receiving such a request?
-Could you describe a time when you received a request from the patient’s family or loved ones to hasten a suffering patient’s death?
  -What happened?
    -What did you do?
    -What was that like for you?
      -What were your thoughts about that?
      -How did you feel on that occasion?
Could you describe a situation where you considered making or would consider a decision to shorten the life of a dying patient who was suffering intractably?
  -Could you provide an example?
  -What was that like for you?
    -What were your thoughts about that?
    -How did you feel on that occasion?
When would you consider it appropriate (in terms of “good” or “bad” deaths) to “intentionally” hasten a patient’s death?
  -What would it take?
  -Are there any differences or exceptions?

Are there times when you experience a conflict between your ethical and professional duty to relieve suffering and your ethical and professional duty not to use means which deliberately hasten death?
  -Could you describe a time when you had such a conflict?
    -What happened? What did you do?
    -How did you feel?
Are there times where you experience a conflict between your own personal standards and beliefs your ethical and professional duty to relieve suffering without hastening death?
  -Could you describe a time when you had such a conflict?
    -What happened? What did you do?
    -How did you feel?
Could I just ask you a couple of final questions?
  -Firstly, what’s the best part of your job?
    -and not really wishing to end on a bad note, but what’s the worst part?
(End of interview)
Is there anything we might have missed or that came up in the interview that you would like to cover or talk further about?

**Supplemental Interview Questions**

(If not raised by the physician, used selectively and when appropriate)

Could I just ask you about your experiences with terminal or palliative sedation as an end of life practice?
- Could you give me an example where you used sedation with a particular patient?
  - What happened in terms of a good or bad death?
  - How did you feel on that occasion?

Is sedation a valid or practical surrogate or alternative to VE or PAS?
- Why or why not?

Patient care for those with a terminal prognosis ultimately needs to progress from a critical or acute focus to one more palliative, for example, the cessation of more aggressive forms of treatment to a regime that emphasises comfort and palliation.
- Could you describe how you negotiate new care goals and treatment options with patients and their loved ones as they become necessary for patients with irreversible disease?
  - What are some of the problems you encounter in such negotiations?
- Could you give me an example of a situation when you needed to do this?
  - What happened?
  - How did you feel?
Appendix B. Participant Information Sheet

Participant Information Sheet

Project Title: End of Life Decisions and Practices: The Experiences of Doctors in Australia.

Who is carrying out the study? The principal researcher is Steven Trankle, a PhD Candidate with the School of Psychology at the University of Western Sydney. This research will form the basis for the degree of Doctor of Philosophy and will be conducted under the supervision of A/Prof Janette Perz (principal supervisor), Dr Emilee Gilbert (supervisor) and Dr John Haw (supervisor).

What is the study about? The purpose of the research is to investigate the end-of-life decision-making and practices of doctors with experience in providing care to dying patients and their loved ones in Australia. The aim is to explore the individual experiences of doctors and their understandings around provision of end-of-life care. This will include issues such as euthanasia, physician-assisted suicide and terminal or palliative sedation and how doctors respond to individual patient requests for such intervention. The knowledge gained from this research will contribute to a greater understanding of the issues currently surrounding Australian end-of-life care and potentially foster further research.

Who will be invited to participate in the study? You have been invited to participate because of your experience as a doctor providing end-of-life care in Australia. The
invitation to participate is also extended to your professional colleagues who have similar experience.

**What does participation involve?** You will be participating in a confidential one-on-one interview with the principal researcher. The interview format is semi-structured but will be collaborative. The researcher will be asking questions about your personal experiences of providing end-of-life care in Australia and will explore those experiences and your understandings around caring for dying patients. Before beginning the interview, you have the opportunity to ask questions and seek further information from the researcher. The entire interview process should take around 60-90 minutes. This discussion will be audio taped to allow the researcher to go over what is said in detail afterwards. The discussion will be strictly confidential and you will be guaranteed anonymity. You will be required to sign a consent form at the interview if you are happy to participate.

**Are there any risks?** Discussing personal experiences of providing end-of-life care to dying patients and their loved ones has the potential for emotional discomfort. The researcher is particularly sensitive to the ethical issues in the study, and will ensure the ethical conduct of all aspects of the research. However, if you find any part of your participation particularly unsettling, or find it raises issues you had not previously considered, please feel free to contact the Doctor’s Advisory Health Service (NSW) 24 hour Help Line on 02 9437 6552. If you wish to discontinue or withdraw your voluntary participation at any time you may do so without giving a reason and without any consequences.

**Confidentiality/Privacy:** All of the information you provide in this study will remain strictly confidential. You will be guaranteed anonymity through the permanent removal of all personally identifiable information and the use of pseudonyms. Thus any potential legal requirement for the researcher to disclose information will be in a de-identified
format. Only the principal researcher and his supervisory panel have access to the de-
identified interview transcripts.

Reimbursement: Participation will not cost you anything, however, if you incur any
travel or parking expenses they will be reimbursed to the amount of $25.

What happens with the results from this research? If you give your permission to
participate by signing the consent form, the results will be disseminated in a thesis as
required for the degree of Doctor of Philosophy. It is also expected that the results will be
published in peer-reviewed journals and presented at conferences or other professional
forums. Any publications arising from this research will not be able to identify you
through any means. If you wish, the results from the study can be sent to you when they
become available.

Further Information and Participation: To obtain further information and arrange
participation, you or your colleagues can contact the principal researcher Steven Trankle
at s.trankle@uws.edu.au or on 0408407600, or the principal research supervisor, A/Prof
Janette Perz at j.perz@uws.edu.au

Thank you for taking the time to consider participating in this research.

This information sheet is for you to keep.

Complaints: The University of Western Sydney Human Research and Ethics Committee have approved
this study. The approval number is H7589. If you have any complaints or reservations about the ethical
conduct of this research, you may contact the Ethics Committee through the Office of Research Services on
Tel 02-4736 0883 Fax 02-4736 0013 or email humanethics@uws.edu.au. Any issues you raise will be
treated in confidence and investigated fully, and you will be informed of the outcome.
Appendix C. HREC Approval

From: Kay Buckley
Sent: Fri 23/10/2009 9:57 AM
To: Janette Perz; Steven Trankl e
Subject: HREC Approval H7589

Notification of Approval

Email on behalf of the UWS Human Research Ethics Committee

Dear Janette and Steven

I'm writing to advise you that the Human Research Ethics Committee has agreed to approve the project.

TITLE: End of Life Decisions and Practices: The Experiences of Doctors in Australia

H7589 Student: Steven Trankl e (Supervisor: Janette Perz)

The Protocol Number for this project is H7589. Please ensure that this number is quoted in all relevant correspondence and on all information sheets, consent forms and other project documentation.

Please note the following:

1) The approval will expire on 31 March 2012. If you require an extension of approval beyond this period, please ensure that you notify the Human Ethics Officer (humanethics@uws.edu.au <humanethics@uws.edu.au> ) prior to this date.

2) Please ensure that you notify the Human Ethics Officer of any future change to the research methodology, recruitment procedure, set of participants or research team.
3) If anything unexpected should occur while carrying out the research, please submit an Adverse Event Form to the Human Ethics Officer. This can be found at

4) Once the project has been completed, a report on its ethical aspects must be submitted to the Human Ethics Officer. This can also be found at

Finally, please contact the Human Ethics Officer, Kay Buckley on (02) 4736 0883 or at k.buckley@uws.edu.au if you require any further information.

The Committee wishes you well with your research.

Yours sincerely
Kay Buckley
Executive Officer
On behalf of the Human Research Ethics Committee
Kay Buckley
Human Ethics Officer
University of Western Sydney
Locked Bag 1797, Penrith Sth DC NSW 1797
Tel: 02 47 360 883
Appendix D. Participant Consent Form

Locked Bag 1797
Penrith South DC NSW 1797 Australia
College of Arts
School of Psychology

Participant Consent Form

Project Title: End of Life Decisions and Practices: The Experiences of Doctors in Australia.

I,……………………………, consent to participate in the research project titled “End of Life Decisions and Practices: The Experiences of Doctors in Australia”.

I acknowledge that:

I have read the participant information sheet and have been given the opportunity to discuss the information and my involvement in the project with the researcher.

The procedures required for the project and the time involved has been explained to me, and any questions I have about the project have been answered to my satisfaction.

I give my full consent to participate in this research that requires a confidential audio taped one-on-one interview and the dissemination of research findings in a thesis, peer reviewed journals and at professional conferences.

I understand that my involvement is confidential and that the information I provide in this study will not be used in any way that reveals my identity.

I understand that I can withdraw from the study at any time, without affecting my relationship with the researcher now or in the future.

Signed:

Name:

Date:

D.O.B