

**ON DEALING WITH DEATH AND DYING: A QUALITATIVE STUDY OF THE
EXPERIENCES OF SURGEONS, ONCOLOGISTS, INTENSIVE CARE, AND PALLIATIVE
MEDICINE SPECIALISTS**

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Tidal Wave

*So many have passed this way before,
ocean rising behind the door,
the sea forestalled no more.
What do you want of me?
So many have passed this way
knowing what's behind the door
needing solace and nothing more.
What do you expect of me?
So many have passed,
wanting my miracle,
not seeing the Sirens behind the door.
Oh god, what do you demand of me?
Where in the lexicon of learning
was I taught
the wave action of this moment.
Never, never more
did I learn the pulling of the tide
on those entrusted to me, to me.
I am not young anymore
God damn, summon me.
So many have passed this way,
and I, one more.
Stand-down and let it pass.
Ocean falling behind the door.
Tidal wave,
taunt me no more.*

Frank L. Meyskens, MD

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To those close to me who have died and from whom I learnt significant lessons, here is hoping that your legacy is honoured.

Abstract

This thesis explores the experiences with death and dying of medical specialists who frequently deal with patients with life-threatening illnesses. Thirty-three participants from Surgery, Oncology, Intensive Care, and Palliative Medicine responded to interviews that lasted between 29 and 105 min, with an average length of 48 min. The interviews were analysed thematically. Measures to preserve qualitative rigour were employed from the initial stages of the process until the writing of the results.

From the thematic analysis, four areas were chosen as a focus for the thesis, each was the subject of a separate paper: a) the experiences of surgeons, b) the experiences of palliative medicine specialists, c) the emotional connection as developed in the four specialties, and d) an analysis of commonalities and differences between specialties in how they experienced the death of their patients.

Surgeons' experiences and coping mechanisms, as described in Paper One, were influenced by personality traits favoured in surgical practice, such as distancing from patients. In contrast, participants from cancer surgery displayed a proclivity towards developing a closer relationship with their patients. Sources of support, particularly peer support, were not considered essential.

Palliative medicine specialists were the focus of Paper Two. These participants highlighted the role of emotions, and emphasised their ability to derive positive meaning from their work. Religion was identified as a coping mechanism, and differences were identified in relation to those participants with no religious affiliation. The homogeneity of participants' experiences was attributed to aspects that may refer to the philosophy of practice within palliative care.

Paper Three drew on the emotional connection that developed between participants from all four specialties and their patients. Ambivalence about developing or refraining from establishing an emotional connection with their patients was the central theme. To reconcile the ambivalence, some participants resorted to finding a balance in their exchanges with patients, but tended to employ strategies that invalidated their emotional reactions. Other participants preferred an approach where they reaffirmed the emotional nature of working with dying patients.

The common themes amongst the four specialties were the subject of the fourth paper. These themes were related to two overarching aspects: participants' professional practice, and the impact of their professional role on their personal lives. Professional practice aspects were related to frequent exposure to death and dying, limited training opportunities, decision-making process, and the delivery of bad news. The impact of the professional roles on personal lives was related to these medical specialists' experience of emotional uncertainty, individual differences (e.g. gender, years of medical practice), the impact of dealing with death and dying of their patients, and how they deal with death and dying without support.

The findings presented in this thesis may be valuable in the development of strategies to support medical practitioners to deal with common aspects of medical practice, such as the recognition of one's and others' emotions, as well as to enhance

learning opportunities through medical training. Furthermore, the results suggest that the focus of research should be widened from death itself, to experiences during practitioners' entire contact with patients approaching death, particularly from when an impending death is acknowledged.

Statement of Originality of the Work

I, Sofia Carolina Zambrano Ramos, hereby declare that this work contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution, and, to the best of my knowledge and belief, it contains no material previously published or written by another person, except where due reference has been made in the text.

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1.1 List of publications contained in this thesis

Zambrano, S.C., Chur-Hansen, A. & Crawford, G.B. (2012). On the Emotional Connection of Medical Specialists Dealing with Death and Dying: A Qualitative Study of Oncologists, Surgeons, Intensive Care Specialists and Palliative Medicine Specialists. *BMJ: Supportive & Palliative Care* (In press) Published Online First, DOI:10.1136/bmjspcare-2012-000208

Zambrano, S.C., Chur-Hansen, A. & Crawford, G.B. (2012). The experiences, coping mechanisms and impact of death and dying on palliative medicine specialists. (Accepted for publication in *Palliative & Supportive Care*, July 2012)

1.2 *List of conference presentations based on the thesis*

What can we learn about the way that medical specialists deal with death and dying in a palliative care context? (Zambrano, S.C.; Chur-Hansen, A. & Crawford, G.B.) 11th Australian Palliative Care Conference, September 2011. Cairns, Australia.

On the emotional connection of medical specialists dealing with death and dying (Zambrano, S.C., Chur-Hansen, A. & Crawford, G.B.) Joint meeting of International PsychoOncology Society - 14th World Congress and Clinical Oncological Society of Australia - 39th Annual Scientific Meeting. November 2012, Brisbane, Australia.

Medical specialists caring for the dying: an insight into their experiences and attitudes towards death and dying (Zambrano, S.C., Chur-Hansen, A. & Crawford, G.B.) Joint meeting of International PsychoOncology Society - 14th World Congress and Clinical Oncological Society of Australia - 39th Annual Scientific Meeting. November 2012, Brisbane, Australia.

1.3 *List of poster presentations based on the thesis*

What can we learn about the way that medical specialists deal with death and dying in a palliative care context? Zambrano, S.C., Chur-Hansen, A. & Crawford, G.B. 11th Australian Palliative Care Conference, September 2011. Cairns, Australia.

What can we learn from oncologists' experiences with death and dying?

Recommendations for improvement of medical training and practice. Zambrano S.C, Chur-
Hansen, A, Crawford, GB. Multinational Association for Supportive Care in Cancer
Conference, Athens, Greece 23 - 25 June 2011. (Presented by Crawford, G.B.)

_____ Sofía C. Zambrano R. Date: _____

Preamble

To the reader,

As you read this thesis, I would like you to note that this thesis is formatted as a 'thesis by publication', comprising four articles, an Introduction and a Conclusion that draws the work together. Secondly, please note that my advocacy for a palliative care approach in the care of the dying can be evidenced early in the text. I am a registered Colombian psychologist, with clinical and research experience in psychological aspects of palliative care. While you are reading this thesis, you are asked to consider the thesis in the context of these two issues.

Chapter 1 – Introduction

1 Thesis overview

This thesis furthers the understanding and knowledge about the experiences, emotional responses and coping mechanisms of medical specialists who care for dying patients. The thesis commences with relevant background material, including a literature review of the historical and contemporary relationships between medicine and death. Consideration of the literature for each of the specialties selected for the study is provided: Surgery, Oncology, Intensive Care, and Palliative Medicine. The Introduction concludes with a methodological account, highlighting the need for a qualitative approach with methodological rigour, and a statement on reflexivity. The subsequent four chapters consist of self-contained publications arising from the research. A Conclusion ties together the implications of the combined papers, and includes an evaluation of the contribution of the findings to the field, their significance, and suggestions for future research.

The guiding principle of this thesis contends that the efforts to understand how medical practitioners experience and cope with the death and dying of their patients has been overlooked in research about the end of life, and may hold important answers for the professional relationship, medical practitioners' wellbeing,

and patient care. Therefore, the overarching purpose of this thesis is to generate an understanding of medical specialists' experiences, highlighting the differences and similarities between specialties.

2 Introductory background

Throughout the 20th century and the first decade of the 21st century, so called “western” societal attitudes towards death and dying have been characterised by denial (Clark, 2002; Jalland, 2006; O’Gorman, 1998; Price & Cheek, 2007; Rubinow, 2005). The medical and technological advances that have occurred since the 1900s have created the illusion that illnesses can be cured and that death can be defeated. Although these medical advances have been able to delay the occurrence of death, death remains in the background, particularly in the context of advanced life-limiting illnesses and the doctor-patient relationship.

Care at the end of life is considered an important public health issue for the 21st century (Davies & Higginson, 2004). In spite of medical advances and illness prevention, the burden of chronic disease continues to rise. Cancer and other chronic, life-limiting diseases are an example of health issues affecting the population at present.

In Australia, among the leading causes of death are chronic illnesses such as cancer, heart disease, chronic obstructive pulmonary disease, and chronic kidney disease (AIHW, 2008). In 2010, 30% of all deaths in Australia were due to neoplasm (cancer) and 32% related to diseases of the circulatory system (e.g., heart disease) (ABS, 2010). The Cancer Council reported that more than 43,000 people are estimated to have died from cancer in 2010 (Cancer Council Australia, 2012). Beyond providing an overview of the burden of disease, these statistics make visible the reality of the illnesses that are treated by medical practitioners, the pressure on the health care

system, but most relevantly for this thesis, the fact that people continue to die while receiving medical care.

Societal perceptions of death and dying in the context of chronic illnesses have undergone major transformations. Davies and Higginson (2004) highlight three major changes: a significant increase in life expectancy with an associated aging population due to the availability of medical treatments that prolong life; a shift in the patterns of disease, from acute to chronic conditions; and, the development of new social structures. During the 20th century, these social structures changed as a result of migration to cities, and the smaller composition of families. According to Ariès (1982), before the 1900s, communal and familial structures were crucial for people to adjust and cope with death; people, young and old, died at home, and death was visible and seen as part of life. The discoveries of new technologies, public health initiatives, and the biomedical era signified a shift from death as uncontrollable and inevitable, to an event that could be managed and delayed. In turn, the management of care at the end of life by those who had the knowledge to control it, allowed a distancing from death and its exclusion from public view (Wood & Williamson, 2003). And with an aging population, there is an increase in the prevalence of chronic, life-threatening diseases. With this, the need for increased professional support at the end of life becomes necessary, as culturally, Australian families are less likely to be prepared to deal with death and dying.

Death within the context of advanced life-limiting illnesses is now more likely to occur in a medical environment where clinical and technological advances have made it possible for life to be prolonged. This may generate an expectation by society for the invariable use of treatments aimed at postponing death, and perhaps hindering the adjustment to dying and the reality of death (Enkin, Jadad, & Smith, 2011).

The impact of dealing with death and dying has been measured in communities, families, patients and professional health carers. Notwithstanding, research at the end of life has focused predominantly on patients, bereaved families, caregivers, and nurses (Knight & Emanuel, 2007), leaving a gap in the knowledge of how medical practitioners experience and cope with caring for patients with life-limiting illnesses (Artiss & Levine, 2007).

The underpinnings of the relationship between medicine and death, and the emergence of the denial of death as a characteristic of contemporary attitudes of western society are fundamental in order to understand medical practitioners' contemporary experiences of caring for their patients who die.

3 Medicine and death

Death has always been a fundamental component of medical practice. The desire to restore individuals to health, to find a cure, to postpone death, and when death is inevitable, to support people as they die have always been drivers for development and innovation in medical care. No medical practitioner can practice without exposure to the death of patients. However, the history of medicine and medical training shows differences in how medical practitioners have approached death throughout the centuries.

3.1 From acceptance to denial

A predominant western feature in the evolution of death attitudes is that of a shift from acceptance, to the denial, of death. This has been mediated by the availability of medical interventions that do impact on the course and ultimate outcome of a given illness. From an ethical and historical standpoint, Cowley, Young and Raffin (1992) reviewed the relationship between medicine and death from ancient Greece to contemporary western medicine. For example, the Greeks and the Socratics

avoided medical treatments when illnesses were known to be incurable. Abstaining from providing medical treatments in advanced illness was also regarded as appropriate, as engaging in curative treatments with these patients was associated with losing medical prestige. Cowley et al. (1992) explain how the Stoics and Epicureans seemed to adjust to the same philosophy, although in contrast, they supported the hastening of death and suicide.

Cowley et al. (1992) stress how medical attitudes have changed significantly from the Middle Ages to the 20th century. The end of life in Medieval times was characterised by the replacement of the physician for the priest; “the physicians’ role was further attenuated” (p. 1477), as before this time, the physician used to be called as death neared. Religion was what became important; the sanctity of life was a deterrent for the hastening of death or any other intervention, and thus, God was responsible for death, not the physician. The predominance of religion subsided with the advent of the Renaissance and the Enlightenment, both of which formed the basis of modern medicine. Another important alteration in focus was Sir Francis Bacon’s introduction of the prolongation of life as a new task for medicine: up to that point medical treatments were aimed at identifying the nature of an illness, and to prognosticate. The prolongation of life only became a reality in the 20th century with the discovery of antibiotics and the use of technology.

3.2 *The medicalisation of death*

The contemporary discourse on death and dying is focused on the dominant western ideas of the medicalisation of death as a process whereby medical intervention is critical and necessary. The medicalisation of death is present in medical attempts to prolong life, around death denial, and more recently, with the emergence of the

hospice and palliative care movement, and the establishment and recognition of palliative care as an area of medical specialisation.

In his historical review of death and dying, Ariès (1982) has explained how at first, death was a communal experience, and an expected outcome. The dying would be in charge of their last arrangements and death was seen as part of the cycle of life. However, at the beginning of the 20th century with the advent of scientific and technological advances, death became part of the medical environment. Ariès' writings have been criticised for their methodology and overgeneralisation (Kellehear, 2007; Seymour, 1999; Zimmermann & Rodin, 2004). Notwithstanding, his contributions about death from a societal and cultural perspective are still followed by many because they offer a specific depiction of how western society has conceptualised death over the centuries.

From a medical viewpoint, Ilich (1975) drew on Ariès' premises and critiqued medicine and the medicalisation of life and death. Ilich (1975) explains that "the image of a natural death, death which ought to come under medical care and find us in good health and old age is quite a recent ideal" (p. 123). From Ilich's point of view, these ideals reinforce the need for the involvement of medical practitioners and the use of highly sophisticated medical interventions to restore health and to postpone death, allowing death to occur only when the individual is old and without illnesses.

Byock (2002) refers to the professionalisation of death, describing it as a cultural mechanism of avoidance that allows society the fantasy of denying sickness, disability, dependence and death. It is hidden inside hospitals, allowing the population to maintain a distance from death, and medical practitioners inside those hospitals aim to fulfil this obligation of postponing it. In the United States, according to Wasserman (2008) death is still seen as taboo. Bowling (1983) argued that the

trend of dying in medical institutions or with medical care continues to occur mainly for social rather than medical reasons; the course and characteristics of the illness leads to hospital admissions, despite the wish and the potential for people to be looked after at home. Kellehear (2001) highlighted how Australia is still to write its own “story about dying” (p. 508). However, he described that predominant Australian attitudes resemble closely those of the western world, described mainly in literature originating in the US and the UK. However, the multicultural background of Australian society may bring varied perspectives on death and dying (Lickiss, 2003).

With this 20th century medicalisation of death, the care of the dying is now predominantly in the domain of medical practitioners, with various consequences. For example, Middlewood, Gardner and Gardner (2001) argued that the care the terminally ill receive in hospitals is inappropriate because the needs of the dying do not always fit with the ideology and the culture of acute care hospitals, with their main focus on cure. Patients may receive highly complex, sophisticated and expensive medical interventions without consideration of the long-term goals or outcomes. In this way, there have been reports that in the last 24 hours of life patients receive chemotherapy, blood tests, invasive tests with no improvement to quality of life, and in some cases, a reduction in the quality of remaining life (Braga, 2011; Cintron et al., 2003; Middlewood et al., 2001; Moyano, Zambrano, & Mayungo, 2010; Toscani, Di Giulio, Brunelli, Miccinesi, & Laquintana, 2005). According to Astudillo and Mendinueta (2005), acute care hospitals lack preparation for the holistic care that should be paramount as death approaches.

Hospitals may not be an ideal place for death to occur, with the philosophy of care aimed at curing, prolonging lives, or restoring biological functions. This is significantly different from the philosophy of modern palliative care with its focus on

an individual's quality of life and not the illness itself. The preferred place of death has been another area of specific investigation, with most people electing to die at home. In a population survey in Australia, Foreman, Luke, Hunt and Roder (2006) found that respondents, who had no significant illnesses at the time, if faced with a terminal illness, would prefer to die at home. The incidence of death at home between 2000 and 2002 in the same location of this study was however only 14% for deaths from cancer. In another study in Australia, Currow, Burns and Abernethy (2008) compared the place of death for people with malignant and non-malignant disease, finding a higher incidence of death in hospitals than at home, and that people with a non-cancer terminal illness were more likely to die in aged care facilities than in hospices. Despite a desire for death to occur at home, death is still institutionalised for reasons ranging from caregiver burnout, perceived or real inability of families to provide care for a dying relative, to a lack of resources and community supports for people to die at home.

The medicalisation of death remains as one of the most relevant issues that has been associated with supporting death denial in our society. However, Zimmermann and Rodin (2004) provided an antithetical view to the thesis of death denial. They emphasised how the 'denial of death' became commonplace to understand the medicalisation of death, where in fact, from a sociological perspective, the evidence highlights that if death was taken into the hospitals, it was due to the changes in societal structures and industrial developments. They also stressed that the development of technology and the emergence of palliative care as a specific area of health care have promoted the 'acceptance' of death. Therefore, the invitation of Zimmermann and Rodin (2004) is to focus on ameliorating the suffering of patients at

the end of life, rather than on eradicating the denial of death, as it is quite likely that these attitudes have been present before the medicalisation of death occurred.

Despite these opposing views, what the literature tends to agree upon is that medicine has had a changing relationship with death. The current view is that of the medicalisation of death, where the possibility of postponing death has brought those with life-limiting illnesses to expect that they can be cured, or at the least, have their life prolonged, and where medical practitioners feel compelled and have the responsibility to make it so. Other terms that are used interchangeably with the medicalisation of death are the professionalisation of death, and the sequestration of death. All these terms refer to the way in which death has been secluded in the hospital; a view that has started to change with the development of modern palliative care.

3.3 *Palliative care perspective*

The establishment of palliative care as a medical approach has contributed to a model of care that focuses on the wellbeing of the patient, involves the family beyond the medical needs, and incorporates a psychosocial dimension.

Palliative care originated from the hospice movement and from its beginnings, it intended to provide comfort to individuals approaching death and to their families. As a philosophy of care, the modern hospice movement signified a parting from traditional medical practices toward dying patients. Before this movement, the care of dying patients was characterised by neglect towards those who were incurable with care relegated to charitable organisations that had a more passive role (Clark, 2007).

The World Health Organization (WHO, 2012) defines palliative care as an “approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of

suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual". The World Health Organization (WHO, 2012) further states that palliative care affirms life, provides relief from pain, does not intend to hasten nor postpone death, offers support systems, uses a team approach, enhances quality of life, and may be appropriate earlier in the disease trajectory. The modern hospice movement led to the development of services that have improved the care of the dying. An example is the establishment of palliative medicine as a recognised field of medical specialisation. In the last four or five decades, palliative care and palliative medicine have contributed to the academic literature about the biopsychosocial care of the dying and changed clinical practice (Doyle, Hanks, & MacDonald, 1998).

In Australia, Kristjanson (2003) proposed a *palliative care approach* as the broader application of palliative care principles, for those without or with limited access to palliative care. The *palliative care approach* was introduced as an invitation for other medical groups to incorporate the palliative care philosophy in their care of patients at the end of life, or at an earlier stage of the illness (Kristjanson et al., 2003).

One of the most researched areas in palliative care is that of the goals of care at the end of life and the *good death*. The 'good death' has evolved from a concept where patients were prescribed an idealised end of their life, towards a more autonomous process of decision-making where the control is exerted by the patient and not by the treating doctor (McNamara, 2004). One of the main threats to allowing patients to have autonomy over their end of life, is when physicians and patients fail to communicate effectively (Back et al., 2008; Clayton et al., 2008; Clayton et al., 2007; Kaldjian, Curtis, Shinkunas, & Cannon, 2008; Quill, 2000). Fallowfield, Jenkins and Beveridge (2002) found that physicians tend to hide information from patients in

their attempt to protect them from the harm of knowing that they will die. This lack of transparency about death may reflect the medical practitioner's desire to prolong life (Larson & Tobin, 2000), their lack of skills (Schofield, Green, & Creed, 2008) or personal comfort about discussing end of life issues (Fallowfield et al., 2002; Levin, Moreno, Silvester, & Kissane, 2010). Physician and patient communication at the end of life is intended to cover more than breaking bad news, disclosure of prognosis and advanced directives. According to Back et al. (2008), and Larson and Tobin (2000), depending on patient preferences, amongst the aspects that contribute to a good death are that physicians discuss issues that enable patients to have some control as death approaches, such as organising their affairs, maintaining fulfilling relationships, and understanding whether there are options to withhold or withdraw life-sustaining therapies.

The silence that surrounds the physician and patient when death is imminent has been shown to be detrimental for both the physician's well-being and the patient's coping mechanisms. Death is recognised by both physician and patient, but is not openly acknowledged, with the potential to disrupt their relationship. According to Weisman (1972 as cited in Goldsteen et al., 2006) ignoring death and leaving it unspoken intensifies fear for the patient. Discussing death may be beneficial for both patients and physicians; the patient has sufficient knowledge to make decisions, and the physicians are able to fulfil their roles without an obstacle to being honest with the patient (Goldsteen et al., 2006).

Palliative care specialists have been trained to be open and honest when discussing death and dying issues, and there is evidence that patients benefit from these interactions (Bailey et al., 2005; Gade et al., 2008). However, the palliative phase of a life-limiting illness is most likely to begin when the patient has been under

the care of other medical specialists who may not have communicated as openly with patients. The studies that emphasise the need for physicians to communicate effectively, coincide with the need for all medical practitioners, not just palliative care specialists, to be able to unreservedly approach patients with honesty at the end of life (DesHarnais, Carter, Hennessy, Kurent, & Carter, 2007). Thus, according to a palliative care perspective, instead of continuing with futile treatments, the efforts of medical care would be those of supporting the needs of the patient and the family. These attitudes have started to be negotiated with the introduction of palliative care in the acute care setting (MacLeod, 2008). For example, Zimmermann and Rodin (2004) highlight the developments in palliative care that have promoted its implementation as a service that can be offered to patients along with other medical treatments, from the diagnosis stage, rather than just at the end of life.

Palliative care has challenges of its own. Whilst the principles of palliative care highlight that the focus is on the whole individual, there are critiques that the palliative care approach may tend to concentrate on bodily symptoms rather than on non-physical symptoms. For example, issues that go beyond physical symptom control should be carefully considered and addressed (Breitbart, 2006). MacLeod (2001) warns about the danger of palliative care becoming too technologised and not focused on issues of care at the end of life, and earlier. Kearney (1992) discussed “the danger of selling ourselves short” (p. 45) and emphasised the need to become more than ‘symptomatologists’ (p.46). Another criticism is related to the tendency of wanting to change the culture of death denial. Zimmermann and Rodin (2004) warned that by overemphasising the need of a change from death denial to death acceptance, palliative care may be perceived as promoting the hastening of death. Therefore, they advocate for a shift in the discussion of death denial, such that medical practitioners

and patients might see palliative care as applicable at earlier stages of disease and illness. Zimmermann (2007) further stated that the thesis of death denial, despite the fact that it constitutes an obstacle for palliative care itself, has served as a mechanism for the development of palliative care, since it has allowed advocacy and renewed discussions that have enhanced end of life care.

Additionally, despite palliative care being described as an ideal approach for people facing life-limiting illnesses, the individual challenges to practitioners who frequently face their patients' demise, cannot be overlooked. Current research findings in this area are described in Section 4.5.7 below.

Despite the development and acceptance of palliative care, the philosophy and practice of this area of medical care must reach other specialities that care for people with life-threatening, incurable illnesses. In this respect, medical practitioners' experiences with the death and dying of their patients are crucial to understand barriers and potential enhancers, which once identified can be utilised for the improvement of care at the end of life.

4 Research on medical practitioners' experiences with death and dying

The literature on medical practitioners and how they relate and cope with dying patients is not new. Whilst this relationship has been present throughout the history of medicine, in the 20th century there has been a considerable amount of literature dedicated to the experiences of medical practitioners with death and dying. Most of the literature available is anecdotal and descriptive, especially that which originates from the 1960s. Editorials, commentaries, and letters about personal experiences with the death of patients, or advocating for seeing death and dying from a different perspective, abound in peer-reviewed journals from different medical areas. Publications that are more recent have focused on quantitative studies of how medical

practitioners react to the death of their patients. Few employ qualitative methodologies and this paucity of qualitative research may lead to the omission of relevant aspects of medical practitioners' experiences with death and dying that can only be accessed through qualitative methodologies. Two periods of research can be recognised: one at the start of the hospice movement around the seventies, and a second at the end of the 20th century and the beginning of the 21st century.

4.1 *Classic publications in the seventies*

The first writings were descriptions of how medical practitioners were behaving and should behave with the dying; most of these articles emphasised the lack of training and the need for better education of medical students. Authors usually highlighted the difficulties for medical practitioners when facing dying patients and described the presence of fear, death anxiety, death avoidance and guilt in the medical practitioner.

Marshall, Abrams and Miller (1969) from North America, described how the experience of death in society "...is stripped of its full meaning..." (p. 616) with a patient dying alone because the medical practitioners, the family and the patient preferred to avoid the topic of death. They argued that the role of the medical practitioner at the end of life should be that of someone who remains present throughout the disease trajectory, including involvement in the bereavement care of the family of deceased patients.

In 1974, Mount, Jones and Patterson (1974) published one of the first systematic studies on attitudes towards death and the dying in Canada. They surveyed 638 health professionals and 54 patients, and found that even when patients wanted honesty from health professionals, the medical professionals tended to avoid providing much information about the diagnosis and prognosis of patients with life-threatening

illnesses. They also found that medical residents, the equivalent to junior doctors in training, reported a lack of interest in patients' emotional needs.

In another classic writing about death and medical practitioners in England, Tomblason and Garsed (1977) reflected on physicians' coping mechanisms when dealing with the death and dying of their patients. They emphasised the need for medical practitioners to be able to guide their patients who are dying, while being aware of the impact that death and dying may have on their own lives. The authors noted that first experiences of death and dying for these physicians were likely to have occurred when they were children and did not identify as medical practitioners. In their very first encounters, it was the family's approach that significantly shaped their reactions and ways of responding to death. Later in life, during medical training, Tomblason and Garsed (1977) described how teaching, recognition, or exploration of death and dying related issues were at that time non-existent in medical curricula, with scientific premises taking precedence over the recognition of emotional reactions. As house officers, medical practitioners learned to avoid families and patients, while focusing their interest on the physical condition and keeping busy. The next stage, as outlined by the authors, was that of the "crisis in the adult doctor" (p. 34) where after an overexposure to death and dying, medical practitioners entered a crisis point where they must either renegotiate their view of death as failure, or keep on denying its existence.

4.2 *Pioneering anthropological and sociological studies*

There have been a number of classic anthropological and sociological studies in the area of professional socialisation. Becker, Geer, Hughes and Strauss (1961) employed an ethnographic approach to understand student culture in medical school and how medical students transition to become doctors. Fox (1989) studied medical

socialisation from a sociological perspective. Hafferty (1991) researched the *emotional socialisation* of first year medical students exposed to death and dying both with terminally ill patients and with the dissection of cadavers. In *The Illness Narratives*, Kleinman (1988) discussed the *experience in doctoring* of medical practitioners dealing with patients with chronic illnesses, highlighting how important it is to recognise the difficulties of caring for these patients.

As sociology, nursing, psychology and anthropology have contributed to the palliative care literature, more studies on medical practitioners' attitudes have been undertaken. Writings in the early seventies show a particular concern to make medicine more humane for those facing death. As will be detailed below, in the 21st century there is recognition of the need to educate medical students about death and dying and their emotional response to this inevitable part of their practice, which may be evidenced by the incorporation of these issues into medical course curricula.

4.3 *Contemporary accounts*

Recently, medical practitioners have engaged the medical and non-medical communities with accounts of the challenges of dealing with situations that are personally and professionally demanding in medical practice. Amongst these, the publication of non-academic books highlighting personal experiences is a recent trend. Charon (2006), an internal medicine doctor, emphasises the benefits of what she calls narrative medicine, which is an invitation for health professionals to be open to being moved by the stories of illness. In her book, Charon narrates her own challenging experiences, or situations she has witnessed in her practice, and intertwines them with academic literature to support her viewpoint on the value of these stories. Chen (2008) in a book entitled *Final exam: a surgeon's reflections on mortality* addresses the challenges of negotiating her own humanity and empathy along with teachings that

emphasise the depersonalisation of death and dying. In another book entitled *Vital signs: stories from intensive care*, Hillman (2009) addresses the difficulties faced in the intensive care unit (ICU) due to the availability of treatments that can sustain life, and how ICU doctors face these challenges to best address the needs of families and patients. Medical students have also been given the opportunity to discuss their personal conflicts, in *The soul of a doctor*, third year medical students from Harvard Medical School reflect on their experiences of communication, empathy, and suffering and loss (Pories, Jain, Harper & Groopman, 2006).

4.4 *Contemporary research*

Contemporary research efforts have focused on medical students, interns, residents and practicing physicians. Most of the studies have been undertaken in the acute care setting combining medical practitioners from different areas, as well as students.

4.4.1 *Medical student research*

Medical students may encounter death in different ways before starting their clinical years. One of these ways may be when medical undergraduates study anatomy using cadavers in the early years of their training. According to Rhodes-Kropf et al. (2005), in their study with 3rd year medical students in North America, working on cadavers had a significant impact on how medical practitioners respond and react to death and dying, due to the way in which their responses are shaped through medical education, particularly via the “hidden curriculum”. The “hidden curriculum” (Hafferty, 1988; Rhodes-Kropf et al., 2005), is portrayed as the influence on attitudes, cognitions and behaviours that medical students learn in their interactions with other medical practitioners, outside formal teaching activities, and that they internalise as important to be displayed in their future medical career. For example, at the start of

their training, medical students are taught about empathy and respect for the patient, yet, as they experience the interactions of their senior doctors with patients, who may not necessarily behave as the students were taught, the students may internalise those behaviours as the rule for their future interactions with patients and disregard their explicit teachings (Bouma, 2008). Most of the participants in Rhodes-Kropf et al.'s (2005) study reported that their emotions after a patient's death, and the discussions about those deaths were continually ignored by senior doctors, emphasising the values promoted by the hidden medical curriculum, which seemed to be characterised by a detached outlook on death and a negative view of the expression of emotions.

Redinbaugh et al. (2003), reported that senior physicians were not available for junior medical doctors to debrief about their experiences, which regardless of the level of closeness they had with the patient, were emotional. The reluctance to discuss these issues was usually interpreted by students to be acceptable behaviours to display in their future encounters. As medical practitioners, consequently, they may suppress their emotional reactions, in order to comply with what their mentors deemed appropriate.

In another study with medical students, Williams, Wilson and Olsen (2005) examined the experiences and emotions of first year medical students in their encounters with death, before starting their clinical training. They found that first year medical students seemed to be more at ease with patients dying of old age, and that their biggest concerns were facing the family of the patient and following up on the family's grief. These medical students also considered being trained in coping mechanisms to be important, so that they were able to work with a dying patient.

The teaching of medical students is another area of research. Lloyd-Williams and MacLeod (2004) systematically reviewed the published literature written in

English on the teaching and learning of palliative care in undergraduate medical curricula, including the United States and the United Kingdom. They found that the teaching approach was inconsistent, fragmented and lacking coordination, with a focus on students' gaining knowledge and skills, and less emphasis placed on shaping their attitudes. In a later publication, Janssen, MacLeod, and Walker (2008) discussed critical elements that can be used to teach medical students to care for the dying: a recognition of the context where students were being trained, promoting empathy, allowing early opportunities for patient contact, opening opportunities for students' self-reflection, encouraging students to recognise the importance of self-care, and providing role models with the possibility to develop their abilities to mentor students, so that mentors and senior physicians were able to provide valuable feedback to students. These recommendations are grounded in evidence (MacLeod, 2003). Through an exercise of transformative education with 4th year medical students MacLeod et al. (2003) found that a process in which students documented, reflected, and shared their experiences of caring for dying patients allowed them to discover new ways of seeing death and the dying, and provided a rationale for how to deal with future events. Transformative education, according to the authors, is that which challenges prior beliefs and practices through rational and critical thinking, and where the reflective process leads to changes that continue to be reinforced and tested over time.

Newton, Barber, Clardy, Cleveland and O'Sullivan (2008) considered the impact of medical education on medical students' empathy. In a longitudinal study, they followed four cohorts of medical students for three years during medical school. They found that empathy scores declined significantly over the course of the students' medical training. They also found that those students that chose specialities with less

patient contact had lower scores of empathy. They did not specify which specialties were those with less patient contact, but highlighted that those with high patient contact were internal medicine, family medicine, obstetrics, paediatrics and psychiatry. According to Newton et al. (2008), medical students' decline in empathy scores may be related to the demands of medical training and their newly acquired clinical responsibilities. As students progress through their medical education, gain more experience, practise, and become older, Lloyd-Williams and Dogra (2003) found in the UK that older medical students compared to younger ones, have a more positive attitude towards the dying.

4.4.2 *Medical graduates research*

Schulman-Green (2003) observed in the US that less experienced medical practitioners found it more difficult to deal with issues related to the impending death of their patients. Jackson et al. (2005) found that medical practitioners in training had experienced their emotional responses alone and had not discussed their experiences with older and more experienced counterparts. In contrast, Moores et al. (2007), found that when medical practitioners in the UK were asked about a memorable death, the level of experience or years of practice was not related to the intensity, or experience of emotions. Moores et al. (2007) recruited 188 medical practitioners from different hospitals in the UK and surveyed them about the memorable death of a patient. They found that although medical practitioners reported that they coped well with the death of a patient, they still experienced from moderate to strong emotional reactions. There were no gender differences in these reactions, although Redinbaugh et al. (2003) reported that women usually experienced more intensity in their emotional responses.

In a multi-centre, mixed methods study, Jackson et al. (2005) asked physicians about their most powerful encounters with death in their medical practice. They found that these deaths were experienced at different times in their careers and that the experience of these deaths usually had a crucial impact on decisions, treatments and the relationship style that these physicians had with the specific patient or future patients, such as maintaining emotional distance from patients, or using physical contact as a way to connect with patients. MacLeod (2001) undertook a qualitative study of 10 medical practitioners and their experiences of caring for dying patients. Two themes encompassed participants' experiences: a lack of preparation in end of life training, and turning points, where experience with dying patients served as an educational opportunity that constituted the basis of how they cared for patients.

Further research studies have tried to establish associations between different variables and physicians' experiences with death and dying. For example, Kvale, Berg, Groff & Lange (1999) were specifically interested in the relationship between death anxiety, tolerance of uncertainty, and attachment style in the attitudes of medical practitioners. They found that medical residents in the United States, who had higher levels of death anxiety, had a negative attitude towards dying patients. They also found that tolerance for uncertainty was positively related to death attitudes, such as their level of comfort when treating dying patients, and their perceived ability to communicate with dying patients.

Other research has reported possible coping mechanisms that physicians use when facing the death of a patient. Schulman-Green (2003) suggested that medical practitioners might use eight different styles of coping. These styles were identified as: medicalisation, dehumanising the patient, anger directed at the patient, use of euphemisms, use of humour, denial of their lack of skill, going numb, and talking to

others. However, she also found that medical practitioners found it difficult to share their emotional reactions with other colleagues, as has been reported in other findings in Australia (Ryan, 2001) and the United States (Moon, 2008). The exception in the literature are paediatric consultants, who seem to debrief and find support from their colleagues, as Baverstock and Finlay (2006) found in the UK. However, it appears that the mechanisms of support from medical peers are still inadequate; Schulman-Green (2003) emphasises the need for improved social support within the medical profession.

Although most research has focused on the negative aspects of being exposed to death and dying, particularly as viewed outside the discipline of palliative care, Taubman-Ben-Ari and Weintroub (2008) have shown that caring for the dying could have positive outcomes. In their study of hospital nurses and physicians from different specialities in Israel, they found that with higher levels of exposure to death, optimism, professional self-esteem and lower secondary traumatisation predicted a sense of meaning in life in these professionals. On the other hand, being a nurse, high levels of secondary traumatisation, and high professional self-esteem, predicted more personal growth.

A body of research literature has concentrated on the organisational factors of hospitals. For example, Sorensen and Iedema (2009) found that the organisational culture of the intensive care unit of a teaching hospital contributed to the burden of emotional labour on its staff. Emotional labour is characterised as the organisational requirement for employees to display emotions that are expected as part of their role, such as empathy or avoidance of strong personal reactions. In other words, Sorensen and Iedema (2009) found that the ongoing exposure to death for these professionals, combined with the avoidance of discussions about the impact of deaths on their

professional lives, had a negative influence on their own wellbeing and on how they approached patients.

Most of the available literature refers to medical students and medical practitioners from different fields of medical care. However, research has not compared different medical specialties. A smaller proportion of literature is available on how medical practitioners from specific specialities deal with death and dying.

4.5 *Studies according to medical specialities*

4.5.1 *Research on paediatricians*

In their study of paediatricians faced with child and neonatal deaths, Baverstock and Finlay (2008) in the UK found that most medical consultants were worried about managing the uncertainty of end of life issues in their practice. These medical practitioners usually found it difficult when making decisions about withdrawal of life-sustaining treatments and performing resuscitation. In a previous study with paediatric registrars, i.e., trainee paediatricians, Baverstock and Finlay (2006) also found that the death of paediatric patients was usually deemed more tragic than that of an adult, and these registrars would often admit that these deaths had a persisting personal impact. Another study of paediatric resident doctors, undertaken by Serwint, Rutherford and Hutton (2006) from the US, found that not only the experience of death in medical practice was crucial, but also that most of the physicians who had experienced a personal death, had not discussed it with their families. Thus, personal history, and experiences during their years of training shaped the way in which these medical practitioners communicated about and experienced the death of their patients. The paediatric residents in Serwint et al.'s (2006) study also expressed guilt and sadness after a patient's death.

4.5.2 *Research on general practitioners*

In a qualitative study undertaken in Australia, Zambrano and Barton (2011) found that general practitioners (GPs) have a distinctive relationship with death, since they remained in contact with the patients throughout the illness in different capacities, and even at times providing end of life care. In the analysis of interviews, they found that the moment of death is only one of the stages of what GPs referred to as “the journey with the dying”. It started with their awareness of the impending death of a patient, usually in private, when acknowledging the results of diagnostic investigations and the implications of these investigations. The subsequent stages were: communication of the diagnosis, continuity of care as a transition, the moment of death, and looking after the family after the patient died. Depending on the stage at which participants were caring for patients, participants’ emotional reactions had a personal impact on their own lives.

4.5.3 *Research on emergency medicine specialists*

According to the level of patient and family contact and the possibility of developing a relationship with patients and their relatives, Edlich and Kübler-Ross (1992) considered that deaths in the Emergency Department (ED) deserved particular attention. Some of the particularities of deaths in the ED are that most deaths are unexpected, medical practitioners have little knowledge of the family and the frequency of death in this setting is usually lower, than in other medical settings.

4.5.4 *Research on surgeons*

The literature on surgeons and the care of patients with life-limiting illnesses appears to have evolved over the last 30 years. In the early eighties the drive was for technical knowledge and the need for individualistic surgeons (Hughes, 1985). There has been an increasing focus on the psychological needs of patients (Burton & Parker,

1997), interdisciplinary care (Dunn & Mosenthal, 2007), surgeons' introspection (Page, 2003; Page, 2011), self-care (Dunn, Martensen, & Weissman, 2009; Shanafelt et al., 2010) surgeon-patient relationship (Dunn et al., 2009) and mentoring (Singletary, 2005); which in synthesis, represents a movement from the use of technology to "what being a doctor is all about" (Nuland, 2001p.5). This cultural change in surgical practice is one that is slowly taking place in the United States and in other western countries.

Geoffrey Dunn, one of the advocates for surgical palliative care in North America, has written extensively about the need for surgeons to embrace palliative care principles in their care of patients with life-limiting illnesses (Dunn, 2011a; Dunn, 2001a, 2001b; Dunn, 2011b; Dunn et al., 2002; Dunn & Mosenthal, 2007), including an emphasis on their own self-care (Dunn et al., 2009). Dunn (2011b) denoted that the obstacles to the establishment of palliative care in surgical practice may stem from cognitive, psychological, socio-economic, and spiritual reasons. Amongst the cognitive issues, Dunn highlighted the surgeons' lack of preparation for and knowledge of palliative care practice, and highlighted the dearth of palliative care publications in the surgical literature. The psychological issues related to the aspects of clinical training that appeared to be most highly valued, such as automatic decision-making, a perception of death as failure, the expectation to provide a treatment that cures the illness, and their own personal fear of death. The socio-economic factors were linked to a surgical culture that emphasises leadership and individualism, with a strong preference for highlighting errors. Lastly, considering spiritual reasons, Dunn described surgeons' appreciation of the illness as an entity that was accessed mainly through technology, beyond the relationship with the patient; as well as the denial of

death that permeates the professional relationship, based on unrealistic patient demands and professional goals.

The professional and personal demands of caring for dying patients are challenging in medicine in general, however, the underlying culture of surgical practice may accentuate these challenges for surgeons (Dunn & Milch, 2001; Dunn & Mosenthal, 2007; Guest et al., 2011a, 2011b; Kearney, Weininger, Vachon, Harrison, & Mount, 2009; Tarpley & Tarpley, 2011; Torjuul, Nordam, & Sørli, 2005).

Surgeons have been described to have a stereotypical personality (McGreevy & Wiebe, 2002; Stabile, 2008), temperament (Buchman, Cassell, Ray, & Wax, 2002; Cassell, 1986; Cassell, 1987), or unique surgical persona (Page, 2011) that is characterised by wanting to defeat death, taking risks (Cassell, 1986; Cassell, 1987), possessing authority, power, certainty, coolness under fire, pride in decisiveness, emotional distancing, unwillingness to acknowledge defeat (Nuland, 2001), avoidance of introspection (Page, 2011; Stabile, 2008), self-sufficiency, independence, and resourcefulness (Stabile, 2008). Empirical findings are mixed, and have made it difficult to find evidence for a distinguishable surgical personality (Gargiulo et al., 2006; McGreevy & Wiebe, 2002; Schwartz et al., 1994; Thomas, 1997; Warschkow et al., 2010). However, this conceptualisation continues to provide a rationale to explain surgeons' behaviours, particularly in the face of the death and dying of their patients.

The personality traits described above are highly valued, sought and reinforced in surgical trainees and surgeons (Buchman et al., 2002; Nuland, 2001). However, these attributes may compromise patient care and surgeons' well-being, particularly in the context of death and dying (Cassell, 1986; Cassell, 1987; Nuland, 2001). For example, Nuland (2001) and Page (2003; 2011) have suggested that a lack of introspection may be counterproductive when dealing with non-acute problems, which

are more prevalent at the end of life. When surgeons take no opportunities to think about their bold decisions, they lose the possibility of understanding from where their options for treatments come, or what the underlying reasons might be for offering a certain treatment over another; particularly when they are under pressure to behave as is expected. Nuland (2001) believes that introspection and self-knowledge can guide surgeons “in knowing when to give up on the hope of combating disease and when to soldier on; it prevents [them] from making decisions in which the real aim is to shore up our [their] own personal defences against insecurity (...); it puts [their] fears of passivity and impotence into perspective, so that each failure of therapy is not seen as a failure of one’s self as a surgeon” (p. 5). Page (2003; 2011) conjectures that surgical practitioners are becoming more positive about the need for introspection, and that this may improve their care of their dying patients. Amongst the signs that he has identified are the presence of female surgeons, who are able to respond with the same boldness, whilst preserving sensitivity, as well as the fading of both the “surgical personality” and the expectation for surgeons to portray heroism.

Surgical training does not prepare surgeons well for dealing with patients at the end of life (Dunn et al., 2002). This may be one of the reasons why surgeons have reported that coping with the death of a patient, as well as witnessing patients’ suffering are significant sources of stress (Guest et al., 2011a, 2011b). Despite the rewards of a surgical career, studies of surgeons have identified a high prevalence of burnout (Benson, Sammour, Neuhaus, Findlay, & Hill, 2009; Campbell, Sonnad, Eckhauser, Campbell, & Greenfield, 2001), particularly in younger (Campbell et al., 2001) and female surgeons (Benson et al., 2009). Burnout is a psychological construct that describes the negative impact of work stressors on the individual capacity to overcome those stressors, and the ability to perform tasks as usual (Maslach, Schaufeli,

& Leiter, 2001). Burnout can affect both patient care and surgeons' personal well-being. Burnout is positively associated with early retirement (Campbell et al., 2001), psychiatric morbidity (Guest et al., 2011a, 2011b), suicidal ideation (Shanafelt et al., 2011), medical errors (Shanafelt et al., 2010), and a low quality of life (Guest et al., 2011b).

Patient care may be compromised at the end of life by surgeons who despite the non-curable nature of the illness undertake aggressive treatments, which may prove futile (Cintron et al., 2003; Kwok et al., 2011). Surgical interventions in patients with life-limiting illnesses are associated with high complication rates (McCahill et al., 2003), morbidity and mortality and little positive impact on quality of life, even with symptom improvement (Badgwell et al., 2009). Surgical procedures in these patients are associated with spending more time in hospital and dying in hospital (Cintron et al., 2003; Jones, John, Horseman, Lawrance, & Fozard, 2007; Kwok et al., 2011). Moreover, surgeons have demonstrated difficulty differentiating between surgical interventions with curative and palliative intent (Mosca, Blazer, Wheeler, & Abernethy, 2011).

Caring for patients with advanced life-limiting illnesses poses several dilemmas for surgeons, particularly for those who are unfamiliar with palliative care. The decision making process involved for patients who are not curative may require abilities, such as introspection. This may be a difficult task for some surgeons who have practiced for many years under a different professional paradigm.

4.5.5 *Research on oncologists*

The oncologist's role in the care of patients with life-limiting illnesses is substantial, given that the majority of patients with oncological illnesses will ultimately die (Cherny, 2010). Radiation, surgical, and medical oncologists have crucial roles

both in offering curative and palliative treatments. Literature on radiation oncologists is scarce, as is the literature focusing on surgical oncologists. The majority of studies focus on medical oncologists, yet many of these studies are multidisciplinary in nature, involving other health professionals such as nurses, social workers, psychologists, and other physicians. Consequently, this makes it difficult to distinguish differences for specific disciplines of the multidisciplinary team.

Jackson et al. (2008) observed two distinct types of oncological care, a biomedical and a biopsychosocial focus. In their qualitative study Type I oncologists were distinctive for their concern with biopsychosocial aspects, finding end of life care as a satisfying part of their job, and with confidence in their communication skills. In contrast, Type II focused on a biomedical role and was characterised by a distant relationship, deriving a sense of failure from the inability to offer a better life expectancy. Type II oncologists differed from Type I in that they typically lacked peer support.

Caring for patients with life-limiting illnesses represents challenges at different levels for oncologists. Lyckholm (2001) reflected on the sources of strains and rewards in the oncologist's job; a job characterised by emotion work, unrealistic expectations, experiences that bring about a sense of failure, grief, and administrative problems as a rule and not as an exception. Shanafelt et al. (2003) further added that oncologists may sense that treatments are futile and experience feelings of exhaustion and guilt. Brescia (2004) described medical oncology as a specialty where clinicians experience fear, uncertainty, and loss. Despite the nature of these difficulties faced daily by specialists in oncology, training in these areas has been shown to be insufficient (Buss, Lessen, Sullivan, Von Roenn, & Block, 2007) and is further confused by a consensus about a lack of advice about how to best deal with these issues (Lyckholm, 2001).

Meier et al. (2001) have explored the possibility that these constant emotional experiences may have an impact on patient treatment, as well as on oncologists' wellbeing.

From the oncologist's perspective, a growing body of research has focused on how oncologists care for patients with life-threatening illnesses, highlighting issues of staff stress, communication, and breaking bad news. Stress in oncology staff has been measured particularly in terms of burnout (Asai et al., 2007; Girgis, Hansen, & Goldstein, 2009). In an Australian study, Girgis et al. (2009) found that the factors associated with being at risk of burnout were: having more hours of direct patient contact, inadequate opportunities to take leave, and lack of training in communication skills. However, maintaining a high level of personal achievement, even with significant patient contact was seen as protective against emotional strain. In a study of Japanese oncologists and palliative medicine physicians, Asai et al. (2007) found that oncologists who perceived having scarce time to communicate with patients, as well as lack of confidence in the psychological care of patients, had a higher risk of burning out; furthermore, the oncologists in their sample had higher psychological comorbidity than palliative care specialists.

In a Canadian study with a mixed sample of staff, Dougherty et al. (2009) found that oncology staff had high levels of self-reported stress and identified their workload and insufficient time to grieve their patients' deaths as the stronger predictors of work-related stress. Kovács et al. (2010) identified a further stressor of caring for dying patients, which they characterised as emotional dissonance, and described it as the emotional burden experienced when the clinicians reacted with strong emotions but did not display them because they perceived that this was not part of their role. The dissonance experienced by staff was described as part of the *emotion*

work (Kovács et al., 2010), where clinicians felt a need to hide their emotions and in turn established professional relationships that were not fulfilling.

Communicating with patients with life-limiting illnesses, particularly when breaking bad news of diagnosis and/or prognosis, about change of treatments, or referrals to palliative care, is one of the hardest tasks for oncologists (Cherny, 2010) and one in which their training is limited (Buss et al., 2007). Studies that have focused on the language used when communicating bad news have found that clinicians often use indirect language to lessen the effects of the message. For example, Luftey et al. (1998) found that oncologists negotiated their language according to the cues and the readiness of patients to hear bad news; the words “death” and “dying” were often replaced with indirect language. Rodriguez et al. (2007) similarly highlighted that oncologists employed implicit words to discuss death and dying with patients and their relatives in most of their conversations and whenever the conversation deviated from the topic, they would discuss the probability of death in terms of survival. In a later study, Rodríguez et al. (2008) observed that their participants appeared to talk about life expectancy in terms of availability of treatments, despite the patients wanting to discuss psychosocial aspects of their remaining time. Furthermore, clinicians in their study were more focused on having discussions about positive aspects of the treatments despite an interest of patients to discuss potential negative outcomes.

Artiss and Levine (2007) were concerned with the difficulty for oncologists in maintaining equanimity when a patient is about to die. They recognised that displacement and denial are some of oncologists’ most frequent coping mechanisms. Defence mechanisms were studied by Bernard et al. (2010) in a mixed sample of oncology clinicians (medical oncologists and nurses) and they found that

displacement, rationalisation, and intellectualisation were widely used by clinicians, in an effort to counterbalance emotional stress when communicating with patients.

Baider and Wein (2001) reviewed the literature on the psychological impact of dealing with death and dying for oncologists. They asserted that these issues have not been well documented, even though it is a specialty that is closely linked to dying patients. They postulated that when oncologists are faced with the death of a patient, they are also faced with their own fears and anxieties. Therefore, a better understanding of oncologists' reactions would lead to improved self-care and a better clinical outcome for their patients. Specifically, Baider and Wein discussed an ambivalence regarding empathy, suggesting that despite it bringing personal vulnerability to medical practitioners, it can be considered as a desirable attribute. Empathy, they argued, can work against medical practitioners' psychological wellbeing, a view that is not widely accepted (Newton et al., 2008).

Wolpin, Chabner, Lynch and Penson (2005) were interested in how oncologists coped with the death of their patients and developed a series of multidisciplinary forums, where oncologists and registrars could reflect on particular patients' deaths. These authors placed particular emphasis on the needs of trainees, since based on their observations during these case presentations, trainees usually found it harder to maintain a balance in the professional relationship, in their feelings of failure and in keeping emotional distance with the patients. Blanchard et al. (2010) undertook a study of all oncology residents in France (N=204) and found a high prevalence of burnout (44%). Burnout levels were associated with not feeling rewarded by the type of work, perceiving their general health status as low, and the desire to change specialties or leave medicine. In a survey administered in 2005 of palliative care training for American Fellows in oncology, Buss et al. (2011) found that

Fellows rated their training in palliative care as insufficient; they perceived that the program had a greater emphasis on other areas, but they considered training in palliative care as equally relevant.

Despite the scope of literature on how oncologists approach the death and dying of their patients, many of these investigations are quantitative, and study trainees, or oncologists in multidisciplinary teams rather than focussing specifically on the oncologists.

4.5.6 *Research on intensive care specialists*

Literature on intensive care specialists and the process of dying and the death of their patients indicates that there has been considerable interest in end of life research, particularly in recent years. Mortality data within intensive care units, despite being highly variable, highlight that care at the end of life is unavoidable for all intensive care staff, being a reason why end of life care is intrinsic to intensive care (Aslakson & Pronovost, 2011; Levin et al., 2010). A potential source of conflict between staff members is the decision making process, since most deaths in the ICU are related to the withdrawal and withholding of life-sustaining therapies (Curtis & Vincent, 2010; Yaguchi et al., 2005).

A singularity of the ICU setting is the highly technological nature of the environment where life can be prolonged almost indefinitely and where only through a careful decision making process can actions be taken (Adolph, Frier, Stawicki, Gerlach, & Papadimos, 2011; Chaitin et al., 2003). The majority of the time this process does not include the patient, who is generally under sedation or unable to participate because of their disease process, and the interventions necessary to maintain respiratory function. The focus from the person, instead moving to a focus on technology, is more evident within the intensive care unit. Rady and Johnson

(2004) observed that before admission, patients with advanced life-limiting illnesses frequently did not have informed discussions of alternative treatments that could be provided instead of intensive care therapies, even for those patients with a particularly poor prognosis. Chaitin et al. (2003) discussed how relationships between patients and their medical practitioners have changed in the current western health care system, where the patient has access to a myriad of professionals, but with short interactions that make it difficult for clinicians to understand patients' choices and appropriately assist them to make difficult decisions that match their values. Furthermore, Sorensen and Iedema (2011) found that the decision making process did not take into account family views. They emphasised the need for intensive care specialists to give equal weight to the social competencies required for shared decision making along with technical competencies.

Studies of communication are also at the centre of intensive care research and end of life issues (Iedema, Sorensen, Braithwaite, & Turnbull, 2004; Levin et al., 2010; Schaefer & Block, 2009). Schaefer and Block (2009) highlighted that good communication between the medical practitioner and the family can enhance patient and family outcomes. Levin et al. (2010) discussed the impact of family meetings on clinical outcomes, ultimately facilitating family bereavement.

Within the intensive care setting, the effects of caring for the dying have been studied in nurses and in mixed samples of intensive care staff (Gélinas, Fillion, Robitaille, & Truchon, 2012; Shorter & Stayt, 2010). However, the experiences of intensive care physicians may be different to those of other health professionals (Curtis & Vincent, 2010; Embriaco, Azoulay, & Barrau, 2007). Curtis and Vincent (2010) highlighted that caring for dying patients can cause distress, burnout, depression, and posttraumatic stress within the intensive care setting. Embriaco et al. (2007) estimated

that about 50% of intensive care physicians experience severe burnout. Burnout can affect the individual's job performance, and it can also affect them personally, ultimately having an impact on patient care. Sorensen and Iedema (2009), in an ethnographic study of emotional labour within the intensive care unit, observed that intensive care specialists practiced in isolation, despite being part of an intensive care team. Without sources of social support, practitioners in their study resorted to containing their emotional expressions and avoiding treating patients as people with feelings, emotions, desires and hopes. These behaviours continued even when there were no curative intentions, and the authors noted that these professionals were unable to change to a more supportive role. Sorensen and Iedema concluded that only when death and dying are fully acknowledged within intensive care units, will these workers be able to engage with their dilemmas and adjust to the negative impact of their work.

4.5.7 Research on palliative medicine specialists

Research focusing on the impact of dealing with death and dying in specialists in palliative medicine is still limited (Casarett, Spence, Haskins, & Teno, 2011) which may be related to the fact that palliative medicine is relatively a new area of medical specialisation. The majority of findings deal with the multidisciplinary team (Boston & Mount, 2006; Lindqvist, Tishelman, Hagelin, Clark, Daud, Dickman, Benedetti, Galushko, Lunder, Lundquist, Miccinesi, Sauter, Fürst, et al., 2012; Sinclair, 2011; Slocum-Gori, Hemsworth, Chan, Carson, & Kazanjian, 2011; Webster & Kristjanson, 2002; Yedidia, 2007) or specifically deal with nurses who care for the dying (Dunwoodie & Auret, 2007). A smaller portion of research focuses on physicians (Dunwoodie & Auret, 2007; Swetz, Harrington, Matsuyama, Shanafelt, & Lyckholm, 2009) or compares the differences between health professionals within the

multidisciplinary team (Casarett et al., 2011). Therefore, knowledge regarding palliative medicine specialists' experiences of their work, and of how they incorporate their work experiences into their daily lives, is limited.

Paramount to palliative care practitioners' work is the multidisciplinary nature of their practice, and the focus beyond physical symptoms to include psychological, social, and spiritual concerns (Clark, 2007). Amongst the goals of care, Berger et al. (2000) highlighted the need for palliative care professionals to improve communication and to guide patients' dying process by organising individualised plans of care. Fallowfield et al. (2002) underlined the importance of effective communication with patients, families and colleagues. Kaldjian et al. (2008) further elaborated on the importance of communication, by encouraging discussions that promote adjustment to an unpromising prognosis but which could lead to a more complete end of life experience for the patient and the family. Currier et al. (2008) accentuated the privileged position of palliative care practitioners to facilitate the meaning-making process. Rokach (2005) emphasised the necessity to address patients' needs deriving from physical, social, emotional and spiritual domains. These goals of care stress the significance of the role of the palliative care practitioner in the patient's and family's experience of the person's death and dying.

The challenges of working with patients that are dying have been accentuated in different publications. For example, Kearney et al. (2009) identified the frequent exposure to death, lack of time, workload demands, difficulties in communication, ineffective coping mechanisms, and a potential sense of helplessness coming from emotional responses including grief, depression and guilt, as stressors within the palliative care environment. Rokach (2005) considered role blurring, working with uncertainty, and being aware of the medical impossibility of offering a cure as other

potential sources of stress. Meier and Beresford (2006) further described the personal challenges of intense emotional involvement of professionals with dying patients and how this can be a source of stress and burnout, as well as a source of satisfaction.

The positive and negative impact of dealing with death and dying has been addressed in end of life research. For example, studies of the negative impact underline the potential for burnout, compassion fatigue, moral distress, and vicarious post-traumatic stress in palliative care workers (Kearney et al., 2009; Rokach, 2005; Vachon, 2011). In Australia, in a mixed sample of medical practitioners who provided palliative care, Dunwoodie et al. (2007) found that psychological morbidity and burnout levels were not higher than in other medical specialties. They also found that these medical practitioners' scores of personal accomplishment were high. In a review of 40 decades of literature on the stressors of palliative care, Vachon (2011), highlighted that the majority of research findings into burnout show that staff in palliative care have low levels of burnout when compared to other specialties, or that their levels are comparable to those of other specialties.

The professional rewards that have been identified for palliative care staff are related to experiences including high job satisfaction, compassion satisfaction as opposed to compassion fatigue, and vicarious post-traumatic growth (Boston & Mount, 2006; Kearney et al., 2009; Lindqvist, Tishelman, Hagelin, Clark, Daud, Dickman, Benedetti, Galushko, Lunder, Lundquist, Miccinesi, Sauter, Fürst, et al., 2012; Sinclair, 2011; Slocum-Gori et al., 2011; Swetz et al., 2009; Vachon, 2011; Webster & Kristjanson, 2002; Yedidia, 2007). For example, Webster and Kristjanson (2002) were interested in understanding how palliative care staff derived meaning from their work. In their qualitative study, they found that participants described their work as full of vitality. Working with patients, families and colleagues provided

participants with the opportunity for personal growth and to make meaning in the face of loss and suffering. Sinclair (2011) in a qualitative study, found similar results, highlighting that palliative care staff found their job to be a source of meaning and personal satisfaction.

The doctor-patient relationship within the palliative care environment is characterised by imprecise professional boundaries (Yedidia, 2007). It may be that the flexibility in engaging in professional relationships with patients and families is what allows the opportunity for palliative care staff to find rewards in their work. Yedidia (2007) highlighted that hospice and palliative care workers' mechanisms for coping with having close relationships with patients who ultimately die, are related to appreciating their role during the care of the patient, understanding why they performed well, and learning from patients. Swetz et al. (2009) highlighted that palliative care workers' relationships with their patients are characterised by intense encounters and a high investment in patients that could potentially affect work-life balance. They proposed that this is why these professionals engaged in different activities that helped them restore the balance. Maintaining their well-being, having trusting professional relationships, taking a transcendental perspective in life by acknowledging their mortality, talking with others, and having hobbies, were prioritised in palliative medicine physicians' lives.

It is important to highlight that despite the positive findings on how palliative care staff adjust to the demands and stresses of their work, the efforts that many of these practitioners engage in, in order to find rewards, may at times be difficult to achieve. Vachon (2011) emphasised that the challenges for palliative care practitioners should not be overlooked, particularly when workload, and administrative demands, may not allow staff to engage in the processes that allow them to find rewards in their

professional practice. Palliative care practitioners are an invaluable source of knowledge in order to better understand the impact of working in an environment where death and dying are constantly in the background if not the forefront of all interactions. Their experiences may be useful beyond the palliative care context itself and may enrich the opportunities for specialists from other medical areas to identify alternatives that may help them adjust to the challenges of dealing with death and dying (Yedidia, 2007).

4.6 *Summary*

Available literature findings highlight universal, as well as specific difficulties, needs and pressures for medical specialists, such as surgeons, oncologists, intensive care specialists, and palliative medicine specialists encounter during their careers. Studies from each of the specialties highlight the high prevalence and the potential for burnout in those working with dying patients. The effects of dealing with death and dying can also be measured in terms of their effect on patient care, where futile and aggressive treatments are frequently reported.

The research that has been undertaken in contemporary studies has shown how death and dying may be perceived differently according to the medical specialty in which the medical practitioner has been trained. However, these results have not yet determined what lies behind medical practitioners' attitudes, how those experiences are dealt with in their professional practice and personal lives, and how their medical training might prepare them for managing the death of their patients at personal and professional levels. Studying medical specialists' experiences and attitudes towards patients as they approach death and do die is crucial to understand their attitudes and how they cope with the death of their patients.

5 Rationale for the study

The medical and technological advances of the 20th century have reinforced, in western culture, the belief that death can and should be postponed or even avoided. In the literature, medical practitioners have been described as struggling with the care of their patients as they approach death. These attitudes appear to continue to be reinforced by their medical training and current societal expectations that these doctors should be aloof, invincible and able to manage all situations to which they are exposed.

Although palliative care has offered an alternative perspective in the care of the dying and the World Health Organization advocates for the use of palliative care earlier in the course of the illness (WHO, 2012), not all patients will have access to palliative care services before the illness has advanced significantly. Furthermore, it cannot be assumed that even all palliative medicine practitioners have effectively learned to cope with the emotional demands of their profession. Nowadays, medical practitioners are expected to develop better relationships with their patients, especially when facing a life-threatening illness (Rogers, Karlsen, & Addington-Hall, 2000). Although there have been efforts to ensure that medical practitioners feel at ease with death and dying, medical students still feel that they lack sufficient training to balance their emotional responses with the responsibility of caring for the dying (Redinbaugh et al., 2003; Rhodes-Kropf et al., 2005). On the other hand, older generations of medical practitioners, in their role as mentors or role models, may continue to reinforce the view that death and dying are not areas of care that should be discussed in depth, for example via the “hidden curricula” (Hafferty, 1988), unless in palliative care. Studies on the hidden curricula emphasise the interplay between medical training before clinical years, and the shaping of responses as clinical exposure begins,

generally characterised by a decline in empathy (Hojat et al., 2009) at a time when these skills are more needed. Medical training reinforces practices that do not seem to be endorsed by senior clinicians in the clinical arena, thus shaping undesired characteristics in medical trainees and junior medical practitioners (Jaye, Egan & Parker, 2005) which are perpetuated into future encounters and further postgraduate training.

In this thesis, the medical specialties of Surgery, Oncology, and Intensive Care were chosen for their involvement at different stages in the care of patients with advanced life-threatening illnesses. Palliative Medicine was chosen for the nature of its medical training and practice, which contrasts with the other specialties. Sorensen and Iedema (2009) described how specialties like Oncology and Intensive Care challenge the abilities of professionals practicing in these areas and how these issues have been explored in nursing research, but not to the same extent for medical specialists; a view that is shared by many other researchers. Furthering the research in the four chosen specialties, and comparing participants' experiences with those of other specialists can provide a more comprehensive picture of how medical specialists deal with the challenges of caring for the dying.

Amongst a number of other qualities that medical practitioners should have, the medical and non-medical literature continues to give prominence to the necessity for them to hold knowledge in palliative care, communicate effectively, support the needs of patients with life-threatening illnesses, and cope with the emotional demands of their profession. Whilst most of this research is prescriptive and anecdotal, as noted in the literature review, other research has successfully associated different personal, social, cultural, spiritual, and professional issues with current medical attitudes. However, less research has focused on the meaning of death for medical

professionals, the ways in which they approach the dying, their experiences, and the impact that working with the dying has on their lives, according to their chosen medical specialty. Some oncologists, obstetricians, anaesthetists, intensive care specialists, surgeons, and paediatricians have participated in studies, but these studies have not considered how the training rules and expectations of particular specialties might influence these medical professionals reactions to death.

Thus, the present research aims to generate constructs to understand how medical practitioners from Surgery, Oncology, Intensive Care, and Palliative Medicine experience and cope with the death of their patients.

6 Research questions

As demonstrated by the overview of the available literature, despite ongoing interest and repeated calls for further understanding and investigation, research into medical practitioners and the issues associated with the death of their patients is still limited. Although those studies have yielded interesting results that have identified different issues for medical practitioners when their patients die, the deductive nature of the methods used to explore their responses have failed to explore their whole experience with death. Therefore, this study aims to qualitatively explore the following questions:

- How do medical practitioners from different specialities experience and cope with the death of their patients?
- What are the differences and similarities in how surgeons, oncologists, intensive care specialists, and palliative medicine specialists experience and cope with the death of their patients?

7 Significance / Contribution of the study

Medical practitioners from different fields of medicine, especially those in acute care hospitals, have been reported to not deal adequately with the needs of patients with life-limiting illnesses. For example, these deficiencies can be seen in the issues identified in doctor-patient communication, in the number of highly specialised interventions and treatments during the last days and weeks of life, and in family and patient satisfaction. Additionally, medical practitioners may experience mental health problems such as depression, substance abuse, suicidal thoughts or acts, and burnout and some will leave the profession, because they are not prepared for the tasks they face (Guest et al., 2011b; Kearney et al., 2009; Sorensen & Iedema, 2009).

By further understanding these issues, the results of the present study can inform medical curricula both at postgraduate and undergraduate levels to further contribute to medical education. It also has relevance to the death and dying, and grief literature.

8 Research approach

8.1 The need for a qualitative approach

A qualitative research approach was considered appropriate for answering the research questions. This research was designed in order to provide a better understanding of medical specialists' experiences and coping mechanisms with death and dying, particularly as previous literature findings are mainly quantitative, prescriptive, and anecdotal. Despite the strengths of a quantitative approach, these methodologies are not devised to understand underlying meanings, beliefs and experiences, which can be accessed through qualitative data. Qualitative methods in health and psychological research provide the opportunity to access human

phenomena in an in-depth, comprehensive manner where the participant's perspective rather than the researcher's is privileged.

The analysis of this research uses Thematic Analysis. As described by Braun and Clarke (2006) this versatile and frequently employed method can allow for rich and detailed results from qualitative data. Thematic analysis organises, compares, and finds patterns in the data. There are six stages of data analysis, and although described as a linear process, as in most qualitative research, they are followed as an iterative process, where each of the stages of analysis is revisited as the analysis progresses (Braun and Clarke, 2006). Braun and Clarke delineate the analytical stages of thematic analysis as: 1) data familiarisation, 2) code generation, 3) theme identification, 4) theme review, 5) definition and naming of themes, and 6) report production.

Although other qualitative methods such as ethnography and phenomenological approaches could have been employed in order to conduct this research, these approaches were not chosen as they rely on specific epistemologies, theories, and disciplines (Boyatzis, 1998), and are not typically used in mainstream psychology. The philosophical stance of other approaches may affect the accessibility and translatability of the results to other "fields, orientations, or traditions of inquiry" (Boyatzis, 1998, p.6). In contrast, Thematic Analysis "can be a beneficial bridge between researchers of varying orientations and fields" (Boyatzis, 1998, p.6). As this thesis bridges psychology and medicine, and the targeted journals for publications are biomedical, the decision was made to adopt an approach that "can capture the complexities of meaning" (Guest, MacQueen & Namey, 2012, p.11) whilst preserving the ability to offer practical and applicable results that can be accessed across disciplines.

The procedure for participant recruitment, data collection and data analysis can be found in each of the papers in the subsequent chapters.

9 Academic and scientific rigour

Quality and rigour are paramount to all stages of the research process and are evidenced in researchers' measures to preserve trustworthiness and to control for any biases that may potentially impact on the findings of the research. Several authors have described different principles that can be followed to enhance the trustworthiness of qualitative research. Tracy (2010) put forward a series of unifying criteria for ensuring excellence, underlying most qualitative research. Tracy (2010) highlighted the need for a worthy topic, examined through a process that is rich in rigour, ethical, presented and analysed with sincerity. Furthermore, the credibility of the research process and the resonance of the findings add to the research process by producing what can be considered a meaningful contribution. These criteria constitute the principles of a research process that can be considered thorough, conscientious and self-reflective. Researchers' transparency, reflexive practice, and adherence to ethical principles are considered below.

Lincoln and Guba (1985) proposed four criteria that parallel the notions of internal validity, external validity, reliability and objectivity, but developed them within the qualitative paradigm. They suggested credibility, transferability, dependability and confirmability as criteria that ensure quality of the qualitative research process.

Credibility entails the extent in which the portrayal of participants' accounts is faithful to their responses. In this research, interviews were checked for transcription accuracy by a second researcher (one of the supervisors of this thesis) and participant validation was sought before being analysed. Participant validation is a mechanism

where the opportunity is given to participants to provide feedback on the completeness of the transcripts, as well as to modify any of the contents. Only six of the 33 participants edited minor parts of their transcripts, and another five replied without making changes. It cannot be assumed that those participants who did not reply to the request were in agreement with their transcripts.

Transferability relates to the possibility of extrapolation of the research findings to other contexts: that is, results are useful beyond the setting in which they were interpreted. Transferability can be achieved by describing the setting and the findings in rich detail - 'thick description'. For this research, the clarity of the explanations and descriptions in the papers, and the inclusion of participants' quotes, enhance the detail of the description of the findings. Additionally, published literature in this area resonates with many of the findings, which may be an indication of the transferability of the ideas derived from this thesis to other contexts and settings.

Dependability is the criterion that aims to convey consistency within the findings to ensure that other researchers could 'replicate' the findings, or understand the process well enough to be able to recreate the study. 'Audits' by external people to the research are a mechanism to ensure dependability. In this research, the process of peer reviewing by the academic journal peer review process for each of the papers can be taken as an external audit. The reviews and responses to each paper are appended (Appendices 1, 2 and 3). The paper on emotional connection has been published *online first* in BMJ Palliative and Supportive Care (Chapter 4). The paper on palliative medicine specialists has been accepted for publication in Supportive and Palliative Care (Chapter 3). The response to the paper on Surgeons (Chapter 2) is still under appeal, since the reviewers considered the sample size too small, but further

communication with the editor has been positive and, pending communication with experts in qualitative research, the editor may reconsider the decision.

Lastly, confirmability refers to the ability of the researcher to remain neutral; to represent participants' experiences with transparency. In this research, the PhD candidate and the supervisors of the research compared the coding of a randomly selected transcript and verified coding agreement. Furthermore, an audit trail¹ containing reflections and clear accounts of raw data, reactions and analytical ideas was maintained from the first interview through to data analysis and the writing of the thesis.

9.1 Ethical considerations

Following the principles of the NHMRC National Statement on ethical conduct on human research (NHMRC, 2007), this research addressed the relevant requirements in order to guard the safety of the participants. Participants were assured the right of confidentiality, privacy and anonymity, through informed consent and respectful handling of data. The informed consent granted the participants full knowledge of what the study involved and the aims and objectives of the research. Participants were given the right to withdraw from the study at any time and to interrupt or cancel the interviews if they wanted. None of the participants chose to withdraw from the study.

The recordings of the interviews and the transcriptions, as well as the signed informed consents are stored in a locked cabinet in the Discipline of Psychiatry at The University of Adelaide for seven years (from the commencement of the research). Participants nominated whether they wanted a copy of the transcript (29 out of 33 participants), in order to check and/or add to or delete information provided during

¹ If requested, the audit trail is available for inspection.

the interview (participant validation). Transcriptions had all potential identifying information removed from the written text.

The PhD candidate and the supervisors of the research devised a protocol should the interview cause psychological harm to participants. Before finalising the interview, the interviewer ensured that the participant was not distressed by any of the discussions. In the event that the interview caused distress, information on different resources and who to contact was given. However, no participants reported distress.

9.2 *Reflexivity in theory*

The use of qualitative methodologies requires the researcher to be transparent about his or her own role and position within the research context. As Mauthner and Doucet (2003) explain it, in the process of qualitative analysis “meanings are made, not found” (p. 414); this active process involves a researcher whose role is to interpret participants’ accounts and experiences. Therefore, the researcher should not remain invisible: their presence and role in the research process must be accounted for. As a means to remain transparent, researchers often provide reflexive accounts that contribute to rigour, credibility and quality of the research process (Berg, 2004; Hansen, 2006; Holliday, 2007; Jootun, McGhee, & Marland, 2009). Holliday (2007) asserts that by engaging in reflexivity, subjectivity is accounted for, instead of avoided. Malterud (2001) further states that subjectivity only arises when the effect of the researcher is ignored and left implicit.

Being reflexive, according to Marshall and Rossman (2011) means to make explicit the role of the researcher, the research assumptions, prior observations, personal connections and personal stories. It means to consider anything related to the research process that others may associate with bias, or which could influence the

process of data analysis. Hansen (2006) equates reflexivity to self-awareness, whilst Shaw (2010) defines it as an explicit evaluation of the self.

Mauthner and Doucet (2003) highlight the need for the researcher to locate him or herself in the research socially, emotionally and intellectually. This process requires the researcher to give consideration to preconceptions, cultural expectations and emotional reactions, before, during and after data collection. Hansen (2006) advocates for an honest description of the researcher's role including the impact of personal characteristics, beliefs, training and assumptions; as well as disclosure of information about age, sex, training, background, relationship to participants, funding bodies and personal connections with the research topic.

In synthesis, by being reflexive, the researcher approaches with awareness, honesty and responsibility their own role in the research process and how their personal history and context may influence their interpretation of the information provided by participants.

9.3 *Reflexivity in practice*

My reasons for writing a thesis in this area stem both from personal and professional experiences. These experiences may have influenced my attitudes and assumptions towards this topic. Therefore, I have constantly, during the research process, reflected on the influence that those experiences may have had on my choice of topic, my choice of groups to interview, my choice of supervisors, my approach to the interviewees, the questions I asked during the interviews, the data analysis and the writing of the reports.

What follows, is an account of many of the experiences I have revisited and reflected upon during my doctoral candidature. I will start with an account of the experiences that led me to my choice of topic, continuing with a description of the

experiences derived from my contact with research participants, finishing with an account of experiences as I write and complete the research process.

My interest in this area started when I was completing a placement as a trainee in psychology at a Pain and Palliative Care Clinic at a hospital in Bogotá, Colombia – my home country. While carrying out the activities I was expected to undertake as part of my role, I started noticing how many patients were unaware of their impending death, despite their status being evident to the medical professionals who were treating them. It appeared to me that there was something in the medical environment that seemed to make this transition, from a curative to more palliative intent, difficult. When looking for answers, I would often turn to journal articles or to the supervisors of my placement, two anaesthetists, one with a Fellowship in pain management and the other holding a palliative medicine specialist qualification. The literature offered a ‘state of the art’ view of a ‘problem’ which seemed to be present not only in Colombia, but in most of the western world.

I continued to see the different behaviours that staff members demonstrated when trying to deliver bad news and it was later with my own experience that I inferred that much of their behaviour was influenced by a perceived need to constrain their emotions. This inference was not derived solely from my experience, as it also represents a cultural understanding of how medical practitioners are expected to behave in such circumstances.

After a few months of working with my medical supervisors I had an experience that influenced my research interests greatly. I was asked to see a fourteen-year-old boy who had been diagnosed with lymphoma to see how he was adjusting to his illness and the treatment. I had contact with him every time he was admitted to the hospital over a period of 8 to 10 months. Due to the length of time and the

repeated occasions I visited him, our professional relationship grew strong. At the time, he was being seen by a qualified psychologist, which meant that I did not have the need to follow a specific treatment agenda with him. I was comfortable sitting with him and offering him the opportunity to talk about what was important for him at the time. I never felt I was treating him as a patient, for he always treated me as an old acquaintance, as did his family. Thinking back, I may have not been worried about my boundaries at that stage, or was starting to negotiate a style that sat more comfortably with me, although the level of our relationship never felt uncomfortable or unprofessional. The patient, being only a teenager, lacked contact with people that he could relate to when he was in the hospital, and with me being in my early 20s, he came to treat me as a peer and would frequently share what he would have liked to achieve, places he would like to visit, as well as fantasise about a very first kiss, that he would never be able to give. Unknown to him, as the medical professionals predicted, his disease relapsed and his health deteriorated rapidly. In one of the morning rounds, he was in the midst of the final moments of his life. I was there with the medical team as he died and when we left the room, I could not avoid crying. Up to this stage the only close person in my life who had died had been my grandmother; I was not there when she died, so this was my first direct experience with death. The members of the team were all silent, wistful, and to my surprise, no one talked about what had just happened. Whilst everyone went back to their routine, I stayed with one of the trainees in anaesthesia. He asked me to “pull myself together” and suggested that if I wanted to express any emotional reaction, I should do so in a private place such as the bathroom, not in the hospital corridors where people could see me. I did not appreciate it at the time, but that experience was transformational for me.

It is from that experience that I have asked myself questions like these: Why is it that to show emotions in medicine you have to be hiding from public view? Why is it that there was not an opportunity to talk about an event like this? One that had certainly had an impact on us all, particularly when they had known this young boy for even longer than I had? Why was it that the opportunity to talk about it was denied? And, when and how did they learn that as medical practitioners that is how they were expected to behave? These questions, and those derived from academic literature in the area have nurtured my research interests for the past seven years.

As part of the reflexive process whilst undertaking this research, I have given consideration to how my background may have influenced my expectations of how the medical practitioners in the above situation should have behaved, or should behave when someone dies. Some of those expectations for example, may be related to the way in which I would like to be treated as a patient, or how I would like my relatives to be treated. I also think that due to my training in psychology, I may have been expecting a different doctor-patient relationship. I may also have been influenced by my expectations as a female student about to graduate as a psychologist, as well as by this having been my first professional experience with death. I seem to have assumed that emotions are always to be talked about, when I was unaware of the way in which these medical practitioners had experienced the event and their own strategies to cope with death and dying.

My questions became more relevant as I continued in my placement, as well as later as a practicing psychologist in Colombia. A few years after graduation, I continued to have an interest in palliative care and death and dying. I published several papers with the pain and palliative care group in the hospital where I first did my placement. I also continued formal and informal education in the area, whilst I

waited for the best circumstances to travel abroad and whilst I decided on a program of study. I decided that I wished to focus on the psychosocial aspects of palliative care and identified a program in Masters in Grief and Palliative Care Counselling at the University of Adelaide in Australia.

Before travelling to Australia I was aware that whilst our medical systems – Australian and Colombian – are dissimilar, training in end of life and attitudes towards death and the dying were quite similar. This was not only my impression, but has been corroborated with my reading of the published literature. In spite of the similarities, I have been careful not to extrapolate the Colombian context and my own experiences to those that occur in Australia, or specifically in Adelaide.

As part of my Masters degree, in the research component I undertook a study on General Practitioners' experiences with death and dying. I interviewed 11 General Practitioners from Adelaide and the results highlighted the relevance of examining the particularities of different specialties, rather than medicine as a whole. The results of the study received good reviews when presented at national and international conferences, and were later published in *Death Studies* (Zambrano and Barton, 2009) and the feedback I received encouraged me to continue to explore medical specialists' experiences, this time looking at other specialties involved in caring for dying patients at different stages of the illness progression.

I began my candidature as an international graduate student and I was funded through a scholarship granted by The University of Adelaide, which allowed me to commit to my candidature on a full-time basis. At the beginning of the candidature, my ideas for a topic were broad and unspecific; it was through meetings with my thesis supervisors that I refined the topic, the rationale for the sample and the approach to participants. This shared decision process has been constant and has allowed me to

become more aware of my preconceptions challenging some of my previous understandings. This process has also given me a more grounded view of the area I am researching. However, I cannot escape the underlying western culture in which I am immersed, and has been described as characterised by death denial and fear of death. Thus, although I remain aware of my biases, some of my views may have been compromised by current understandings of death and dying within our society. It should also be acknowledged that the supervisors I chose would have had some influence on my approach and my thinking: a psychologist with a strong qualitative bent and an experienced senior palliative medicine physician with experience in health leadership and teaching and research.

When considering the specialties that we chose to interview, I am also aware that by having been trained within the palliative care setting, I may have a palliative care lens in relation to how medical practitioners are expected to deal with the end of life. However, I am also aware that there are individual differences as well as differences in the aspects that may have more relevance in the training of some medical specialties; therefore I have strived to distance myself from those expectations, so that I am able to listen to the accounts of the specialists that I have interviewed, keeping my palliative care knowledge “in the margins”. I have learned from the participants many aspects of how they experience and cope with death and dying, which have enabled me to understand their behaviours in a more informed manner. Whilst undertaking the interviews, I was mindful of my responses to participants and participants’ stories; for example, the feeling of admiration after listening to how they dealt with challenging issues. My awareness enabled me to explore those emotional reactions, to understand my responses better and I was conscious of them as I undertook the analysis of participants’ interviews.

As the research process comes to a close with the writing of this thesis, I have been able to reflect on previous understandings and ideas. I believe that I have been able to assemble an account of participants' experiences whilst remaining faithful to the data.

Chapter 2 - How do Surgeons Experience and Cope with the Death and Dying of their Patients?: A Qualitative Study in the Context of Life-limiting Illnesses.

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Statement of Authorship

How do surgeons experience and cope with the death and dying of their patients?: A qualitative study in the context of life-limiting illnesses. (World Journal of Surgery, 2012 – Submitted paper)

Ms. Sofia Carolina Zambrano Ramos (PhD Candidate)

I was responsible for the conception of the research upon which this paper is based. I produced the first draft of the manuscript and submitted the final manuscript. I completed the literature search, data collection and data analysis. As the primary author, I have been in contact with the journal and have been responsible of responding to reviewers and editors based on prior discussions with and consent from ACH and GBC.

_____ Sofia C Zambrano R. Date: _____

Professor Anna Chur-Hansen and A/Professor Gregory B. Crawford

Anna Chur-Hansen and Gregory B. Crawford were the supervisors of my doctoral candidature. As supervisors and co-authors, their role was to assist me in the initial stages of conceptualisation of the research, and to refine and critically analyse the drafts, which included making suggestions and providing editorial input. Additionally, GBC participated in the initial stages of participant recruitment. ACH checked the interview transcriptions for accuracy. GBC and ACH participated in the coding of one interview, to ensure consistency of the findings.

We, Anna Chur-Hansen and Gregory B. Crawford, hereby certify that this statement of contribution is accurate, and give our permission for this paper to be incorporated

in Ms. Sofia Zambrano's submission for the degree of Doctor of Philosophy from the
University of Adelaide.

_____ Anna Chur-Hansen Date: _____

_____ Gregory B. Crawford Date: _____

1 Abstract

Background: This qualitative study explores surgeons' experiences and coping mechanisms with the death of their patients in the context of life-limiting illnesses.

Methods: Nine Australian surgeons participated in in-depth interviews.

Thematic analysis of the interview transcriptions allowed for the identification of themes and subthemes. Methodological trustworthiness and rigour were preserved at all stages of the research process.

Results: The essence of surgical practice, comprising participants' descriptions of their identity as surgeons, influenced their experiences and coping mechanisms when dealing with death and dying. Distancing from patients, wanting to *fix* problems, *doing* in terms of operating on a patient, prominence of their personal ability, high personal responsibility for patient outcomes, and giving hope and having a mixed surgical practice as coping mechanisms, were subthemes.

Discussion: Death and dying are a part of surgical practice and surgeons face challenges as they care for dying patients. Despite participants stating that they felt less affected by dealing with patients dying of life-limiting illnesses as compared with unexpected deaths, their descriptions of their encounters, reactions and behaviours, as well as their use of language suggest that these deaths have a lasting impact.

Potential areas for improvement of surgical practice, and teaching about death and dying in surgery are addressed. Furthermore, the results of this study suggest the need to expand the research in this area.

2 Introduction

Surgeons have a significant role in the care of patients with life-limiting illnesses (Bradley & Brasel, 2008; Dunn & Milch, 2001). Caring for these patients

can be professionally and personally demanding (Dunn & Milch, 2001; Guest et al., 2011a; Kearney et al., 2009; Torjuul et al., 2005).

The underlying culture of surgical practice may accentuate the challenges of dealing with patients at the end of life (Page, 2011). The surgeon's personality (McGreevy & Wiebe, 2002; Stabile, 2008), temperament (Buchman et al., 2002; Cassell, 1986; Cassell, 1987) or unique surgical persona (Page, 2011), are desirable, sometimes stereotypical traits that are highly valued, sought and reinforced in surgical trainees and professional surgeons (Buchman et al., 2002; Nuland, 2001). Wanting to defeat death, taking risks (Cassell, 1986; Cassell, 1987), pride in decisiveness, emotional distancing, unwillingness to acknowledge defeat (Nuland, 2001) avoidance of introspection (Page, 2011; Stabile, 2008), self-sufficiency, independence, and resourcefulness, (Stabile, 2008) are some of these traits. However, these attributes may compromise patient care and surgeons' well-being, particularly in the context of death and dying (Cassell, 1986; Cassell, 1987; Nuland, 2001).

Patient care may be compromised at the end of life by surgeons who undertake aggressive treatments, which may prove futile in dying patients (Cintron et al., 2003; Kwok et al., 2011). Surgical interventions in patients with life-limiting illnesses are associated with high complication rates (Badgwell et al., 2009; McCahill et al., 2003), morbidity and mortality and little impact in quality of life, even with symptom improvement (Badgwell et al., 2009). Surgical procedures in these patients are associated with spending more time in hospital and dying in the hospital (Cintron et al., 2003; Jones et al., 2007; Kwok et al., 2011). Moreover, surgeons find it difficult to differentiate between surgical interventions with curative and palliative intent (Mosca et al., 2011).

On the other hand, surgeons have reported the capacity to cope with death and suffering as a substantial source of stress (Guest et al., 2011b). Surgeons have a high prevalence of burnout (Benson et al., 2009; Campbell et al., 2001), with statistics identifying younger (Campbell et al., 2001) and female surgeons (Benson et al., 2009) as more at risk. Additionally, burnout in surgeons is positively associated with early retirement (Campbell et al., 2001), psychiatric morbidity (Guest et al., 2011b), medical errors (Shanafelt et al., 2009), and suicidal ideation (Shanafelt et al., 2011), and negatively, with high quality of life (Guest et al., 2011b).

This study aimed to explore the research questions: ‘What are surgeons’ experiences when caring for patients with advanced life-limiting illnesses?’ And, “What coping mechanisms do they use in these situations?”

3 Methodology

A qualitative research perspective guided the study. Data from in-depth interviews were analysed through Thematic Analysis following the guidelines by Braun and Clarke (Braun & Clarke, 2006). Thematic Analysis is an established qualitative method employed for data organisation in meaningful units of analysis that allow for the identification of themes and subthemes (Braun & Clarke, 2006). Quality and rigour are paramount to all stages of the research process and are evidenced in researchers’ transparency, transferability of results, credibility, resonance, meaningful contribution, and adherence to ethical principles (Tracy, 2010).

3.1 Data collection

The University of Adelaide Human Research Ethics Committee approved the study. A purposeful sampling technique was used for participant recruitment. Participants’ gender, age and years of medical practice were used as the main selection criteria. One of the authors, GBC, a palliative medicine specialist, invited prospective

participants via email. The first author, a psychologist with professional and research experience in palliative care contacted those surgeons who expressed their intention to participate and she carried out all interviews between May and September, 2010. She was unknown to the participants.

3.2 Interviews

Semi-structured, in-depth interviews, ranging between 29 to 105 minutes, with an average of 50 minutes were conducted and tape-recorded with participants' consent and were transcribed verbatim by the interviewer. Interviews were guided by the participant's responses and included topics such as: a) medical specialists' experiences with dying patients within the context of life-limiting illnesses; b) coping mechanisms; and c) perceived preparation and training to deal with death and dying. An audit trail was kept during data collection and data analysis. The audit trail guided the decision to end sampling when data saturation was reached, meaning that no new themes emerged during the final interviews.

3.3 Participants

Twelve surgeons were invited to participate. Nine accepted, 3 women and 6 men. All but one specialist were working on a full-time basis. Their years of medical practice ranged from 10 to 44 years with an average of 26 years of practice. Their areas of expertise were general, upper gastrointestinal, colo-rectal, and breast surgery. These surgeons were practising in major teaching hospitals in the city of Adelaide, Australia.

3.4 Data analysis

The thematic analysis was carried out following the six stages described by Braun and Clarke (Braun & Clarke, 2006): 1) data familiarisation, 2) code generation, 3) theme search, 4) theme review, 5) theme definition and naming, and 6) report preparation.

Interview transcripts were imported into Nvivo 8 (QSR International, 2008), which facilitated the coding process and the identification of themes. All authors verified their coding agreement of one interview. The first author analysed all subsequent interviews; emerging themes were defined and redefined amongst all authors, until the main themes were established. Through the process of constant comparison emerging themes were contrasted with each of the interviews to ensure sound interpretation of participants' experiences.

Methodological rigour and trustworthiness were enhanced through checking of the themes by the second author (ACH), a registered health psychologist. Participant validation of the transcripts was attempted: Seven out of nine participants requested their interview transcripts and one participant edited typographical errors and minor corrections that improved the readability of the transcript.

4 Results

Participants' contact and involvement with dying patients, within the context of life-limiting illnesses, can be explained under three major overarching themes: essence of surgical practice, experiences with death and dying, and coping mechanisms (see Figure 1).

4.1 The essence of surgical practice

The essence of surgical practice encompasses the aspects that participants perceived and described as those that differentiated surgery and the role of the surgeon from other medical specialties. These elements seemed to exert considerable influence in participants' experiences and coping mechanisms when treating patients with life-limiting illnesses. The subthemes of this category were: 1) perceived role as surgeons, 2) relationship style, 3) decision making process, and 4) use of language (See Table 1

for illustrative quotes).

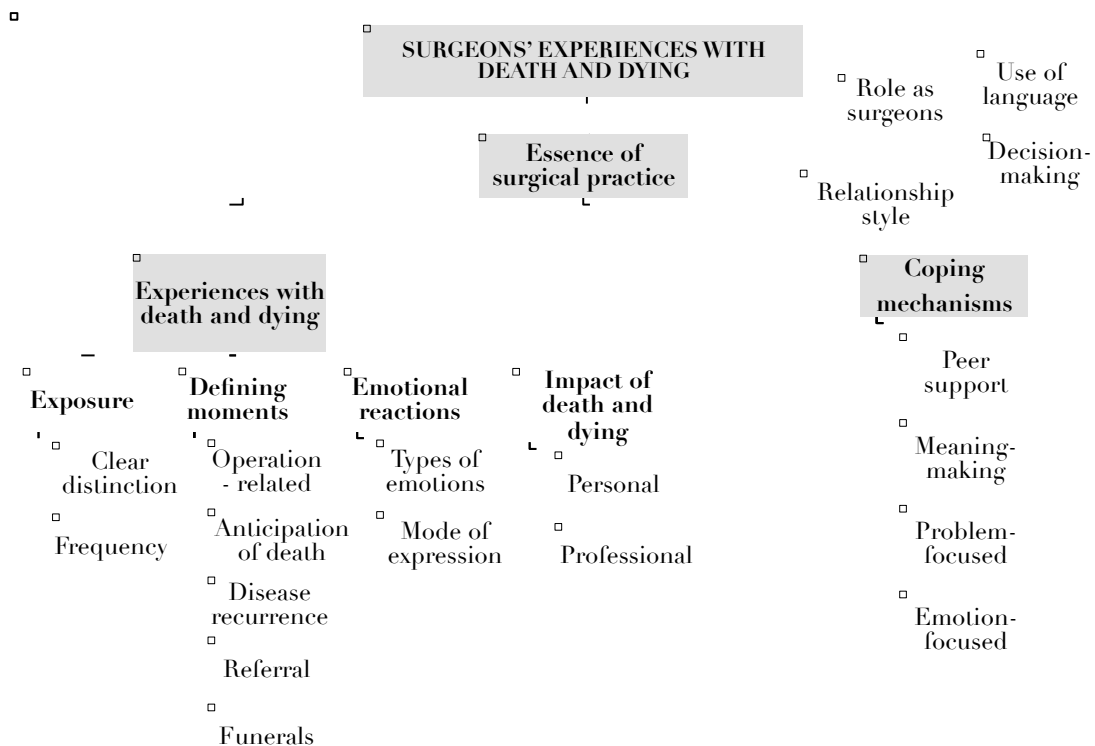


Figure 1. Overview of themes and subthemes

Perceived role as surgeons. Participants described their involvement in the death and dying of their patients by recounting aspects of their perceived role as surgeons. These aspects were characterised as: ‘wanting to *fix* problems’, ‘*doing* in terms of operating on the patient’, ‘prominence of personal ability’, ‘less exposure as senior surgeons’, and ‘short relationship with patients’.

Most surgeons described as an attribute of the ‘surgeon’s personality’ their status as ‘people who like to fix things’. They expressed their commitment to cure the patient’s illness even in situations where the likelihood of cure was minimal. They showed an awareness of potential negative consequences of this behaviour, but specified that before ‘giving up’ on a patient, they would ensure that *all* alternatives were exhausted.

Additionally, many participants viewed their involvement in the care of patients with life-limiting illnesses as that of always having to offer the possibility of

performing an operation on the patient. As surgeons, *doing* something for a patient equated only to performing a surgical procedure. This view had some exceptions, particularly from surgeons whose practice was mainly in oncological surgery, where *doing* had a meaning beyond the operation – e.g. providing information or continuing care.

Participants stated that one of the main differences with other specialties was the nature of their treatments. In surgery, it was not the efficiency of a drug that would have an effect on the illness, but the manual skill of the surgeon. Thus, with the prominence of their personal ability, they were more likely to feel personal responsibility for patient outcomes, even in the cases where the decision to operate was made with the endorsement of a multi-disciplinary team.

Another distinctive aspect of the surgeon's role was the tendency to have less contact with dying patients as they became more senior, particularly if patients were not going to be offered a surgical procedure. Participants explained that due to the current training model in public hospitals, the Resident Medical Officers and surgical trainees had more continuity of contact with inpatients, whereas senior surgeons provided a more consultative function, not always with direct patient contact.

Furthermore, participants described a short relationship with patients who were at the end of life. They would often have intense contact in the days before and after the surgery, progressing to more sporadic contact or no contact at all. Their perceived role was to assess the condition of the patient, decide a possible treatment, perform an operation or decide not to, follow up, and refer back to the treating medical professional. As exceptions, there were a few participants, both female and male, who felt they had a role when specific patients were receiving hospice care. One surgeon consistently kept in contact and wanted to be informed about the status of his

dying patients who had no surgical alternatives and had been referred to other services. One participant stated that he would lose contact with patients because they were always taken to a different setting (home or hospice), due to there not being an inpatient palliative care unit where his surgical practice occurred.

Relationship style. Participants described a relationship style that was characterised by a 'high level of detachment during surgery', and by 'remaining emotionally distant from patients'.

Many of the participants agreed on the need for a level of detachment from the patient during the surgical procedure. Thus, they stated a preference for not wanting to know much about the patient, so that such knowledge would not compromise their objectivity inside the operating room.

For the majority of participants, their professional relationship with patients was characterised by remaining emotionally distant. They defended a private stance, which meant that if any emotions were to surface, they would only occur in private and not in front of the patients or staff members. A smaller proportion of participants stated a preference for engaging in closer relationships, which they described as rewarding and needed, for a better impact on the patient's well-being. The participants who preferred the latter approach tended to have a practice in cancer surgery.

Female surgeons expressed that they could have a more open stance with their patients, where touch was allowed without misinterpretation, as well as being able to acknowledge their emotions in front of patients. Fewer male surgeons advocated for this approach.

With regards to age, the more senior participants stated that when they started practicing in surgery they would get more attached, but through personal experience learnt that they should distance emotionally from patients.

Table 1. Illustrative quotations of the essence of surgical practice

| Subtheme | Subcategory | Quote |
|--------------------|----------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Role as surgeons | Wanting to fix problems | <i>"Surgeons are people who like to fix things. I think you do have that fixer personality. For a surgeon, if somebody has something that is incurable, or you treat that cancer and it's come back, then, there can be that "oh what can I do to fix it?" this sort of attitude which may not always be appropriate." (Surgeon 8)</i> |
| | Less exposure as senior surgeons | <i>"... the students don't see senior people talking to patients about death and dying because we don't. Most of it is done by the registrar staff, and the people who are full time in the hospital itself." (Surgeon 5)</i> |
| | Personal ability | <i>"... I think the differences are that sometimes the ability to deal with their disease is entirely depending on your physical abilities. So, your skill is maybe the limiting factor. (...) with us it may depend very much on how good we are and how courageous we are, and that is a challenge." (Surgeon 6)</i> |
| Relationship style | High level of detachment | <i>"I think when you are operating it is not about the person, it is about the anatomy and their disease. I think you certainly learn that quite strongly." (Surgeon 8)</i> |
| Decision-making | | <i>"I think with surgery you have to make decisions fairly quickly and make them on the run and you've got to basically make decisions sometimes with incomplete information and you've got to trust your judgment on that, in case that it goes wrong (...) for a surgeon, once you do something it is irreversible, so there is a bit more responsibility to make sure you make your decision right..."(Surgeon 2)</i> |
| Use of language | | <i>"... in my practice, most of them have cancer and when you win it is fantastic, when you lose, it is sort of well, it is better than not having intervened." (Surgeon 6)</i> |

Decision-making. Participants' decision-making process was described as another defining feature of the practice of surgery. The irreversibility of surgical procedures, and the trajectory of illnesses, pressured surgeons into making definitive decisions, sometimes with incomplete information. Due to these aspects, surgeons expressed having a high sense of responsibility for patient outcome, regardless of how positive or negative it was. In addition, participants stated that it was becoming common practice to have a shared decision making process, in consultation with multidisciplinary teams, however, they believed that the responsibility ultimately fell upon the individual surgeon.

Use of language. Surgeons' language frequently alluded to their high sense of personal responsibility for patient outcome. Expressions such as 'when you win it is fantastic', 'our inability to cure is our failure', 'how courageous we are', 'a failure of something I've done because I couldn't help her', highlighted the underlying pressure to intervene surgically, to save lives, and to cure patients even in stages where the disease was far advanced.

4.2 *Experiences with death and dying*

Surgeons' experiences with death and dying, in the context of life-limiting illnesses, can be described under four different subthemes: 1) exposure to death and dying, 2) defining moments, 3) emotional reactions, and 4) impact of death and dying (see Table 2 for illustrative quotes).

Exposure to death and dying. Surgeons' exposure to death and dying is a subtheme that incorporates the descriptions of their contact with dying patients.

The underlying mechanism for the death had a significant impact on how the individual surgeon rationalised or explained the experience. Deaths that were taken more personally were those that occurred perioperatively; often in these situations the patient was still under the care of the surgeon. Deaths as a result of disease progression were less unexpected or able to be attributed to a failure of treatment, however only a few surgeons reacted to these types of death with less sense of personal responsibility and more acceptance. When surgeons compared the deaths of patients with advanced illnesses, to those who died as a result of trauma or medical error, they differentiated them by saying that the latter were more memorable and had more personal impact on them.

The frequency of deaths due to progressive disease differed according to the area of surgery of each specialist. Those in cancer surgery were exposed more

frequently, in contrast with those who had less cancer patients and had a more mixed practice.

Defining moments. As a subtheme, defining moments include the main situations in which surgeons described having challenging interactions with patients or being affected by a specific circumstance.

Participants described having challenging conversations with patients in different circumstances related to surgical procedures, these included: when being unable to perform surgery, starting an operation but failing to accomplish the intended outcome, or after the operation if there were postoperative complications. Unexpected outcomes were always difficult and talking with patients or patients' relatives after these occurrences was described as hard.

Additionally, participants described the anticipation of death as a defining moment that had more meaning than death itself, since the realisation that the illness could not be cured changed their interaction with the patient. This was similar to when the disease recurred and when needing to seek support from other disciplines, such as medical oncology or palliative care. This might be seen as a public acknowledgement of '*failure*'.

Another challenge was the decision about attending funerals. Almost all participants had made an active decision to not attend, as this would cross the boundary between the personal and the professional.

One aspect that seemed to protect participants during most *defining moments* was having the opportunity to have contact with palliative care services. Most surgeons identified palliative care as a source of support, particularly in these transitions.

In contrast, almost all participants felt that their training at undergraduate and postgraduate levels did not prepare them explicitly to deal with these situations.

Instead, it was through role modelling and by seeing how others dealt with these situations, that they developed their approach to the dying. This was particularly for the more senior surgeons. Participants who graduated more recently, received more preparation, but still described it as insufficient.

Emotional reactions. The emotional reactions associated with participants' experiences with dying patients were diverse. Most of the participants described feelings of sadness, disappointment, distress, disbelief, and frustration; other participants referred to having regrets about specific courses of action, feeling a sense of failure, but they were also accepting that when having a life-limiting illness, deaths do happen. Their emotional responses were associated with the age of the patient; younger patients elicited more negative emotions, whereas deaths in older patients, who seemed to have lived a good life, were differentiated as less lamentable.

Participants' expression of emotion was frequently publically repressed, particularly for male surgeons, although the majority of the women surgeons agreed with this position. Repressing their emotions was associated with having the emotional response lingering for a few days after the death of specific patients, 'being haunted with the faces of patients who have died', or waking up at night remembering specific cases.

In general, despite the underlying tendency to not let their emotions intrude in their practice, there was a tendency where not only the younger surgeons were more aware of their emotions, but also, some of the older surgeons were reconsidering their distant approach to patients. This aspect may also have a relationship with the type of practice, since those older surgeons who described this approach were those who had a practice mainly in cancer surgery.

Table 2. Illustrative quotations of surgeons' experiences with death and dying

| Subtheme | Subcategory | Quote |
|-----------------------------------------------|--------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Defining moments | Operation-related | <i>"If we can't offer him a cure, then we've actually got to say, well, "we are not going to do it", but as a surgeon, you don't want to say that, you'd like to keep hoping that you do, (...) You are not operating because you can't offer them a cure and that hurts when you tell a patient that you are not operating because you can't offer them a cure." (Surgeon 7)</i> |
| Emotional reactions | Diverse reactions | <i>"[I felt] quite profound disappointment for her, that the disease had altered in a way that it wasn't going to be really compatible... unlikely to be compatible with her survival, so, having to tell someone that is extremely difficult." (Surgeon 4)</i> |
| | Private expression of emotions | <i>"...it's never really concerned me that the families may see me upset, but you try not to become a blubbing wreck, because that's not a very good professional model, but at the same time I think it is actually okay to be affected by those things, but you do to some extent try and do it in your own space, rather than with families." (Surgeon 9)</i> |
| Impact of dealing with death and dying | Awareness of their mortality | <i>"... it deepens your experience of living in a way. I mean, I guess many people only ever face thoughts of mortality when somebody close to them dies, whereas when you are dealing with cancer patients, then you are dealing with mortality on a regular basis. So, you think more about it..." (Surgeon 5)</i> |

Impact of death and dying. Working in an environment where patients die on a regular basis brought a heightened awareness of life and death. Many participants described a constant awareness of their own mortality, as well as self-identification with dying patients. Dealing with dying patients was a learning opportunity for many surgeons; they described gaining perspective on life by knowing the hardships that other people endure.

Participants recognised an impact on their own family. For example, some of them described the avoidance of discussions about stressful cases at home, or returning home exhausted and wanting to be alone after particularly difficult days.

Professionally, participants felt that dealing with dying patients hardened them. They often felt inadequate when having to see patients who did not have surgical options, having a tendency to avoid or postpone those encounters.

One participant was not able to identify how working with the dying could have an impact on their life.

4.3 *Coping mechanisms*

When probed about how they dealt with the challenging situations of dealing with death and dying, participants described a variety of coping mechanisms. In synthesis, their coping strategies were focused on meaning-making, peer support, problem-centred, and/or emotion-centred. These strategies were at times preventative or reactive. That is, in cases where they could anticipate their response or had experienced similar scenarios, they would employ the strategy before the event; in the latter it was once the situation had occurred that they did something in response to their reaction (see Table 3 for illustrative quotes).

Meaning-making. As a way of finding meaning, participants expressed the ability to identify positive aspects in the presence of death. For example, when they had witnessed positive changes in a patient who was dying, such as, wishes being fulfilled or achieving a desired goal, participants perceived the patient's death as less negative than those who did not know as much about their patients. For the latter, death itself was a negative aspect, as participants had no information on patients' goals that would have allowed them to identify positive outcomes.

Problem-focused. A common way of coping with discussions about death and dying, or telling bad news was the perceived need to offer hope to patients. Described as a mechanism to communicate bad news, participants stated that due to the uncertainty of death, they would always emphasise that even though medically there were not many chances for cure, some people could have spontaneous remission, live longer than expected, or even die of a different cause. By offering more optimistic or uncertain prognoses, participants also avoided "being wrong", due to having patients

that had at times outlived their predictions or who had recovered from their disease without medical explanation.

Another strategy to ease their discomfort when telling bad news was to shift the conversation from the 'bad news' to making the patient aware of how positive it was for them to know that their life was finite. This was intended both to help the patient cope with the news, as well as for the surgeon to communicate the news.

An additional strategy for coping was the participants' preference for having a surgical practice that was not focused on a specific set of patients or diagnosis. Having a mixed practice protected them from constant 'failure', by being able to mix the cases with sad results with those of successful procedures on patients who were going to live longer and not die of a life-limiting disease.

Another coping mechanism was the realisation that in order to deal with the difficult situations, participants needed to have work-life balance, by this they meant having good support outside work, found in family and friends, as well as having other non-professional activities.

Peer support. Participants stated their preference for talking about the death of patients with their colleagues. Although preferred, this alternative was not used often or systematically. It was preferred in the face of receiving counselling from someone who was outside the clinical setting, and above talking to family members. Colleagues seemed to offer more understanding due to having been in similar situations. Participants also described having a scheduled clinical or audit meeting to talk about patients who had died, but the discussions in this arena were more about the personal and professional performance and possible responsibility for the death, rather than a space to discuss personal issues or reactions.

Table 3. Exemplary quotations of surgeons' coping mechanisms with death and dying

| Subtheme | Quote |
|------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Meaning-making | "So patients who I know who die, of my patients, those that have reached a point where they are ready to die, I can understand and that's okay. The ones who are angry or not ready to die, it is harder to see that." (Surgeon 7) |
| Problem-focused | "... it was a way out for me, to be able to cope with it, to be able to tell patients, that there was some degree of hope, so you weren't just giving them this terrible news, that they were to die and so on (...) experience taught me that you cannot be too categorical about these things, and therefore, why should a patient be told that they only have got six months to live? (...) I find it easier to say to somebody, "Look, the situation is bad, but it is not, it could be worse". (Surgeon 5) |
| | "... You need a lot of normal stuff as well, you need normal people, you need gallbladders, you need hernias, you need things that everyday people have that they are going to get better from, because otherwise, your whole practice is following people up and you don't have time to do new things and do operations... as a surgeon, I am actually best at operating, so if my whole time is following up people I'm not going to get any more operations to do. (...) You need plenty of them to balance all the others that are going to be more difficult." (Surgeon 7) |
| Social | "I think the only thing is being able to talk with somebody, and you know, as a pride I have (colleague) and I have my wife. Which of course is pretty helpful, although she was a (health professional) she can't sort of give you counsel in the sense of knowing what it is like being a surgeon, whereas somebody like (colleague) can." (Surgeon 5) |
| Emotion-focused | "... the classic thing is that you intellectualise a lot of the bad things you see, by trying to say that you understand the disease and that you know the natural history of things go that way and sometimes you can't alter things (...) if you can't cause a positive effect, then it is often because no one can, (...) it still worries you, it's still important, and it is still something that you don't like, but it is something that you have to accept and kind of get on with it." (Surgeon 4) |

Emotion-focused. As a strategy to cope with surgical interventions, some surgeons preferred not to know much about the patient and their personal situation. By knowing too much, they felt their objectivity could be compromised, and they would

feel more pressure when operating on them. Participants also preferred to abstain from connecting emotionally with patients as a strategy for self-protection.

Participants stated that they intellectualised death; this meant that in order to put their emotional response into perspective they rationalised the facts of the illness to distance themselves from the feeling of personal responsibility for the outcome. By using this defence mechanism, participants were also able to accept that being unable to cure was not due to their personal ability, but because of present limitations in medical discoveries, which may resolve in the future.

Overall, participants' approach to their patients' death and dying was characterised by a high sense of personal responsibility for patient outcomes. When facing the defining moments of their contact with patients at the end of life, their resources were bound to the aspects that provided them with a sense of identity as surgeons. The essence of surgical practice influenced their behaviours and reactions.

5 Discussion

Surgeons' experiences with death and dying in the context of life-limiting illnesses, as well as their coping mechanisms were influenced and justified by the traits they described as the essence of surgical practice.

These traits have been discussed in anecdotal accounts and ethnographic studies (Buchman et al., 2002; Cassell, 1986; Cassell, 1987; McGreevy & Wiebe, 2002; Nuland, 2001; Page, 2011; Stabile, 2008), and they have been thought to affect surgical care in death and dying situations (Buchman et al., 2002; Cassell, 1986; Nuland, 2001). This research further contributes to understanding the interplay between the 'surgical personality' and surgeons' experiences of the death of their patients.

The data obtained in this study suggest that there is a tendency for surgeons who work in cancer surgery to be less emotionally distant from patients. By engaging in close relationships, these surgeons are able to recognise more positive aspects in their patients' deaths than their counterparts who establish strict boundaries and who might be more likely to consider death as defeat. Similar results were found in a sample of cancer surgeons in the US (Guest et al., 2011a, 2011b) and studies suggest that a career in surgical oncology can offer personal growth and career satisfaction (Shanafelt, 2008) for surgeons.

One of the reasons why cancer surgeons may have identified positive aspects in their patients' death might be the fact that they have continuing relationships with them and may be able to witness the patient's adjustment to the illness. Page (Page, 2003) suggests that postoperative care should not cease after the surgical procedure, but should continue through the progression of the illness, for the contrary can be equivalent to a sense of non-ownership (Page, 2003), or patient abandonment (Nuland, 2001). This may help surgeons to reframe their reactions and ease the transition to caring for dying patients (Dunn & Milch, 2001; Nuland, 2001), an approach some of the non-cancer surgeons in this study were beginning to move towards.

Nevertheless, despite being able to find positive aspects, cancer surgeons or those who dealt with incurable illnesses, felt vulnerable when their patients died, more so than surgeons who had a mixed surgical practice. Guest et al. (2011a, 2011b) suggest that surgeons in subspecialties with high death rates can benefit from changes at organisational and personal levels. These improvements include: having a workplace that reduces the difficulty to take leave and promotes work-life balance, engaging in mentoring programs, questioning the 'culture of silence' by being more

open about the impact of their work, and receiving more training in communication skills to diminish their anxieties when communicating with dying patients and their families.

Surgeons emphasised the need for a level of detachment from the patient, in order to engage in an objective decision-making process. Although this technique might be useful in trauma or acute cases (Cassell, 1987; Page, 2011), at the end of life doctor-patient communication and shared decision-making is vital in order to provide the best possible support and to avoid futile treatments. Studies show that effective communication is a surgical challenge (Barnett, 2002; Burton & Parker, 1997; Girgis, Sanson-Fisher, & McCarthy, 1997; McLafferty, Williams, Lambert, & Dunnington, 2006).

In line with doctor-patient communication, a significant proportion of surgeons engaged in giving hope to patients as a means to cope with the delivery of bad news, as well as to show empathy to patients. A distinctive aspect of the hope provided was that it changed the focus of the discussion to the possibility of outcomes with a low likelihood, such as medically unexplained remissions or dying of other causes. Surgeons in this study avoided offering estimates of life expectancy because they did not want to be wrong; they remembered odd cases where patients outlived their expectations. However, their statements may mislead patients who are in a vulnerable position when receiving bad news (Hack, Degner, & Parker, 2005).

'Unrealistic' hope, in the long-term, can cause harm by failing to prepare the patient for the future (Prigerson, 1992; Trice & Prigerson, 2009). Almost half a century ago surgeons were actively encouraged to break bad news "with an optimism (...) for the simple truth is that no physician can be absolutely certain of prognosis (...) all of us (surgeons) are aware that proven spontaneous complete regressions or cures have been

reported in almost all types of cancer (...) so it is with firmness that the surgeons can offer hope; for as with everything else, there are no absolutes” (Martin, 1968). Despite several recommendations advocating for the avoidance of misleading optimism (Barclay, Blackhall, & Tulsky, 2007; Mack et al., 2007; van Vliet et al., 2011; Whitney, McCullough, Fruge, McGuire, & Volk, 2008) and patients’ preferences for honesty (Hagerty et al., 2005), this obsolescent approach to hope seemed to prevail in surgical care for many of the participants in this study.

Additionally, those participants who stated shifting the focus of the bad news to positive aspects, such as emphasising that at least patients know what they will die of, may be denying patients the opportunity to learn to adjust to their prognosis, or to complete important tasks. Patients report they need time to let the news sink in (van Vliet et al., 2011) and clinicians cannot prevent patients from experiencing sadness (Whitney et al., 2008). Clinicians can, however, offer *realistic* hope that can lead the patient not to feel abandoned or deceived.

Lastly, the surgeons in this study stated a preference for finding support from peers. In spite of this, they specified that they did not turn to colleagues unless under specific circumstances, relying on their own ability to cope with challenging situations. Due to the high rates of burnout in surgery (Benson et al., 2009; Shanafelt et al., 2011) and the identification of dealing with death and dying as a stressor (Guest et al., 2011b), providing opportunities where surgeons can feel comfortable discussing their reactions might improve their adjustment in the short and long-term; as well as encouraging and allowing for work-life balance (McGreevy & Wiebe, 2002).

There are limitations to this study. Firstly, the data were obtained from the surgeons’ perspective but were not triangulated with views of patients or family members. Secondly, attempts for participant validation of the transcripts were made,

but not all participants responded; this may be due to some participants considering that there was no need to reply if they had no information to be edited in the transcripts.

Qualitative research does not aim to have generalisable results, however, the findings of this research can be extrapolated to other contexts where surgeons may have similar experiences to those of this sample; the richness of the data allow for identification of comparable circumstances. Further research is needed, particularly to describe differences amongst surgical subspecialties.

Death and dying are integral and unavoidable parts of surgical practice and surgeons, like other medical practitioners, face challenges as they care for dying patients. Despite participants stating that they feel less affected by dealing with patients with life-limiting illnesses, their descriptions of their encounters, reactions and behaviours, as well as their use of language suggest that these deaths have a lasting impact. The results of this study provide a clearer way to understand the complexities of end of life care and the impact of patients' deaths on surgeons.

6 Acknowledgements

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Chapter 3 - The Experiences, Coping Mechanisms and Impact of Death and Dying on Palliative Medicine Specialists

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Statement of Contributions

The experiences, coping mechanisms and impact of death and dying on palliative medicine specialists (Palliative and Supportive Care, 2012. Accepted paper)

Ms. Sofia Carolina Zambrano Ramos (PhD Candidate)

I was responsible for the conception of the research upon which this paper is based. I produced the first draft of the manuscript and submitted the final manuscript. I completed the literature search, data collection and data analysis. As the primary author, I have been in contact with the journal and have been responsible of responding to reviewers and editors based on prior discussions with and consent from ACH and GBC.

_____ Sofia C Zambrano R. Date: _____

Professor Anna Chur-Hansen and A/Professor Gregory B. Crawford

Anna Chur-Hansen and Gregory B. Crawford were the supervisors of my doctoral candidature. As supervisors and co-authors, their role was to assist me in the initial stages of conceptualisation of the research, and to refine and critically analyse the drafts, which included making suggestions and providing editorial input. Additionally, GBC participated in the initial stages of participant recruitment. ACH checked the interview transcriptions for accuracy. GBC and ACH participated in the coding of one interview, to ensure consistency of the findings.

We, Anna Chur-Hansen and Gregory B. Crawford, hereby certify that this statement of contribution is accurate, and give our permission for this paper to be incorporated

in Ms. Sofia Zambrano's submission for the degree of Doctor of Philosophy from the
University of Adelaide.

_____ Anna Chur-Hansen Date: _____

_____ Gregory B. Crawford Date: _____

1 Abstract

Background: Research on the experiences, coping mechanisms and impact of death and dying on the lives of palliative medicine specialists is limited. Most research focuses on the multidisciplinary team or on nurses who work with the dying. Fewer studies consider medical professionals trained in palliative medicine. This study explored the experiences, coping mechanisms and impact of death and dying on palliative medicine specialists when dealing with their patients at the end of life.

Methods: A qualitative research approach guided the study, one-on-one interview data were analysed thematically. A purposeful sampling technique was employed for participant recruitment. Seven palliative medicine specialists practicing in one city participated in open-ended, in depth interviews.

Results: The analysis of participants' accounts identified 3 distinct themes. These were *Being with the dying*; *Being affected by death and dying* and *Adjusting to the impact of death and dying*.

Significance: This study further contributes to the understanding of the impact of death and dying on professionals who care for dying patients and their families. Despite the stressors and the potential for burnout and compassion fatigue, these participants employed strategies that enhanced meaning-making and emphasised the rewards of their work. However, the consequences of work stressors cannot be underestimated in the practice of palliative care.

Keywords: Palliative medicine physicians, psychological adjustment, life experiences, end of life care.

2 Introduction

Palliative care aims to prevent and alleviate suffering and provide support to people with life-limiting illnesses, and their families. Multidisciplinary care is

paramount, focusing beyond physical symptoms, to include psychological, social, and spiritual concerns (Clark, 2007).

Professionals practicing in palliative care guide the patients' dying process by organising individualised plans for patient care (Berger et al., 2000); communicating effectively with patients, families and colleagues (Fallowfield et al., 2002); facilitating meaning-making (Currier et al., 2008); having discussions that promote adjustment to an unpromising prognosis but which could lead to a more complete end of life experience for the patient and the family (Kaldjian et al., 2008); improving symptom control; and focussing on patients' needs deriving from physical, social, emotional and spiritual domains (Rokach, 2005).

Working with dying people can be challenging. Some identified stressors are frequent exposure to death, lack of time, workload demands, difficulties in communication, ineffective coping mechanisms, and a potential sense of helplessness coming from emotional responses including grief, depression and guilt (Kearney et al., 2009); as well as role blurring, working with uncertainty, and being aware of the medical impossibility of offering a cure (Rokach, 2005).

Burnout, compassion fatigue, and vicarious post-traumatic stress can occur in palliative care workers (Kearney et al., 2009; Rokach, 2005; Vachon, 2011); nevertheless, palliative care has the potential for professional rewards, e.g. to experience high job satisfaction, compassion satisfaction, and vicarious post-traumatic growth from contact with dying patients (Boston & Mount, 2006; Kearney et al., 2009; Lindqvist, Tishelman, Hagelin, Clark, Daud, Dickman, Benedetti, Galushko, Lunder, Lundquist, Miccinesi, Sauter, Furst, et al., 2012; Sinclair, 2011; Slocum-Gori et al., 2011; Swetz et al., 2009; Vachon, 2011; Webster & Kristjanson, 2002; Yedidia, 2007).

Research on the impact of dealing with death and dying on palliative care staff is limited (Casarett et al., 2011). Most research focuses on the multidisciplinary team (Boston & Mount, 2006; Lindqvist, Tishelman, Hagelin, Clark, Daud, Dickman, Benedetti, Galushko, Lunder, Lundquist, Miccinesi, Sauter, Furst, et al., 2012; Sinclair, 2011; Slocum-Gori et al., 2011; Webster & Kristjanson, 2002; Yedidia, 2007) or on nurses who work with the dying (Dunwoodie & Auret, 2007); fewer studies consider physicians (Dunwoodie & Auret, 2007; Swetz et al., 2009), or compare the differences between health professionals within the multidisciplinary team (Casarett et al., 2011). Little is known about how palliative medicine specialists incorporate their work experiences into their daily lives.

This study explores the experiences of a sample of palliative medicine specialists when dealing with death and dying, the impact of death, and their coping mechanisms.

3 Methodology

A qualitative research approach was used. Interview data were analysed thematically (Braun & Clarke, 2006). The University of Adelaide Human Research Ethics Committee (H-033-2010) provided ethical approval.

3.1 Interviews

The first author (SCZ), a female psychologist with professional and research experience in the palliative care setting, conducted individual, open-ended, semi-structured, in-depth interviews in participants' consulting rooms between May and September 2010. The interviews focused on participants' experiences with death and dying, coping mechanisms, and perceived preparation to deal with death and dying. Interviews were tape-recorded and transcribed verbatim by the interviewer. Interviews lasted between 30 and 74 minutes (mean 56 minutes).

Measures to ensure methodological rigour and trustworthiness included: de-identification of transcripts to preserve confidentiality and anonymity; checking of themes by 2 other researchers (ACH and GBC); and, the opportunity for participant validation of the transcripts (3 participants approved their transcripts and 2 made minor editions). An audit trail was maintained throughout the research process.

3.2 *Participants*

A purposeful sampling technique was employed. Variation in relation to age, gender, and years of practice was sought.

Eight palliative medicine physicians practicing in one city were approached by GBC and invited to participate. All accepted, but only seven were interviewed due to data saturation: five men and two women.

Participants' years in medical practice ranged from 8 to over 3 decades (Mean=28 years). Four were working on a part-time basis, and 5 practiced and observed religious beliefs in a mainstream religion. Six participants held a specialist palliative medicine qualification from the Royal Australasian College of Physicians, and one was an advanced trainee. They all practiced in specialist palliative care services, based in tertiary hospitals at different locations.

3.3 *Data analysis*

Transcripts were imported to an NVivo 8 (QSR International, 2008) database and analysed thematically. One transcript was randomly selected and all authors verified coding agreement. Following data familiarisation, coding and interpretation of all other transcripts was undertaken individually by SCZ. Emerging themes were discussed and agreed upon by all authors. Final themes and subthemes were identified through patterns in the data. Data analysis was iterative.

4 Results

Three overarching themes were identified in participants' accounts of their experiences with their patients' death and dying within the palliative care setting: 1) *Being with the dying*, 2) *Being affected by death and dying*, and 3) *Adjusting to the impact of death and dying* (Figure 1).

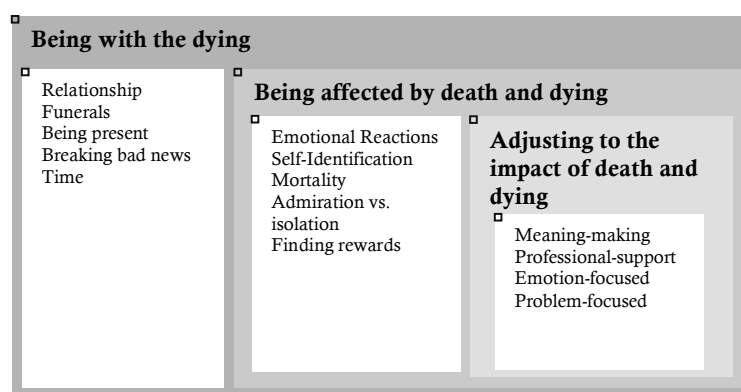


Figure 1. Overarching themes and subthemes of palliative medicine specialists' experiences and coping mechanisms when dealing with death and dying.

4.1 *Being with the dying*

The shared experience of palliative medicine specialists with patients and patients' families at the end of life included: a) relationship, b) being present, c) attending funerals, d) breaking bad news, and e) time (Table 1).

Relationship. Participants described their level of personal and emotional connection with patients as varying according to the length of the relationship and their level of personal involvement in each case, with a tendency to develop intense connections.

The intensity of this closeness was a recurring theme. Blurred boundaries were accepted so long as participants were aware of their level of involvement with patients and could assess and renegotiate boundaries. This relationship style was preferred in order to dignify the doctor-patient encounter, to help patients achieve a good death, and as a meaning-making strategy for the medical professional. Sharing of the

participant's emotions was seen as crucial for patients and families to feel empathy, sympathy, and the shared humanity of the medical professional.

Being present. Being present occurred in a variety of ways. Care usually transitioned from less to more dedicated care, particularly if palliative care started at an early stage of the illness. Caring for dying patients in different settings allowed participants to establish a meaningful relationship with patients, as well as to be able to have a '*picture of them as whole people*' (Participant 4). Their availability in different settings was seen as beneficial for patient care, family support, and for the specialists to feel more comfortable with the care of the patient. At the moment of death, it was unusual for participants to be with the patient. Being a palliative medicine specialist was considered as an opportunity to know patients and to be present in a way that no other medical specialty or health profession could. Being present changed according to the seniority, the role of the palliative medicine specialist and the evolution of palliative medicine as a specialty. As consultants, particularly in teaching hospitals, the role came with a diversification, where less direct, '*hands on*', patient contact occurred to give space to junior medical professionals and residents; however, these were recognised as invaluable teaching opportunities. When they desired more patient contact, participants negotiated their level of involvement.

Attending funerals. Participants' contact with the dying and their families did not always cease with the death of the patient. The majority of participants discussed their preference for attending some funerals for a variety of reasons. Funerals showed the family that their contact with the health system did not stop with their relative's death. Additionally, funerals were useful for participants to gain a different perspective of the deceased. Thus, funerals provided a closure of the relationship. Furthermore, funerals were a controlled opportunity to reflect on participants' own responses to

death and dying. Attending funerals occurred on a case-by-case basis, particularly with those families where there was more closeness; some participants refrained from it due to time pressure. Other participants reflected on professional boundaries but still believed it was on occasions beneficial for the family.

Breaking bad news. Breaking bad news was a constant task in which participants engaged. In some circumstances, participants were the first health professional the patient encountered who clearly described the diagnosis and the prognosis of the illness. Despite finding the task a difficult aspect of their role, they acknowledged that they had many skills, not only due to their training in communication, but because of their approach to death and dying.

Time. Participants described having more time to see patients, in contrast with other medical professionals; this was seen as an opportunity to focus on aspects beyond the illness. Those participants who had an administrative workload in addition to patient care had less time for patient care, and identified this as a drawback of their role.

Table 1. Illustrative quotations for ‘Being with the Dying’

| Subtheme | Quotation |
|----------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Relationship | <i>“you still need to have those human feelings, and if you don’t have those, if you are cold and hard and lacking that empathy and compassion and sense of secrecy, you probably are not a good doctor to be working in this area.” (Palliative Medicine Specialist 2)</i> |
| Funerals | <i>“I think it gives time to reflect on the person’s life and to acknowledge your own feelings and to sort of step away from the pressure of work, to reflect on the person’s life and your own response. (...)” (Palliative Medicine Specialist 7)</i> |
| Being present | <i>“as hard as that was, it was also having the opportunity to see her in all the different places, that most clinicians are sort of stuck in one bit, so they are either in the hospital or they are GPs seeing patients at home, whereas that is the lovely thing about palliative care, it is having that opportunity of seeing people in lots of different venues so you have a picture of them as whole people.” (Palliative Medicine Specialist 4)</i> |
| Time | <i>“Because of the nature of the work that we do, you get an awful lot more time with patients, so I can go and sit and talk to a patient for an hour and nobody is timing me, and saying “you’ve got ten others” and it might be that I’ve got 10 other patients, but if I think that an hour of my time is worthwhile then no one is going to question it.” (Palliative Medicine Specialist 4)</i> |

4.2 *Being affected by death and dying [positively and negatively]*

Participants' reactions and the consequences, positive and negative, of exposure to patients' death and dying included: a) emotional reactions, b) identifying with patients, c) being reminded of their mortality, d) receiving admiration – at risk of isolation, and e) finding rewards (Table 2).

Emotional reactions. Participants' reactions to the death of their patients were characterised by feelings of sadness, relief and less often by guilt. Participants mentioned crying or 'tearing up'. Crying was not seen with a negative connotation, even in the presence of the patient or a relative of the patient. Participants described experiencing grief at a professional level and differentiated it from heartfelt personal losses. Emotional reactions were short-lived, generally whilst being present and a few moments after encounters with patients or relatives. Funerals, memorials held in their workplace, and structured meetings were opportunities to revisit emotional reactions. On other occasions, participants were reminded of specific patients when treating patients with similar characteristics. Being aware of the reasons why patients came to mind eased their reactions. The cumulative effect of dealing with many deaths over a short period of time, of caring for a series of patients with very intense or close relationships, or deaths where goals for treatment were not achieved (e.g. poor symptom control), were deemed to be particularly difficult.

Identifying with patients. Participants highlighted situations in which patients' circumstances were a reminder of their own. Treating people similar to themselves or to their family members was confronting. Participants said that they employed increased awareness and recognition of their emotions to manage these situations.

Being reminded of their mortality. Working in a setting where all their patients were ultimately going to die was a constant reminder of mortality.

Receiving admiration – at risk of isolation. By supporting patients and families at the end of life, participants dealt with sensitive issues for medicine and society as a whole. Participants reported being admired for working in palliative care and were constantly complimented by patients and friends. Despite being admired, participants admitted being careful in their conversations with friends and family, to abstain from being considered as being too immersed in death and dying and existential issues, for example when socialising.

Table 2. Illustrative quotations for ‘Affected by Death and Dying’

| Subtheme | Quotation |
|----------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Emotional reactions | “I think also comfortable in showing our emotions, I mean, I have been doing medicine for a long time now, sort of over 30 years and when someone dies, I don’t cry, as a routine, but things are very emotional, and I think it is (...) it brings tears to your eyes, and it is emotional and I think we need to recognize that...” (Palliative Medicine Specialist 7) |
| Self-identification | “She’d made me feel vulnerable, because of the fact that she had children the same age, and I could see myself, I wasn’t that much older than her then, and I could see myself in her shoes and identified with her in a way that, you know, I don’t so much with an 85 year old who I’d still see as much older than me, although the gap is closing.” (Palliative Medicine Specialist 5) |
| Reminder of own mortality | “I am intensely aware of the gift of being alive, I assume nothing about life, that doesn’t make me careless, I am like everyone else, I make my plans. But underneath it, there is this absolutely constant reminder that I am mortal and so I, I guess I review my life more than I otherwise would if I hadn’t been exposed to this work.” (Palliative Medicine Specialist 5) |
| Finding rewards | “So, professionally it is terrific, and I am thankful just to be able to come into work, a work I really like with a really great group of people and making a difference, I think, and I think in palliative care it is never too late to make a difference, and I think that’s wonderful part...” (Palliative Medicine Specialist 7) |

Finding rewards. Participants described their work as rewarding, a career where the ‘rewards outweigh the cost’ of dealing with death and dying. Rewards included: making a difference for patients and families at the end of life, being able to offer symptom control, helping patients achieve peaceful deaths, having a privileged access

to the patient's life and honouring the medical encounter beyond the physical nature of the illness, and addressing psychosocial and spiritual aspects of the patient at a time when family, friends, and other health professionals do not know how to act.

4.3 *Adjusting to the impact of death and dying*

Participants downplayed the negative impact of dealing with death and dying by reframing their experiences in a way that highlighted positive meaning, both for their patients and themselves. Participants adjusted to their work in a variety of ways, including: a) meaning-making, b) professional support, c) emotion-focused coping, and d) problem-focused coping (Table 3).

Meaning-making. Meaning was sought in terms of *biological* explanations of illness progression, such as making reference to life expectancy statistics after a life-limiting diagnosis, as well as accepting death as part of life. Religious and spiritual interpretations were comforting for those with religious beliefs, with death as a transition to an afterlife. Some participants with religious beliefs, who worked with atheist or agnostic palliative medicine specialists, stated an inability to understand how those colleagues could deal with their work. However, those who did not subscribe to religiosity felt comforted knowing that patients had had a good life and would live through the memories of their relatives. Participants made meaning of their patients' life-stage, referring in particular to how deaths in older patients were less dissonant. Furthermore, participants' meaning-making processes accentuated the legacy of a patient's death for their own lives, where personal growth and living their lives without regrets were crucial.

Professional support. Participants experienced satisfaction with their ability to share the emotional impact of their job with their colleagues or other members of the multidisciplinary team. Besides the formal systems in place for them to vent their

reactions, such as debriefing, monthly review meetings, and workplace memorials to remember patients, participants described a strong support system within their practices. In addition, they highlighted forming strong bonds with some colleagues and confiding in them. Relying on others was not seen as a weakness but fundamental to work stability.

Emotion-focused coping. When dealing with the emotional impact of their work, participants expressed a preference for establishing close relationships whilst keeping boundaries. Most participants were comfortable with not having strict boundaries, but awareness of their involvement was fundamental to control their responses. Self-protection was in the background of their relationships and was important so as to not compromise patient care, nor their own psychological well-being. Their awareness was instrumental for decision-making practices, such as when to talk to colleagues or when to seek help. Amongst the participants who held religious beliefs, praying was a coping mechanism.

Table 3. Illustrative quotations for ‘Adjusting to the Impact of Death and Dying’

| Subtheme | Quotation |
|-----------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Meaning-making | “My understanding of death is that it is a beginning, not an end, it is not the worst thing that happens to human beings, I recite the creed and my view of it has changed over the years, but I do believe that our existence on this earth is not finite, that the spiritual part of who we are as a living entity is a reality that is not lost (...)” (Palliative Medicine Specialist 3) |
| Professional-support | “People trust each other enough to kind of say they’ve been struggling. (account of a time when the doctor was facing a difficult time). So I was able to say to my colleagues “I’m sorry, I am actually not going to be of much use for a while”. (...) we’ve kind of done that for each other when they have been struggling.” (Palliative Medicine Specialist 5) |
| Emotion-focused | “I don’t delineate my boundaries in terms of “this is work and I leave it at the door” those boundaries are quite blurred, but they are not blurred in a context of me thinking that all my patients are my friends. I am pretty comfortable with where those boundaries sit (...)”. (Palliative Medicine Specialist 4) |
| Problem-focused | “I believe very strongly that we should be healthy in these challenging situations, that we should have |

Problem-focused coping. Participants' awareness of the importance of their psychological well-being made them advocates of strategies aimed at reducing the negative impact of their work. Managing their workload and striving for work-life balance was fundamental, and arrangements were made to achieve it. Having a variety of activities, such as time for research, sharing after-hours commitments, and taking time off, were implemented as needed. For some participants having a part-time load further contributed to their self-care.

5 Discussion

This study explored the experiences, coping mechanisms and impact of death and dying on palliative medicine specialists. The analysis of participants' accounts allowed for the identification of three distinct themes; *Being with the dying*, *Being affected by death and dying*, and strategies for *Adjusting to the impact of death and dying*.

Overall, participants' experiences were characterised by feeling comfortable performing the tasks inherent to their role as palliative medicine specialists. Working in palliative care, despite making participants feel emotionally vulnerable, brought satisfaction and they experienced personal growth from their contact with the dying. These results share similarities with findings from other studies (Casarett et al., 2011; Penderell & Brazil, 2010; Sinclair, 2011; Swetz et al., 2009).

The participants in this study employed strategies that can be associated with burnout prevention and the experience of compassion satisfaction (Kearney et al., 2009; Maslach & Leiter, 2008; Maslach et al., 2001; Slocum-Gori et al., 2011; Vachon, 2011). A satisfying workload, having varied work-related activities, being able to share the workload at stressful times, and having a sense of community were fundamental

for participants. Swetz et al. (2009) reported that palliative care physicians used professional relationships for burnout prevention and preferred to talk to colleagues over family and friends. Relying on colleagues may offer a shared understanding that enables effective coping. Moreover, having a sense of community may foster sharing of emotional, personal reactions to patients, which has been found to promote satisfaction in palliative care (Yedidia, 2007).

Participants believed that displaying and sharing their emotions with patients and families was beneficial for the doctor-patient encounter. Physicians who share their own vulnerability have been found to have a constructive interaction with patients, develop an exceptional ability to understand the patient, and build trusting relationships (Malterud, Fredriksen, & Gjerde, 2009; Malterud & Hollnagel, 2005) provided that emotions are displayed in the service of the patient and/or the family (Malterud et al., 2009).

Participants had a tendency to find rewards and employed meaning-making strategies in order to cope with the daily impact of their contact with dying patients and their families. Having a transcendent perspective has been found to prevent burnout (Swetz et al., 2009). Furthermore, participants accentuated the value of self-awareness in their day-to-day practice, which has been found to be paramount to clinicians' self-care (Kearney et al., 2009).

The consequences of certain work stressors cannot be underestimated. Despite the overall positive experience of caring for the dying, this was possible when participants found meaning, had good sources of support, and engaged in self-awareness. Participants emphasised their vulnerability when dealing with the cumulative effect of caring for many patients, when having difficult days, when seeing patients with whom they had a close relationship, or when caring for those who shared

similar characteristics with themselves. Ultimately, the rewards outweighed the cost of dealing with death and dying. However, not all physicians may be able to find rewards in their work with dying patients. Additional challenges were related to dealing with aspects beyond the death of the patient, such as organisational demands, and having difficulties with colleagues' approaches.

For example, with regards to finding meaning through religious and spiritual interpretations, differences in religious beliefs may isolate participants with no religious affiliation from those who find meaning in death through their belief in an afterlife. Furthermore, despite 'spirituality emerging as a concept void of religion' (Sinclair, Pereira, & Raffin, 2006), the close relationship between spirituality, religiosity, and palliative care, may deter prospective palliative medicine specialists who hold no religious beliefs, from entering palliative care training. However, participants who held no religious beliefs were able to find meaning in the death of their patients. Medical professionals' religious beliefs may also impact on patient care (Seale, 2010).

This study has several limitations. Participants practiced in the same city. Cultural and location differences could be explored quantitatively in future research. Only palliative medicine specialists currently working were interviewed. The inclusion of physicians who have left palliative medicine would be valuable to better understand where coping failed, or where the work was deemed unrewarding. Furthermore, triangulating the research by interviewing patients, families, and/or nurses may show a different perspective of palliative medicine specialists' experiences with death and dying. Interestingly, this group of participants was fairly homogeneous in their coping methods, perceptions and experiences with death and dying. These results may reflect the mainstream philosophy of care within palliative medicine, rather than the individual impact of dealing with death and dying; participants may have refrained

from discussing particular personal difficulties due to social desirability bias, given the typical portrayal of the positive adjustment to dealing with death and dying, which may have become an expectation from their perspective.

This study further contributes to the understanding of the impact of death and dying on professionals who care for dying patients and their families. Despite the stressors and the potential for burnout and compassion fatigue, these participants employed strategies that enhanced meaning-making and emphasised the rewards of their job.

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Chapter 4 - On the Emotional Connection of Medical Specialists Dealing with Death and Dying: A Qualitative Study of Oncologists, Surgeons, Intensive Care Specialists and Palliative Medicine Specialists

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Statement of Contributions

On the emotional connection of medical specialists dealing with death and dying: A qualitative study of oncologists, surgeons, intensive care specialists and palliative medicine specialists (BMJ Supportive and Palliative Care, 2012.

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Ms. Sofia Carolina Zambrano Ramos (PhD Candidate)

I was responsible for the conception of the research upon which this paper is based. I produced the first draft of the manuscript and submitted the final manuscript. I completed the literature search, data collection and data analysis. As the primary author, I have been in contact with the journal and have been responsible of responding to reviewers and editors based on prior discussions with and consent from ACH and GBC.

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Professor Anna Chur-Hansen and A/Professor Gregory B. Crawford

Anna Chur-Hansen and Gregory B. Crawford were the supervisors of my doctoral candidature. As supervisors and co-authors, their role was to assist me in the initial stages of conceptualisation of the research, and to refine and critically analyse the drafts, which included making suggestions and providing editorial input.

Additionally, GBC participated in the initial stages of participant recruitment. ACH checked the interview transcriptions for accuracy. GBC and ACH participated in the coding of one interview, to ensure consistency of the findings.

We, Anna Chur-Hansen and Gregory B. Crawford, hereby certify that this statement

of contribution is accurate, and give our permission for this paper to be incorporated in Ms. Sofia Zambrano's submission for the degree of Doctor of Philosophy from the University of Adelaide.

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1 Abstract

Objectives: This paper reports on qualitative data exploring the experiences and coping mechanisms of medical specialists from the specialties of surgery, oncology, intensive care, and palliative medicine, when dealing with death and dying and their emotional connection with dying patients in the context of a life-threatening illness.

Methods: Thirty-three semi-structured individual interviews were analysed using Thematic Analysis.

Results: One of the key themes of medical specialists' experiences with death and dying was the ambivalence about developing emotional connections with patients and families. Advantages of not engaging emotionally with patients were related to preserving objectivity in the decision making process, whilst a perceived disadvantage was the loss of the opportunity to engage in meaningful relationships that could positively influence both patients, families, and the medical specialist. Finding a balance in the face of ambivalence was a preferred approach and participants employed a variety of coping strategies.

Conclusions: Participants took different positions about the emotional connection that should develop with their dying patients and their families. Although there was agreement about finding a balance between objectivity and connection, their strategies to achieve this seem to be subjective; prescribed by individual notions. By sharing perspectives and learning how other colleagues deal with similar issues, there is an opportunity for medical practitioners to develop a well-rounded approach to dealing with death and dying, which may enhance personal and professional relationships and may ultimately influence future generations of medical practitioners.

2 Introduction

Medical practitioners require knowledge in palliative care (Gibbins, McCoubrie, Alexander, Kinzel, & Forbes, 2009), effective communication skills (Gibbins et al., 2009; Levin et al., 2010; Nestel et al., 2011), the ability to support the needs of patients with a life-threatening illness (Lacey & Sanderson, 2010; Levin et al., 2010), and the ability to cope with the emotional demands of their profession (Aase, Nordrehaug, & Malterud, 2008). Additionally, medical practitioners serve as role models for junior doctors and medical students around issues related to death and dying (Borgstrom, Cohn, & Barclay, 2010). However, their responses to death and dying remain distinctly unexplored.

Medical practitioners are known to be at risk of “burnout”, “compassion fatigue” and mental health issues from their contact with dying patients. The frequency of death in palliative medicine can lead to depression and grief (Kearney et al., 2009; Sorensen & Iedema, 2009). In oncology, intensive care, and oncological surgery, medical practitioners may experience high levels of anxiety, burnout, stress and psychiatric morbidities (Guest et al., 2011b; Sorensen & Iedema, 2009). Beyond these negative effects, caring for patients at the end of life can be rewarding and conducive to personal growth (Balch & Copeland, 2007; Kearney et al., 2009). Discrepancies between the positive and negative impact of dealing with death and dying are associated with differences in coping strategies, availability of support, and the quality of the relationships with patients and families (Balch & Copeland, 2007; Kearney et al., 2009). Studying medical specialists’ experiences and attitudes towards death and dying patients is crucial to understand their adjustment to their patients’ death.

In order to gain an understanding of the experiences of medical specialists with death and dying, four medical specialties were selected. Surgery (general, upper gastrointestinal, colo-rectal, and breast surgeons), oncology, and intensive care were chosen because of their involvement at different stages in the trajectory of illness experienced by patients with potentially fatal illnesses. Palliative medicine was chosen due to its philosophy of care and its acceptance of death as part of life.

The research questions addressed in the study are: 'How do medical specialists experience the death and dying of their patients in the context of an advanced life threatening illness?' And 'How do they cope with these experiences?'

This paper reports on one particular aspect of the research findings, specifically: the experiences of medical specialists when developing an emotional connection with patients and how they cope with these experiences.

3 Methodology

3.1 Research perspective

A qualitative research approach was employed. Data were analysed thematically; a method that allows for the discovery of patterns in the data by organising and constantly comparing participants' experiences (Braun & Clarke, 2006).

3.2 Interviews

The University of Adelaide Human Research Ethics Committee approved the study (H-033-2010). The primary research approach consisted of semi-structured, in-depth interviews, conducted by the first author, a female psychologist with professional and research experience in palliative care. The interviews explored medical specialists' experiences with patients within the context of a life-threatening illness, their coping mechanisms, perceived differences between specialties, and

perceived preparation and training to deal with death and dying. Many of the interview questions were guided by the interviewee's responses. Interviews were also complemented by previous participants' responses, employing the process of constant comparison, which ensured that saturation of data was reached. Saturation refers to the point at which collected data is repetitive, is not conducive to new information, nor complements previous understandings of participants' experiences (Mason, 2010; Morse, 1995; Sandelowski, 1995).

The first author carried out all interviews between May and September, 2010. Interviews were audiotaped with participants' consent and transcribed by the interviewer. Transcripts were de-identified and identifying information excluded. Measures of trustworthiness and rigour included the checking of resultant themes by the second author (ACH), a registered health psychologist. Participant validation of the transcripts was sought. Twenty-nine out of 33 participants requested their interview transcripts and six altered or edited some information. Changes were of identifying information, typographical errors, medical terminology and minor editions that improved transcript readability. An audit trail was maintained throughout the research.

3.3 Data collection

Purposeful sampling was used to allow the selection of targeted informants. Participants were selected according to their specialty and gender, as well as dispersion in ages and years of practice. Eligible participants were practicing in the city of Adelaide at the time of the interview. One of the authors (GBC), a palliative medicine specialist, contacted potential participants via email. After expressing their interest, the first author, who was unknown to the participants, contacted them to schedule a

meeting. Interviews lasted between 29 and 105 minutes, with an average of 48 minutes.

In this study, saturation occurred with different numbers of participants in each of the specialties. This variation can be attributable to the dissimilarity in the experiences as narrated by some of the groups; whilst the experiences of intensive care specialists were more uniform, those of oncologists had more variations, which required more participants to be able to identify the 'mainstream storyline' (Morse, 1995). Thus, the 'negative case perspectives' or exceptional accounts were also saturated (Morse, 1995; QSR International, 2008).

3.4 Participants

A total of 52 specialists were contacted. Thirty-seven (71%) agreed to participate in the study but only 33 were interviewed due to data saturation: Eleven oncologists, nine surgeons, six intensive care specialists and seven palliative medicine specialists. Years of medical practice ranged from six to 45 years, with an average of 25 years. Ten participants were women and 23 were men. Twenty-four were working full-time.

3.5 Data Analysis

Data were analysed using NVivo 8 (QSR International, 2008). Following the stages of thematic analysis (Braun & Clarke, 2006), the first author familiarised herself with the data by reading and re-reading all transcripts, and referring to the audit trail. All authors compared their coding of one interview to verify coding agreement. The first author analysed all other interviews; emerging themes were discussed with all authors until the main themes were defined and redefined.

Interviews were initially coded line by line. Themes and patterns were identified by medical specialty and for the entire sample. Similarities and differences

were identified in experiences and coping strategies. As part of the iterative process, key themes were contrasted and compared with each of the transcripts, ensuring an accurate representation and interpretation of participants' responses.

4 Results

A salient theme in the remarks and reflections of the participants about their experiences with dying patients and their families was their ambivalence towards developing an emotional connection. This theme was constant across all four medical specialties and influenced participants' experiences of the death of their patients.

This ambivalence was characterised by a dichotomy: 'getting emotionally involved' and 'seeking emotional distance'. These subthemes were complemented by a third: 'finding a balance' in the emotional connection.

4.1 Getting emotionally involved

A perceived need of participants to establish an emotional connection with patients was an identified subtheme. Engaging emotionally with patients appeared to have positive psychological and professional effects for these medical specialists. Allowing the expression of emotions and personal content resulted in a more effective relationship; treatments were deemed to be more effective and participants were transparent about their emotions. Participants from all four specialties highlighted these positive effects, with the majority of palliative medicine specialists emphasising this view.

The need to engage emotionally with patients prevailed under specific circumstances. These circumstances can be categorised as: having known the patient for a considerable length of time, growing older, identifying at a personal level with the patient's demographics, and, having life experiences which remind them of their own vulnerability.

A long-term involvement with patients opened up the possibility for a relationship to develop, where the interviewees felt more familiarity with patients. This was at times a two-way relationship where the specialist might disclose personal information.

Participants also described a tendency to become more emotionally involved as they grew older (Table 1). However, some participants stated that their increased experience with death and dying had emotionally hardened them. Participants who were at the onset of their medical practice described a difficult transition, particularly in oncology, where they came from having sporadic contact with little personal involvement, to having more intense relationships with patients when they were specialists.

Knowing the patient for an extended period of time was more common for oncologists and palliative medicine specialists. Intensive care specialists wondered if patients were to spend more time in the Intensive Care Unit, they might become more emotionally involved than they reported. Surgeons also reported more connection with patients for whom they cared for a longer time period. However, long-term relationships with dying patients occurred less often for surgeons than for oncologists.

Whilst being emotionally open was a preferred approach, participants stated an underlying apprehension about “giving too much of themselves.” Some of the associated risks of being emotionally involved were: finding it hard to continue to see a patient, abruptly withdrawing from already established connections with patients, getting too close, finding it hard to let go, and seeing patients as friends.

For example, finding it hard to let go meant that a close relationship with patients could lead them to make every effort to continue treatments and offer possibilities that might not be realistically possible (Table 1).

Likewise, the risk of seeing patients as friends represented a greater possibility of feeling the impact of a patient’s death in a more personal way (Table 1).

These risks show the preferences of specialists to “seek emotional distance” or “to find a balance”.

Table 1. Illustrative quotations for subtheme: Getting emotionally involved

| | |
|-------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Growing older | <i>“I have become maybe a bit more emotionally involved, because as you get older you experience things in your own life, for instance, the death of parents, you have children. So now, certainly, you are 20 years older and you are talking to somebody (...) and they are a parent and you have experienced that yourself, maybe in a way you almost become more empathetic (...) you do tend to identify, personalise it a bit more. (...) Maybe, as you get older, as you experience more, maybe there is a tendency to be more emotionally involved.” (Intensive Care specialist 6)</i> |
| Finding it hard to let go | <i>“When it gets to a point where there is no further active treatment available, you find it quite hard to let go, and it can sometimes work both ways as well, so, I think that how you manage that and how that is done, can be really important to help patients deal with their final stage.” (Oncologist 10)</i> |
| Risk of seeing patients as friends | <i>“... a sense of great disappointment that I’ve kind of lost a friend that I’d grown close to, because we’d... me as a surgeon and her as a patient, gone through a lot, and we juggled some very tricky situations (...) they are a little bit like friends that have died, you know?” (Surgeon 4)</i> |

4.2 Seeking emotional distance

As a subtheme, seeking emotional distance represented the other end of the dichotomy. It was described as the preference to remain emotionally uninvolved, particularly due to the specialists’ view that an emotional connection with patients was problematic (Table 2).

Seeking emotional distance was characterised by abstaining from forming a relationship because of the need to remain objective, as well as the certainty that the relationship would end in the death of the patient.

By maintaining emotional distance, specialists believed that they preserved professionalism and had the patient’s interests at hand (Table 2).

A consideration was the personal impact of getting emotionally involved with a patient who was ultimately going to die. Participants felt emotionally unprepared to engage in relationships where the end result was the death of the patient (Table 2).

Practitioners who preferred an interaction devoid from emotional exchanges were mostly surgeons; only a few intensive care specialists and oncologists expressed this view. No palliative medicine specialists espoused this approach. Many of these participants had, at an earlier stage of their career, been emotionally involved with their patients, and based on those experiences, made the active decision to not get involved. Another supporting reason to seek emotional distance, particularly for surgeons, was the need to feel in control during the surgical procedure; inside the operating room their only concern was the physical body of the patient.

Seeking emotional distance was also related to a tendency to ignore any emotional impact on colleagues, or share their own vulnerability; neither to provide debriefing opportunities for junior staff and medical students nor to discuss the emotional impact of specific death and dying situations. Many specialists expressed uncertainty about how other colleagues dealt with their emotional encounters with patients. The majority of surgeons reported not sharing their emotions with peers, whilst only some oncologists and fewer intensive care specialists described this approach. Additionally, palliative medicine and intensive care specialists recognised the advantage of teamwork for debriefing opportunities, whereas oncologists and surgeons had fewer opportunities for this.

Despite upholding the view of distancing emotionally from patients, when some of these participants reconsidered specific situations, they realised that they did establish some degree of emotional involvement with patients, but that it was not overtly demonstrated or discussed, thus continuing to conceal their emotions (Table

2). Furthermore, a selection of surgeons advocated a need for emotional involvement with patients.

In many of the statements supporting the view of seeking emotional distance, participants used apologetic expressions to defend the validity of their approach, as if being uninvolved was the more difficult choice. The majority of palliative medicine specialists were accustomed to sharing the emotional impact of their work with their colleagues.

Table 2. Illustrative quotations for subtheme: Seeking emotional distance

| | |
|-------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Seeking emotional distance | <p>“... I remember as an intern getting involved, emotionally with the families, and it doesn't do you any good. I mean, because at the end of the day you don't really help the family very much and you don't help yourself very much, and in many ways, it is not being cold-hearted, it is just being unprofessional. You can't afford to get in there and be a family member. You are a doctor; you are there to give them your professional support. That can be a manner of things but you've got to still maintain a certain sort of emotional detachment, if you are to give them the best of your professional ability.” (Surgeon 1)</p> |
| Preserving professionalism | <p>“I don't want to know about their life outside of the operating theatre and the consulting room because I think I'd find that it would make the situation much more difficult for me, and I think I'd start to lose my objectivity. I mean, I'm here to provide a service, the best I can. I am not here to becoming entwined in their lives.” (Surgeon 6)</p> |
| Having the certainty that the patient is going to die | <p>“It seems like an unkind thing to say, but I think I've prefaced my remarks in full, already, that most of the relationships you're going to have are going to end badly. And I don't feel either emotionally equipped, or time rich enough, or inclined, to want to engage in a protracted, deep relationship that is going to end in someone's death, because I don't quite see that as my role.” (Oncologist 2)</p> |
| Concealing emotions | <p>“...even though one tries not to get emotionally involved, there have been occasions, well, I always get emotionally involved but I try not to show it, but there have been occasions where I have shown it.” (Surgeon 5)</p> |

4.3 Finding a balance

The dichotomy between becoming emotionally involved or maintaining emotional distance, particularly after highlighting the risks of getting emotionally

overinvolved or being unprofessional, was a motivation to find alternatives to overcome these risks (Table 3).

Coping strategies were practiced regardless of medical specialty, age or gender, and were described as: being aware of their level of emotional engagement, protecting themselves, putting emotions into perspective, respecting the emotions of the patient's family, overcoming their emotions without having time to grieve, and being busy.

Being aware of their level of emotional engagement meant that a conscious assessment of their emotional response would lead participants to recognise the extent of their involvement. They might rethink their decisions, sometimes with peers, to ensure that the decisions were made for the patient and not for themselves. This mechanism was explained in terms of maintaining objectivity (Table 3).

Participants who resorted to protecting themselves frequently checked for the effects of over involvement on their wellbeing, to ensure their ability to continue to work with emotionally demanding cases.

Other strategies for finding a balance were focused on the regulation of the intensity of the emotions and the length of the emotional response. For example, 'putting emotions into perspective' meant that responding with emotions was appropriate, due to the emotional nature of working with dying patients, but the response had to be short-lived. The emotional involvement was limited to the situation as it was happening, but was manageable afterwards (Table 3).

Similarly, respecting the emotions of the patient's family was a mechanism for participants to measure the intensity of their own response in order not to override the family's and patient's own emotions; not wanting to put the grieving family in the difficult position of consoling the medical professional (Table 3).

Likewise, participants overcame their emotions without having time to grieve. They expressed that any reaction had to stop as they left the patient’s room, or after a consultation. This was to ensure that they were able to continue to work without their reaction influencing the next patient’s care.

Lastly, participants discussed a preference for being busy. Engaging in different daily activities allowed them to forget about particular patients. However, in their personal time, sleeping or being at home or with friends, these cases could come to mind, particularly if there were some unresolved issues or emotions.

Table 3. Illustrative quotations for subtheme: Finding a balance

| | |
|-------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Finding a balance | <p><i>“You can’t connect on a level of great intimacy with everyone, you’d just go under, I would. So there is a professional distancing. By the same token, when I am sitting with someone in a room, it is rare for me not to feel a connection, without which I couldn’t do the work I do. I couldn’t do it. So, there is a paradox there. But I guess there is also a balance. There is a connection, but it is not, it doesn’t necessarily become intense or intimate with exceptions.” (Palliative Medicine Specialist 5)</i></p> |
| Being aware of their emotional engagement | <p><i>“If you are conscious that it can happen, then you question your decisions and can more easily recognise that your emotions are affecting your judgement. When you start asking yourself “am I thinking correctly? Is this what the patient needs or is in his/her best interest?” then you know you have become or are becoming vulnerable. So the next best thing to do is to discuss it with another colleague in your area and ask for their opinion. If they have a different opinion, you just know that you have to back off a little, to distance yourself from your emotions, so you can think properly.” (Palliative Medicine Specialist 6)</i></p> |
| Putting emotions into perspective | <p><i>“There is some emotion in that to me, that is emotion like you watch a movie, like a sad movie, you are walking to a situation where there is sadness and you get your emotions get mixed up with the other people’s emotions and tears are contagious, but you can walk away from that (...) you feel temporarily sad while being caught up in an event, but it doesn’t linger particularly much. But you still need to have those human feelings, and if you don’t have those, if you are cold and hard and lacking that empathy and compassion and sense of secrecy, you probably are not a good doctor to be working in this area.” (Palliative Medicine Specialist 2)</i></p> |
| Respecting the emotions of the patient’s family | <p><i>“I don’t think that it is appropriate for me to cry, because I think that is taking away from the family. Now, a tear in the eye, certainly, but full-on crying, that is completely unprofessional and is completely, somehow demeaning the patient’s intensity of emotions.” (Oncologist 11)</i></p> |

“Overcoming their emotions” and “being busy” sometimes meant that the emotional response might be considered later in private. This approach appeared to be problematic, as most participants did not appear to have allocated time for this reflection, except palliative medicine specialists who reported having periodic peer review or sought informal outlets.

By making use of those strategies, participants felt in control of their emotions in order to not impair their decision-making or transgress their professional philosophy.

In general, participants expressed uncertainty about deciding which approach, between being emotionally distant or being emotionally engaged, was best for their professional relationship with patients, and highlighted their ignorance of their colleagues’ practices.

5 Discussion

This study sought to understand the experiences and coping mechanisms of medical specialists when developing an emotional connection with dying patients. Participants’ responses were characterised by ambivalence between developing an emotional connection and seeking emotional distance. At the core of the ambivalence was the preference for an approach where they could find a balance in their emotional exchanges with patients.

To find balance, participants reported coping mechanisms, such as the preference to move on without having time to grieve, or being busy, which may have detrimental effects on physicians’ psychological wellbeing by suppressing emotional responses (Shapiro, 2011; Steinmetz, Walsh, Gabel, & Williams, 1993). Palliative medicine specialists have identified these same circumstances as stressors (Kearney et al., 2009), and oncologists report that the lack of time to grieve a patient’s death can

act as a work-related stressor (Dougherty et al., 2009). Alternatives for finding a balance, such as putting the emotional reaction into perspective, and experiencing emotions privately, may reaffirm the emotional nature of working with dying patients.

Despite the expectation for medical practitioners and trainees to learn to deal with the challenges associated with caring for the dying, difficulties are continuously faced. Medical students' first experiences with death, often with the study of anatomy, involve learning to be emotionally distant (Hafferty, 1988), and their experiences with the dying are characterised by a similar tension between emotional connection and detachment (Kelly & Nisker, 2010). This finding has been replicated in studies of medical residents (Luthy et al., 2009), and oncologists (Jackson et al., 2008; Kelly & Nisker, 2010).

There is evidence of a positive correlation between years of medical practice and the impact of reduced emotional connection with dying patients (Peisah, Latif, Wilhelm, & Williams, 2009); this contradicts our findings. Although a few participants expressed that over time they have become emotionally hardened to death, most participants stated that with increased years of clinical practice they were more likely to identify with patients and to become more emotionally involved. This has implications for patient care, medical specialists' well-being, and medical education.

Firstly, those medical professionals who felt overinvolved expressed a need to withdraw from patients' care and found it hard to discuss changes in the focus of care. This may support reported findings where medical practitioners fail to have timely discussions about end of life with their patients, which can lead to poor care (Quill, 2000).

Secondly, medical specialists who were unable to find a resolution to the conflict between emotional connection and detachment may face constant stress, potentially leading to burnout, compassion fatigue, mental health issues, risk behaviours, and early retirement (Guest et al., 2011b; Kearney et al., 2009; Sorensen & Iedema, 2009).

Thirdly, senior medical practitioners are frequently seen as role models (Shapiro, 2011). If senior clinicians are unprepared to reflect on their practice and share their emotional responses, junior medical specialists and those still in training may not learn these skills, thus perpetuating withdrawal from patients as an appropriate coping mechanism.

In order to evolve, an approach from “the top” is required. Medical training still has a strong apprenticeship model with students learning from senior medical practitioners not only from the intended knowledge-base, but also from what has been called the “hidden curriculum” (Hafferty, 1998; Rhodes-Kropf et al., 2005). It is unlikely that change will occur unless more senior medical practitioners’ behaviours and practices are addressed.

A possible intervention might be to encourage older generations of medical practitioners to discover the positive effects of recognising the emotional nature of their work, for example, through learning strategies such as reflective practice, self-awareness, self-control and situational awareness (Kearney et al., 2009; Lucey & Souba, 2010). This may lead to more supportive relationships, and in turn, to more satisfactory relationships with patients and may have an impact on patient care; palliative medicine works under this model (Yedidia, 2007). Nevertheless, such a recommendation needs careful implementation given that practitioners may face difficulties after establishing emotional connections with patients. The participants in

this study who withdrew from the care of the patient demonstrated this difficulty. Therefore, rather than just emphasising the need for a connection with their own emotions, medical practitioners need to explore alternatives and styles where neither their wellbeing nor the patients' is compromised. Clinical or professional supervision may facilitate this process (Firth, 2011; Ramirez, Addington-Hall, & Richards, 1998).

The differences between specialties show some disparity in reactions. As reported by others, oncologists seemed to be more affected when establishing emotional relationships (Dougherty et al., 2009; Jackson et al., 2008; Kovács et al., 2010; Steinmetz et al., 1993). This research shows that many practitioners from other specialties also experience these dilemmas. Recognising that self-identification plays a key role highlights that those practitioners who are vulnerable are perhaps any medical practitioner dealing with patients at the end of life. Although surgery has been described as a specialty that favours a "culture of bravado" (Balch & Shanafelt, 2011) some of the surgeons interviewed stated their preference for care that was less emotionally distant, beyond the traditional view of emotions as inhibitors of objectivity.

Despite the burden of dealing with death and dying, some participants clearly preferred to deal with this in isolation. Many practitioners stated unfamiliarity with their colleagues' approaches, as well as the extent to which they should discuss emotional issues unless their colleagues were visibly upset. These specialists did not appear to seek opportunities, or have safe arenas, to discuss their emotions. Specialists are faced with many uncertainties in their job; relying on colleagues may provide more certainty, at least to recognise how other peers might approach a similar situation. This individualistic posture was more common in surgery and oncology, whereas intensive care and palliative medicine specialists seemed to rely on their teams and find support

in them. Additionally, the role of spirituality on emotional connection was not mentioned by the participants in this study, but has been flagged in other research (Astrow & Sulmasy, 2004; Edwards, Pang, Shiu, & Chan, 2010).

A possible limitation of this study is that the researcher who invited potential participants was known to many of them. Medical specialists may have felt obliged to participate. However, some did choose not to participate. The sample of 33 medical specialists from a city in Australia may seem too small to extrapolate to other contexts. Despite this, the results are consistent with previous research in the area. The study was not triangulated; patients and family members of these medical practitioners were not interviewed. The patients and families may have different perspectives regarding their medical professionals' emotional reactions and behaviours, which cannot be validated from the data collected for this research.

The findings presented in this paper further contribute to the understanding of medical specialists' adjustment to the death and dying of their patients. The depth of the data and the perspectives of the four different medical specialties involved in this study provide a broader and more inclusive assessment of the impact of death and dying on medical specialists. Furthermore, these findings could be explored in larger samples and in other medical specialties. Additionally, the qualitative nature of the study and the mechanisms employed to preserve rigour contribute to the resonance and transferability of the findings of this study to other contexts.

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Chapter 5 – The Commonalities of Dealing with Death and Dying in Four Medical Specialties: A Qualitative Study of Specialists in Surgery, Oncology, Intensive Care, and Palliative Medicine.

Paper status: Text in manuscript (to be submitted for peer-review)

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Statement of Contributions

The commonalities of dealing with death and dying in four medical specialties:
A qualitative study of specialists in Surgery, Oncology, Intensive Care, and Palliative
Medicine. (Text in manuscript)

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I was responsible for the conception of the research upon which this paper is based. I produced the first draft of the manuscript and submitted the final manuscript. I completed the literature search, data collection and data analysis. As the primary author, I have been in contact with the journal and have been responsible of responding to reviewers and editors based on prior discussions with and consent from ACH and GBC.

_____ Sofia C Zambrano R. Date: _____

Professor Anna Chur-Hansen and A/Professor Gregory B. Crawford

Anna Chur-Hansen and Gregory B. Crawford were the supervisors of my doctoral candidature. As supervisors and co-authors, their role was to assist me in the initial stages of conceptualisation of the research, and to refine and critically analyse the drafts, which included making suggestions and providing editorial input.

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We, Anna Chur-Hansen and Gregory B. Crawford, hereby certify that this statement

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_____ Anna Chur-Hansen Date: _____

_____ Gregory B. Crawford Date: _____

1 Abstract

Background: A variety of medical specialists care for patients with life-limiting illnesses such as cancer. The literature has focused on how doctors should communicate with the dying, and how they meet the emotional demands of their profession. Despite these focuses, the findings are limited and mostly prescriptive, anecdotal or quantitative. This qualitative study explored medical specialists' experiences and coping mechanisms when dealing with the death of their patients, and examined common themes amongst the four specialties by identifying the similarities in and differences between how they dealt with the death and dying of their patients.

Methodology: Data were collected through one-on-one, in-depth interviews and analysed through Thematic Analysis. Consistent with qualitative methodology, sampling ceased at data saturation. Thirty-three medical specialists from Intensive Care (n=6), Palliative Medicine (n=7), Surgery (n=9), and Oncology (n=11) participated. These specialties were chosen for their involvement at different stages of the trajectory of life-limiting illnesses.

Results: Common themes were related to two overarching concepts: *Participants' professional practice*, and *Impact of the professional on the personal*. Professional practice aspects were related to frequent exposure to death and dying, limited training opportunities to learn about working with the dying, decision-making process, and the delivery of bad news. On the other hand, the impact of the professional on the personal was related to experiences of emotional uncertainty, individual differences beyond the specialty in which they practice, the transformational impact of dealing with death and dying, and dealing with death and dying in solitude.

Discussion: The themes identified in this study may be valuable in the development of strategies to support medical practitioners in dealing with common aspects of their medical practice, as well as to enhance learning opportunities through medical training that recognises the emotional aspects of physicians' interactions with dying patients.

2 Introduction

In the context of life-limiting illnesses, death is the product of a process in which health deteriorates at different rates. Medical practitioners treating patients with these illnesses are faced with supporting patients and their families at a time in which medical treatments cannot offer the possibility of a cure.

The experiences of medical practitioners, the impact of dealing with death and dying, and their coping mechanisms in this context, remain largely unexplored. This is particularly so in medical specialties that are in frequent contact with patients with life-limiting illnesses. Available findings highlight universal, as well as specific aspects and needs that medical specialists, such as surgeons, oncologists, intensive care specialists, and palliative medicine specialists encounter during their careers. For example, research on surgeons highlights the surgical culture of practice as a factor that may accentuate the challenges in adjusting to dealing with death and dying (Dunn & Milch, 2001; Guest et al., 2011a; Kearney et al., 2009; Torjuul et al., 2005). Relevant to this culture is the surgical personality, which is characterised by stereotypical traits that emphasise the need to defeat death, taking risks (Cassell, 1986; Cassell, 1987), pride in decisiveness, emotional distancing, unwillingness to acknowledge defeat (Nuland, 2001), and avoidance of introspection (Page, 2011; Stabile, 2008), amongst other traits. For oncologists, it is the emotional nature of their work, where feelings of fear, uncertainty, loss (Brescia, 2004), exhaustion, guilt and the oncologist's sense that treatments are futile (Shanafelt et al., 2003), become a recurrent experience. In the intensive care setting, the focus of research has been the decision making process, particularly around the withdrawal and withholding of life-sustaining therapies (Curtis & Vincent, 2010; Yaguchi et al., 2005). Lastly, for palliative medicine specialists, research highlights the multidisciplinary nature of care

(Clark, 2007) and the need to address patients' needs beyond the physical illness (Currier et al., 2008; Rokach, 2005), in the context of constant exposure to death and dying (Kearney et al., 2009; Meier et al., 2001).

The stressors faced by medical specialists have been highlighted and addressed in previous research. Studies from each of the specialties highlight the high prevalence and the potential for burnout in those working with dying patients (Asai et al., 2007; Benson et al., 2009; Campbell et al., 2001; Embriaco et al., 2007; Girgis et al., 2009; Kearney et al., 2009; Rokach, 2005; Vachon, 2011). The effects of dealing with death and dying can also be measured in terms of their effect on patient care, where futile and aggressive treatments are frequently reported (Cintron et al., 2003; Kwok et al., 2011).

Contemporary studies lack an explanation of the aspects that lie behind medical practitioners' behaviours when dealing with dying patients, how those experiences are dealt with in their professional practice and personal lives, and how their medical training might prepare them for managing the death of their patients on personal and professional levels. Studying medical specialists' experiences and attitudes towards death and dying patients is crucial to understand their adjustment to their patients' death and dying.

This study sought to identify common themes, highlighting the similarities and differences of the experiences and the impact of dealing with death and dying on medical practitioners from four medical specialties that were chosen due to their involvement at different stages of the illness trajectory: surgery, oncology, intensive care, and palliative medicine.

3 Methodology

The study adopted a qualitative approach to medical specialists' experiences with the death and dying of their patients. Interview data were analysed thematically following Braun and Clarke's methodology (Braun & Clarke, 2006).

3.1 Data collection

Ethical approval was obtained from the University of Adelaide Human Research Ethics Committee. Purposeful sampling was used for participant recruitment ensuring heterogeneity in age, gender, years of practice, and specialty. Participants working as specialists in Surgery, Oncology, Intensive Care, and Palliative Medicine, in the city of Adelaide, in 2010, were invited to participate via email by GBC.

3.2 Interviews

Participants who consented were contacted and interviewed by the first author (SCZ), a psychologist with experience in palliative care, in their consulting rooms, or at a public place, between May and September 2010.

In-depth, semi-structured, one-on-one interviews were audiotape-recorded with permission. Topics addressed during the interviews included participants' experiences with death and dying in medical practice, their coping mechanisms and their perceived training in learning to deal with death and dying. Questions were led by participants' responses and were complemented with salient content from previous interviews as a strategy for saturation. Interviews (n=33) lasted between 29 and 105 minutes, with an average of 48 minutes.

3.3 Participants

Sampling ceased at saturation with a different number of participants per specialty. The difference was due to the variation in participants' responses. Intensive

care specialists' experiences were more homogeneous, whilst oncologists had more variability and thus, it took more participants to reach saturation.

A total of 52 specialists were invited to participate. Thirty-seven (71%) agreed, but due to data saturation only 33 were interviewed: Eleven oncologists, nine surgeons, seven palliative medicine specialists, and six intensive care specialists.

Twenty-three participants were men. Their years of medical practice ranged from six to 45 years, with an average of 25 years. Twenty-four were working full-time.

3.4 Data analysis

Interviews were transcribed verbatim by SCZ with identifying information removed from them; transcripts were coded in an NVivo 8 (QSR International, 2008) database. Thematic analysis (Braun & Clarke, 2006) guided the process. Initial codes were defined and redefined following the process of constant comparison, independently by the first author; themes and subthemes were established amongst all authors by finding patterns in the data and ensuring a faithful representation of participants' experiences.

3.5 Rigour

Measures to preserve trustworthiness and methodological rigour were implemented throughout the research process (Tracy, 2010). An audit trail was maintained from the first interview through to write-up. Interviews were read by a second researcher (ACH) and were sent for participant validation. Six participants edited minor parts of their transcripts. All authors compared the coding of a randomly selected transcript and verified coding agreement. Researchers' transparency, reflexive practice and adherence to ethical principles were followed at all research stages.

4 Results

The thematic analysis allowed for the identification of common themes, between the four medical specialties under study, that were experienced and how they coped with the death and dying of their patients in the context of life-limiting illnesses (Figure 1). These themes describe common aspects that the participants brought to discussion during the interviews and that represent crucial elements of their personal and professional response to their patients' death. Some aspects appeared to have a unique relevance for a specific specialty, whilst others were more general aspects as medical practitioners; together, these themes affected participants' experiences and their coping mechanisms when facing the death of their patients. The data falls into two overarching categories: 1) professional practice (Table 1), and 2) the impact of the professional on the personal (Table 2). These categories are presented within eight premises. Similarities amongst and differences between specialties are explored in each of the premises.

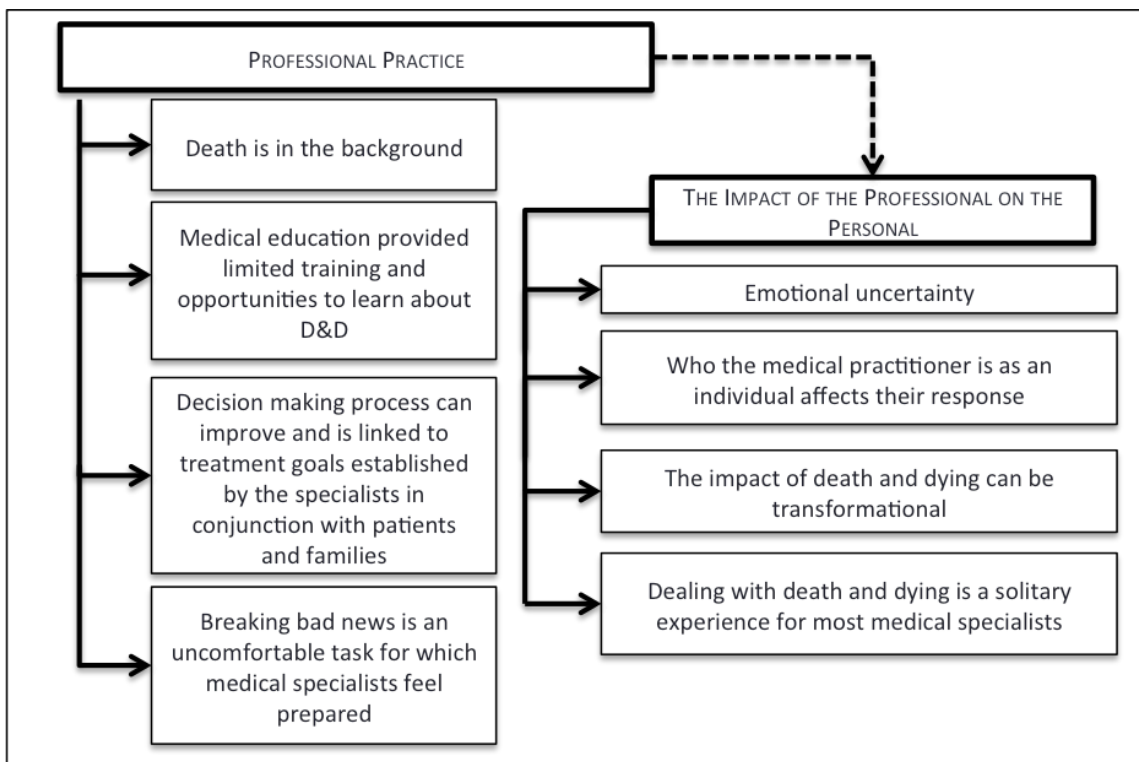


Figure 1. Common themes in the experiences of medical specialists

4.1 *Professional practice*

4.1.1 *Premise 1: Death is in the background of all interactions with patients with life-limiting illnesses.*

Participants stated that in the context of life-limiting illnesses there was an awareness that death was in the background of their interactions with patients. In particular, oncologists emphasised the nature of cancer and how despite the success of treatments, the possibility of dying was latent in all exchanges with patients. Palliative medicine specialists expected that all their patients would die under their care. The proportion of patients dying in intensive care remained high, although intensive care specialists were faced with different types of deaths to oncologists and palliative medicine specialists. Surgeons, on the other hand, particularly those with a mixed practice involving a smaller proportion of cancer patients, had less frequent contact with patients at the end of their lives.

Participants' frequent exposure to death and dying validated their assertion that death was inherent to their encounters with patients and families; however, particularly in oncology and surgery, death generally remained in the background, discussed only at specific times. Patients who are imminently likely to die were ultimately referred to palliative medicine or intensive care. Another difference was related to having patients directly dying under their care, whilst surgeons and oncologists would generally transfer patient care to intensive care or palliative care, it was for the latter two that death was more frequent.

The majority of participants discussed the expectedness of death as a relevant factor in how they adjusted to a patient's death. Some medical practitioners stated starting the grieving process, not from the moment of death, but from when the

disease was advanced and death became expected. This was possible due to having the certainty that most patients with life-limiting illnesses were ultimately going to die.

A differing aspect between specialties was the different stages of illness progression at which they encountered patients. Oncologists and surgeons would most frequently encounter patients with not many physically noticeable changes in their appearance, and witnessed the deterioration of their health progressively, at the same time that their relationship grew stronger. In palliative medicine and intensive care, the contrast was generally marked by receiving frail and very sick patients whose health was deteriorating, with a shorter time to establish a relationship and with a need for more immediate decision-making. Oncologists mentioned having the advantage of being able to give the bad news gradually over a series of appointments.

4.1.2 Premise 2: Medical education provided limited training and opportunities to learn about death and dying.

Participants described having medical education that lacked instruction about death and dying related issues. Due to their limited experiences, participants believed that it was with experience, exposure, and through an individual process, that most of their learning occurred. Only a few participants stated having been prepared well in terms of what medical training could have offered.

Some of the participants who developed an interest in caring for the dying, the majority in palliative medicine, but including some participants from the other medical specialties, remembered specific experiences from their training, which served as learning opportunities. As a commonality, most of these experiences were given a value that the participants attributed to having found on their own, or through a passionate role model. Senior medical specialists infrequently used these situations as

learning opportunities. All participants suggested that dealing with death and dying could only be learnt from experience.

Participants described having an early artificial or misguided exposure to death and dying, characterised both by a limited exposure as medical students, or an overexposure as registrars (i.e. medical practitioners who were now in a training scheme), particularly in oncology, where their main contact with patients was in hospital wards with patients with advanced, critical disease who were close to death. This offered most oncologists a contrasting view as they also had more contact with patients whose illness was controlled or in remission. The exposure to death and dying as registrars was regarded as an initiation to future challenges, and participants were expected to leave the specialty if they felt that the potential challenges were too hard. This expectation was more common in the accounts of oncologists and intensive care specialists.

4.1.3 Premise 3: The decision making process can improve and is linked to treatment goals established by the specialists in conjunction with the patients and/or families.

As patients reach different stages of their disease, crucial decisions are made between the patients, relatives and the specialists. The process of reaching a decision is different for each of the specialties. Surgeons embraced a more paternalistic decision-making process, where they felt that by having the training and the knowledge, they were in a privileged position to decide what was the best course of action; despite defending this stance, they stated that patient autonomy was respected. Oncologists offered patients all possible options, including options that were not of significant benefit for patients; participants showed censure at their patients choosing those alternatives, but observed patient autonomy. In intensive care, specialists favoured

relatives' decision-making, or in sporadic cases, the patients' (patients are generally under sedation when in intensive care because of disease or treatments), however intensive care specialists used their clinical judgement to know which treatments to offer; they did not want the family to have to make a decision of withdrawing treatments, and feeling guilty about their relative's death. Only one intensive care specialist felt that establishing the point at which to not offer active treatments was very difficult to reach and he stated wanting to be on the 'safe side' by postponing the decision until there was more certainty. Within palliative care, it was during the transition from active to a purely palliative focus of care that the decision making process was of great import, as the patient got closer to the end of life, family involvement, guided by patients' instructions was usually guiding the process.

Another significant aspect of the decision making process that was different for the four specialties was the interdisciplinary and inter-professional feature of the decision making; intensive care and palliative care decisions were made usually in consultations with other team members involved, such as surgeons or oncologists. In oncology and surgery, most of the initial decision-making was made individually, unless they sought the formal or informal advice of peers. When decisions had to be made in conjunction with another specialty, particularly between oncology and intensive care, or surgery and intensive care, intensive care physicians expressed the difficulties of trying to reach consensus, mentioning that oftentimes they had to resort to decision support from treatment ethics committees.

With regards to family involvement in the decision-making process, there were some differences amongst the specialties. Whilst for palliative medicine and intensive care the role of the family and having time for family meetings was crucial, despite

how difficult some conversations and families could be, some oncologists and surgeons considered family members to be confounding factors in the process.

4.1.4 Premise 4: Breaking bad news is an uncomfortable task for which medical specialists feel prepared.

One of the hardest tasks for participants, particularly for oncologists and surgeons was the breaking of bad news. Participants discussed the moment of the realisation that the illness was incurable, or when they had to change from active to palliative treatments, as being personally distressing. They were comfortable with the actual communication process of the bad news, but these conversations generated discomfort, particularly if they had developed close relationships with these patients or if there were too many of those conversations over a short period of time. For oncologists it was perceived as being more uncomfortable to break bad news to patients with whom they had not had time to establish a relationship.

Oncologists and surgeons, when compared to intensive care and palliative medicine specialists, had the discussions of the most difficult transitions (from active to palliative treatments). However, palliative medicine specialists and intensive care specialists frequently found themselves being the first professionals to actually discuss the patient's prognosis and the changed focus of care. These conversations were considered as frustrating, with some frustration directed towards the medical specialists, who had apparently avoided this difficult conversation with the likelihood that the patients had not had the earliest opportunity to understand their situation and make any decisions in the face of this knowledge. A justification for patients being unaware of their prognosis and life expectancy, was given by some oncologists in terms of patients not being prepared to hear the news or that they processed the information slowly and in their own way.

Table 1. Illustrative quotations for ‘Professional Practice’

| Premise | Quotation |
|-----------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Death is in the background | <p>“I think particularly in my job, I wouldn’t say the majority, but well, perhaps the majority of my patients do die, or are in the process of dying, so it is not something that I come to work and that’s kind of an unusual thing, that’s what I do for a living, so I don’t separate it off from the rest of my work.”</p> <p>(Oncologist 4)</p> |
| Medical education provided limited training and opportunities to learn about death and dying | <p>“... I think when you finish medical school you are not really prepared well for death. You are sort of desensitized a bit to it, because of everything else that you do, but I don’t think that you are necessarily well-prepared for how you interact with the family, or how you talk to people that are dying...”</p> <p>(Oncologist 8)</p> |
| Decision making process can improve and is linked to treatment goals established by the specialists in conjunction with patients and families | <p>“I always say to the families, “look, if we end up withdrawing therapy on your relative, I am never going to ask you if we can do this”. We will come to this decision together but at the end of the day, it is a medical decision, or it is a decision that the patient will make for us; it would be obvious to us what the right thing to do is. ”</p> <p>(Intensive care specialist 6)</p> |
| Breaking bad news can be an uncomfortable task for which medical specialists feel prepared | <p>“It is something that needs to be done. It is something that we can do, sensitively and with support. And it is often something that people really value, because if it is done properly, people can at least ask the questions that they need to ask and feel that they’ve been listened to. So, it’s something else from which you can get a lot of satisfaction, however hard it is to do. But there are certainly situations where I just have to screw up the courage to get through the door, when you know that what you are going to talk about is just going to devastate people, but that’s part of the job. Sometimes at the end of it, if I’ve got a couple of family meetings, where I am doing that thing, at the end of the day I am completely exhausted.”</p> <p>(Palliative Care Specialist 5)</p> |

4.2 The impact of the professional on the personal

4.2.1 Premise 5: Emotional uncertainty is a frequent experience despite emotional reactions being considered as common and necessary.

Participants’ accounts reported a level of emotional uncertainty, characterised by not knowing how and when to express their emotions. Questions about what degree of emotion was an appropriate response, or what was the most accepted way to

experience them, who to share them with, or how much emotion could or should be present during the decision-making process, were discussed frequently during the interviews. This uncertainty led some participants to be hesitant about their inner emotional experiences; qualifying them as unprofessional and attempting to disguise them. An underlying uncertainty about their colleagues' practices was common, despite the fact that participants from all specialties described their contact with dying patients as interactions where emotional reactions were common for the patient, the relatives, and for themselves.

Participants felt vulnerable and experienced stronger emotions through self-identification with one or various aspects of a patient's life. All participants discussed experiencing sadness and relief at different stages of their contact with patients. Frustration and disappointment were common reactions. They described their emotions as a natural response, as long as they were an appropriate and measured reaction. Whenever emotions arose during a consultation, they were seen as a statement of the medical practitioner's accountability of their feelings in the service of the patient or the family. Emotions were usually deferred with the expectation of considering them later in private, yet participants reported having no time to reflect or experience their emotions. (For an in depth account on participants' emotional connection see: Zambrano, Chur-Hansen & Crawford (2012).

4.2.2 Premise 6: Who the medical specialist is as an individual affects their response.

Personal characteristics of the participants were interconnected to their experience of their patients' deaths. Being a junior practitioner was contrasted with being a more senior medical practitioner. On the one hand, some participants believed that the younger the participant, the less likely they were to be emotionally

involved with patients. However, other participants highlighted that as younger medical practitioner, their inexperience could lead them to encounter strong emotional reactions. For senior medical practitioners similar hypotheses were employed. More exposure could lead the professional becoming emotionally hardened to death and dying; or through experience and self-identification, senior medical practitioners gained more awareness of death, therefore being more vulnerable. This remained as a dilemma, although there was a tendency for participants, particularly oncology, intensive and palliative medicine, to recognise that the older they got, the more vulnerable they felt.

Female medical practitioners had a propensity to believe that being women allowed them to outwardly show their emotions and use touch with less apprehension than if they were men. Men did not openly express any of these views.

Participants' reasons to practice in their chosen fields had a relationship with how they perceived their patients' deaths. For example, those professionals who chose their specialty due to mainly a biomedical interest whether in science, research, or in curing patients, had a tendency to feel less comfortable with death and dying processes; adjusting to death by aspiring for cases where patients had better outcomes, or diversifying their practice to include cases where patients were not going to die. This was more common for some participants within surgery and oncology, although many other participants from these specialties described having an interest in the psychosocial aspects beyond the illness itself.

4.2.3 Premise 7: The impact of death and dying can be transformational.

Participants identified ways in which death and dying had an impact in their lives. For example, working with dying patients was perceived as a hard task, but one that was considered and accepted as an intrinsic part of the job. Some of the negative

effects mentioned by participants included the likelihood of leaving the specialty early, which was described and perceived as a widespread belief, despite the fact that not all participants stated this consideration of early retirement. The frequency of having many end of life conversations or breaking bad news often over a short period of time, as well as having too many critically ill patients simultaneously, were perceived as personally and professionally depleting. Professional grief was experienced not as a general rule, but under circumstances that varied from patient to patient, and specialist to specialist; common factors were: identifying with the patients' circumstances, knowing the patient for a long time, and developing close relationships with them. Participants also highlighted the constant awareness of their own mortality as an effect of working with dying patients and the potential that this might increase the likelihood of developing burnout.

The impact of working with dying patients was constant in participants' practice, therefore they found themselves ascribing value to these experiences. The majority of participants were able to perceive gains from their involvement with dying patients. These gains were generally described in terms of a transformational outcome in the participants' lives. For example, participants expressed feeling privileged to have the opportunity to work with patients at the end of life. The majority of participants expressed that the awareness of mortality led them to gain perspective in life and aimed at living their own lives with this understanding in mind.

Despite their perceived lack of training, participants believed that through experience, they developed mechanisms to adjust to their patients' deaths. For example, by seeing death beyond the moment of death itself and giving it a meaning based on how patients lived their last months and achieved personal goals.

Achieving a sense of closing the relationship with patients, attending funerals – particularly for palliative medicine specialists – compartmentalising emotions, acknowledging the sadness but moving on, and ‘having a life outside medicine’ were other mechanisms employed by the participants.

Some medical specialists seemed more prone to have difficulties in transforming their patient’s death into a positive experience and they preferred to abstain from establishing a relationship with patients, when they were aware that patients would die from the illness they were being treated for, or alternatively, withdrawing from the patient’s care. Some of these participants found more balance in the purpose of their work by involving themselves in research, others were able to reflect on past experiences and form a sense of meaning from them.

4.2.4 Premise 8: Dealing with death and dying is a solitary experience for most medical specialists.

Despite death being in the background for all specialties, and being a shared experience amongst peers, the majority of participants stated uncertainty about their colleagues’ experiences and practices. Participants were rarely offered an opportunity to talk about patients’ deaths that had a personal impact, as there was a common belief that whoever was in need of help would commence such conversation. The participants also expressed a preference for experiencing emotions in private and in their own time, coupled with their preference to keep their reactions to themselves, which resulted in a solitary experience, despite acknowledging that when they did know that their peers were experiencing similar difficult emotions, it helped them to normalise their own experiences. Some participants admitted that they avoided discussing the personal impact of dealing with death and dying, as this might be perceived as weakness in a competitive environment.

Other participants mentioned having trusted colleagues with whom they discussed troubling cases, but these were talks about aspects of clinical management, instead of their own emotional responses. Colleagues, rather than a mental health professional or relatives, were considered a more preferable source of support and for discussion, yet peer consultation was not conducted systematically.

Most participants talked about having family support, however they usually emphasised that they protected their relatives from the knowledge of how awful illnesses could be; they would not give their relatives in-depth details about cases, thereby limiting their own ability to truly express their emotions.

Lack of time to experience their emotions was another factor cited by participants to explain their preference for reflecting on emotions in isolation. By having immediate competing clinical demands and a need to see other patients after experiencing difficult emotions, they believed that they had to hold on to their response, so as to respect the subsequent patient. At the end of a working day, participants were left to reflect on their emotions, however the separation between work and home led them to contain their emotions for future opportunities, that were generally not there or not sought.

Table 2. Illustrative quotations for ‘*The impact of the professional on the personal*’

| Premise | Quotation |
|---------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Emotional uncertainty is a frequent experience despite emotional reactions being considered as common and necessary | <p>“Is this [crying during withdrawal of therapy] what the professional person should be doing?. And I don’t know, I don’t know whether it was or it wasn’t.”</p> <p>(Intensive care specialist 6)</p> |
| Who the medical practitioner is as an individual affects their response | <p>“She’d made me feel vulnerable, because of the fact that she had children the same age, and I could see myself, I wasn’t that much older than her then, and I could see myself in her shoes and identified with her in a way that, you know, I don’t so much with an 85 year old who I’d still see as much older than me, although the gap is closing. That was</p> |

quite an intense connection and I felt sadness about her death”

(Palliative Medicine Specialist 5)

The impact of death and dying can be transformational

“I guess as you always come across sad stories, it makes you sad, but you just need to enjoy things for the time that you have them (...), I am not sure, I'd be more affectionate with my daughters, than perhaps I'd be if I was in another speciality, you know you have got to cherish every day that you have, and that you never know what can happen. And there can be some pretty horrific things that can occur, and so, when things are going along you have to enjoy them as much as you can and enjoy every moment. I guess I used to somewhat see these situations, and you'd worry with how you could try and prevent these things, but there is not much you can do to try and prevent them, so you just enjoy every moment that you can.”

(Intensive care specialist 1)

Dealing with death and dying is a solitary experience for most medical specialists

“(...) I don't think anyone ever asked how I was coping emotionally with it and I think that was a failure of the system (...) you can't just assume that registrars are okay with death and dying”

(Oncologist 1)

5 Discussion

This study investigated the commonalities of the experiences and coping mechanisms of medical specialists from surgery, oncology, intensive care, and palliative medicine, when dealing with the death and dying of their patients in the context of life-limiting illnesses. Despite the similarities and differences, the eight premises derived from the data analysis have demonstrated that these factors interconnect participants' educational experiences with professional expectations and practices that ultimately had personal consequences for these participants.

One of the main differences between medical specialities was how participants acknowledged the anticipation of the death of the patients, which in oncology and surgery was frequently unheeded until late stages. Some of these specialists felt a pressure to offer as many treatments as possible, and these findings are consistent with published literature on medical futility (Braga et al., 2007; Jox, Schaider, Marckmann,

& Borasio, 2012). A possible explanation for the fact that it was in oncology and surgery that these practices were described as more likely to happen, can be related to the covenant of care between these specialists and their patients, due to the agreements that are made at early stages of the disease, that continue static despite the changing health of the patient. The covenant of care has been described in surgery as a contract to fight the disease (Cassell, Buchman, Streat, & Stewart, 2003) and in oncology can be understood in terms of protecting patients from harmful news (Rodriguez et al., 2008). A potential side-effect of these behaviours is that when participants perform an assessment of their performance after the death of the patient, in the effort to reframe the death, the realisation that they may have over treated a patient may affect the specialists' adjustment to dealing with death and dying and could lead them to burnout or compassion fatigue (Collins, Block, Arnold, & Christakis, 2009; Kearney et al., 2009; Kovács et al., 2010). These factors were different for intensive care specialists; they often discussed attempts to accelerate the discussion with families about death and dying, as there was a sense that the treatment that they were providing was only prolonging the inevitability of death. This is despite working in an environment where it is possible to continue life support.

Another important finding is the emotional uncertainty frequently experienced by participants. Some of the specialists made an effort to emotionally annul themselves as individuals, to portray themselves as independent and objective, yet some of those emotions were leading them to act in a way that did not benefit them personally, nor provide the best possible patient care. Oncology clinical practice has been frequently described as producing a large degree of emotional dissonance, characterised by a tension between what is felt and what is shown (Kovács et al., 2010). The effects of experiencing that tension can lead to burnout (Kovács et al., 2010).

Furthermore, for the participants, death and dying were shared experiences amongst colleagues, yet the majority did not know how they were expected to deal with specific aspects of dealing with dying patients. The lack of communication about emotional aspects of their care may add to their experience of emotional uncertainty or inadequacy in their emotional reactions. By opening opportunities within the medical culture of care to discuss the emotional aspects of their job, it may enhance participants' opportunities to adjust to the challenges that they experience in isolation (Meier et al., 2001). Without skills to face their patients' deaths, it becomes a trial and error solitary experience.

Participants discussed having time to process their emotions before the death took place, indicating that their grieving process was likely to start with the anticipation of death, which frequently occurred early in their relationship with the patient. This distinction is fundamental since the specific reactions at the time of death may be different to those of other acute stages, where medical specialists may need more support. There needs to be recognition of the impact of the death of a patient not only on the medical specialist who may be providing direct care at the time of the death, but also consideration for those medical practitioners who had involvement at other times in the patient's life, so that their reactions are not disenfranchised. In grief literature, disenfranchised grief (Doka, 1989) describes the grief that is socially unacknowledged. This finding highlights the need to widen the focus from *death* itself to the *dying process*. Literature on professional grief is scarce (Lyckholm, 2001; Papadatou, 2009) yet participants' experiences with dying, and with death itself requires more open recognition.

Medical specialists' perception that dealing with death and dying can only be learnt from experience, may lead them to models of teaching where learning is not

enhanced, by missing teaching opportunities and perpetuating the expectation that if someone is in need of help, they would look for support themselves, or deal with it in isolation. Previous literature emphasises the need for availability of support, particularly for those who experience intense reactions (Moore et al., 2007) as well as for those exposed to dying patients early in their medical education (Gibbins, McCoubrie, & Forbes, 2011; Gibbins, McCoubrie, Maher, Wee, & Forbes, 2010; MacLeod, 2001)

Limitations of this research should be acknowledged. Participants were practicing in the same city in Australia, and cultural differences were not apparent in the data; however the results of this study coincide with results from previous research conducted in different parts of the world. A further limitation is the potential recruitment bias; GBC established initial contact with the participants and his status as a known palliative medicine specialist may have influenced some participants to agree to participate; despite this potential influence a proportion of those medical specialists who were contacted, declined the invitation to participate. Another limitation is related to the triangulation of the sources; patients, family members and other members of the healthcare team were not interviewed, therefore relying solely on the perspectives of the specialists themselves. Nevertheless, by including medical specialists from four different areas, some aspects were triangulated.

This study offers a qualitative perspective on the experiences, impact, and coping mechanisms when dealing with death and dying, from the perspective of four medical specialties. These are medical specialties where the professional converges with the personal on a daily basis, yet professionals appeared to lack preparation to face this challenging aspect of their practice. Despite emotions being a personal experience, the areas in which these specialists practice are conditioned to having

constant and frequent contact with dying patients. Yet, they lack mechanisms to face an aspect that could be addressed in medical education, to better prepare them for challenges that will be present all throughout their future as professionals.

Future research could include other medical specialties that deal with different life-limiting illnesses, such as cardiology and respiratory medicine. The differences and similarities demonstrated in a sample of medical specialists where death and dying are frequently part of their clinical experience, must also raise the question of how other medical practitioners that have contact with these issues on a less frequent basis experience and deal with these same issues.

Chapter 6 – Conclusion

1 Summary of findings

This thesis explored the experiences with death and dying of participants from four medical specialties that frequently deal with patients at the end of life, particularly in the context of life-limiting illnesses. Each medical specialty was analysed separately and then the analysis focused on the experiences of the four medical specialties under study. Differences and similarities between the specialties were identified, particularly in how they developed an emotional connection with their patients, their training, and the common dilemmas they faced in their daily practice. The findings allowed for the identification of personal, professional, and traditional aspects of current medical culture that have influenced how participants experienced the death of their patients. The majority of these aspects were interconnected, and the analysis provided an in-depth perspective to their behaviours and reactions.

Paper One focused on the experiences of surgeons with the death and dying of their patients. The results indicated that their experiences and coping mechanisms were influenced by personality traits favoured in surgical practice. However, participants who practiced in cancer surgery, showed evidence of pulling away from traditional behaviours, such as distancing from patients. These changes resulted in

more fulfilling interactions and therefore helped them to adjust to their patients' deaths in a different way than those who did not establish these relationships. Another relevant factor was hope-giving behaviours in medical professionals, which were characterised by offering patients hope for unrealistic outcomes. Sources of support, particularly peer support, are rudimentary in their practice, with a tendency to believe it is not needed, yet the shared understanding was described as something from which they benefited. These findings contribute to existing literature by identifying the factors that underlie surgeons' behaviours when facing the death and dying of their patients, and provide a contribution to the literature regarding the differences amongst surgical subspecialties and the tendency to move away from traditional practices of maintaining personal distance with patients.

Paper Two investigated specialists in palliative medicine and their experiences with dying patients. Participants indicated that their emotions played an important role in their encounters with patients, and emphasised their ability to derive positive meaning from their work. Despite the positive impact, the strains of working with the dying were specified. Religion was identified as a coping mechanism, and some participants for whom religion was important, made reference to their inability to understand their colleagues without religious beliefs, particularly in how they coped with their daily experiences of their patients' deaths: for them, religion was identified a source of meaning that facilitated and underpinned their work with the dying. This perception of needing to hold religious beliefs may be a factor that discourages some professionals from entering palliative medicine training. Furthermore, the uniformity of participants' experiences was attributed to aspects that may refer to the philosophy of practice within palliative care, rather than a personal response to their patients' deaths.

Paper Three considered the differences and similarities amongst the four specialties for one of the salient themes, which was related to how participants developed an emotional connection with their patients. Participants' accounts evidenced ambivalence towards developing or refraining from establishing an emotional connection with their patients. To reconcile the ambivalence, some participants resorted to finding a balance in their exchanges with patients, but tended to employ strategies that invalidated their emotional reactions. Other participants preferred an approach where they reaffirmed the emotional nature of working with dying patients. Self-identification played a significant role in how participants adjusted to their patients' end of life, with a tendency to feel more of an emotional connection, and more grief, with those patients with whom they personally identified. A relationship between years of practice and self-identification was recognised; the more the years of practice and personal life experience, the more the participants were at risk of encountering patients that were similar to them. Instead of becoming emotionally colder, they became more emotionally involved as they grew older. Further findings related to participants' influence in teaching younger generations of medical practitioners, and their avoidance of discussions about death and dying and their emotional reactions. These aspects were discussed in terms of how medical students could perceive their own emotions as inadequate and undesirable. Participants' tendency to process their emotions in isolation was highlighted. The findings of this study contribute to current research by substantiating the need for medical curricula to address the importance of recognising one's own and others' emotions within medicine.

The fourth study highlighted the common themes amongst the four specialties by identifying the similarities and differences of how they dealt with the death and

dying of their patients. The common themes were related to two overarching aspects: participants' professional practice, and the impact of the professional on the personal. Professional practice aspects were related to frequent exposure to death and dying, limited training opportunities to learn about working with the dying, decision-making process, and the delivery of bad news. On the other hand, the impact of the professional on the personal, was related to their experience of emotional uncertainty, individual differences beyond the specialty in which they practice, the transformational impact of dealing with death and dying, and dealing with death and dying in solitude. The themes identified in this study are valuable in the development of strategies to support medical practitioners to deal with common aspects of their medical practice, as well as to enhance learning opportunities through medical training that recognises the emotional aspects of physicians' interactions with dying patients. Furthermore, the results suggest that the focus of research should be widened from death itself, to medical practitioners' experiences during their entire contact with dying patients, particularly from when a patient's impending death is acknowledged.

In addition to the findings considered in each of the papers, other interesting areas remain in the data to be explored. The data corpus is substantial and rich. The four papers that comprise this thesis represent the findings of a selection of the main categories that arose from the data. Future publications will focus on other subsections of thematic material.

2 Significance of the findings

The findings presented in this thesis reflect and further the understandings of material documented in previous research, in relation to how medical practitioners experience and cope with their patients' death and dying. Some of the findings of this

thesis have been described in anecdotic, individual accounts, and journal editorials. Yet, the results of this thesis add to the growing literature of systematic attempts to understand physicians' experiences with the death and dying of their patients and the impact of this component of their professional work on their personal lives. Many of the results may have resonance with the reader, and it may feel as if they have been explored before. The reality is that academic literature lacks evidence in this area, as amply described elsewhere in this thesis.

Dealing with the death of a patient is part of the professional and personal lives of medical specialists, as well as other health professionals who care for the medically unwell. Findings from previous research studies highlight the experience of vulnerability, and emotions like sadness and guilt. The results of this thesis go one step further by elucidating the circumstances that may be related to the experience of those reactions.

From the participants' perspective, the lack of training and preparation to deal with the death and dying of a patient is an aspect of their practice that was considered as a factor that contributes to their tendency to invalidate their emotional reactions. Not only does denying their own emotions become an accepted practice, but also participants believed that they had no other alternatives to deal with their reactions, unless they resorted to practices that they considered unprofessional, such as openly expressing their emotions. Likewise, the lack of familiarity and awareness about how to appropriately deal with their own emotional reactions, led them to experience discomfort, due to having an uncertainty of what was the most appropriate reaction. Beyond the individual responsibility to adjust to dealing with death and dying, there was a perception, particularly for the specialists in intensive care, surgery, and oncology, that their workplace did not offer opportunities to discuss the effects of

dealing with death and dying. Participants' solutions were directed to employing mechanisms of avoidance, which included postponing difficult conversations, withdrawing from patient care, and referring patient care to other medical services. The identification of these issues highlights a need to offer participants more certainty and a need to normalise their reactions to a patient's death, by creating mechanisms of support that are directed at acknowledging the risks and benefits of dealing with death and dying. For example, the findings showed that only when palliative medicine practitioners crossed what are believed to be professional boundaries, by attending funerals or through other means, they were able to find more meaning in their career.

Beyond the denial of death, participants referred to an unspoken awareness of death being in the background. Instead of denying death, or death going misdiagnosed, discussions about death and dying were deferred to future encounters with patients, particularly in those specialties with a high compromise for patient cure such as oncology and surgery. Specific specialist training can incorporate these aspects to further support those professionals who employ these mechanisms with the intention of protecting patients from psychological stress, whilst at the same time protecting themselves from causing suffering to these patients.

It is important to highlight here that not all patient deaths were experienced in the same way, nor that all deaths have a potential to challenge medical practitioners' coping mechanisms. It was those deaths where the professional became personal, which tended to occur when participants had aspects in common with patients and could identify themselves or members of their family with the patients' situation, or when participants encountered over a short period of time that many of their patients died, relapsed or had other '*bad*' outcomes related to their illness progression.

Despite these experiences being common amongst the participants in this thesis, a surprising finding is the real or perceived lack of support and training provided to them. Participants seem to have been left to cope alone, with little support from their workplace, and with minimal skills to face these situations that become not only a personal challenge, but also a professional one, due to lacking resources to know what responses are and are not appropriate. It is not about denying the individual approaches and mechanisms that medical practitioners use to face what is ultimately a personal experience but it is about how they are left alone without certainty about what the best approaches are when dealing with their own emotions.

The focus on the four chosen medical specialties allowed an investigation of aspects that were specific to each of them, as well as more general aspects of dealing with death and dying as medical practitioners. Whilst most of these professionals experience an initial similar training, and are exposed to similar patients, their approach to death and dying is not necessarily the same, as evidenced in papers three and four.

3 Implications of the findings

Medical specialists interviewed for this thesis believed that dealing with death and dying is a relevant topic and that they can receive more support from their peers and their workplace. However, they also believed that they could only learn through experience; which is one of the reasons why experiential learning should continue to be offered as an alternative to improve training (Alexander, Keitz, Sloane, & Tulsy, 2006; MacLeod et al., 2003). However, these efforts cannot be implemented solely at undergraduate and postgraduate medical education levels. The findings of this thesis, as well as those of previous research highlight that via ‘the hidden curriculum’ (Hafferty, 1988; Rhodes-Kropf et al., 2005), medical students’ and junior medical

practitioners' experiences in the hospital setting can be shaped with behaviours and attitudes that are different to those that were taught. The findings suggest that whilst medical education is an area where improvements can be generated, further education and support is needed to change the behaviours and attitudes of medical practitioners already in clinical practice. Therefore the importance of initiatives that promote continuing professional development in this specific area or practice, particularly for medical practitioners in academic settings, cannot be overemphasised, for in their role as mentors and teachers they are in a position to make a difference (Emanuel & Librach, 2011; Jaye, Egan & Parker, 2005). Thus, opportunities for senior medical practitioners to draw upon their status as mentors and to take advantage of teaching opportunities should be highlighted in professional development. Furthermore, models of formal and informal debriefing should be further explored within groups of senior medical practitioners.

Participants held the belief that through their initial training years, medical practitioners made the decision to pursue a specialty with full awareness of the implications of their choice. This rationale led them to believe that most practitioners did not feel vulnerable, or at least counted with mechanisms that allowed them to process their responses; otherwise they would leave the profession. This reasoning may be one of the explanations as to why discussions about the impact of death and dying are not considered as part of their role. In addition, the loneliness and emotional uncertainty experienced by participants deserves more recognition in medicine, so that medical practitioners are able to share their experiences and find comfort in the experiences of others. To reduce uncertainty and isolation, the peer support practiced by some participants could be adopted by medical practitioners more generally.

The challenges of dealing with death and dying were highlighted as an area of utmost importance in the lives of medical practitioners who deal with patients with life-limiting illnesses. Their openness and preparedness to discuss the value of their experiences and the professional and personal challenges that constantly confront them, makes this an area where continued interest might yield alternatives to better support them.

3.1 A different way to die

Further implications of these findings suggest that patients who die under the care of different medical specialties, despite having the same prognosis, could be facing a different end of life experience.

All specialties seem to have a different covenant of care, and it is the covenant, which may predict the medical specialist's adjustment to the death of a particular patient and the treatment the patient experiences. Oncologists and palliative medicine specialists developed a similar style of relationships with patients; in the end, reaching closure and suggesting options for the future was more difficult for oncologists, since their commitment was a different one from their initial contact with patients.

Whilst oncologists and surgeons endeavoured to maximise patients' treatments and curative attempts, intensive care specialists and palliative medicine specialists seemed to maximise the quality of end of life for the individual patient and their family. Palliative care may lead to a more autonomous death and dying process, whilst other medical specialties may constrain the ethical principle of autonomy by engaging in a decision making process that focuses on treatments, without weighing the preferences of the patient.

Palliative care units and intensive care units differ from each other, yet intensive care specialists admitted feeling closer to palliative medicine specialists, in terms of anticipating death and looking for alternatives that were not futile. The two also had in common the misunderstandings that other medical specialists commonly held about their approach and practice at the end of life.

4 Contribution of the findings

This research offers contributions to palliative and end of life care literature, particularly in two extensive areas: a) grief literature, and b) medical education.

4.1 Contribution to grief literature

Medical practitioners' experiences of grief have not been studied in depth; paediatric deaths are those that have been studied more frequently (Baverstock & Finlay, 2006, 2008; Plante & Cyr, 2011), whilst the responses to adult deaths remain unexplored outside the nursing and social work literature.

This thesis contributes to the grief literature by highlighting aspects of medical specialists' experiences of anticipatory grief, and grief responses after the death of their patients. The findings highlight the need to focus before the death itself has occurred, inviting medical practitioners to take into account the moment in which the inevitability of death is realised, which generally occurs at earlier stages of diagnosis and discussions about prognosis. Medical specialists' anticipated responses to patient death included withdrawing from patient care, denying the opportunity to engage in emotional connections with their patients, thereby avoiding crucial discussions.

There has been an inclination to think that the experience of professional grief is not as important as that of grieving a family member or a relative. The paucity of research on health professionals' grief tends to confirm this impression (Papadatou,

2009). Yet, a mounting body of literature is demonstrating that, within a professional context, grief is an aspect of dealing with death and dying of patients.

A further area where these results have the potential to make a contribution is in disenfranchised grief, in terms of medical practitioners' reactions being misunderstood or perceived as inappropriate or unprofessional. Disenfranchised grief is the grief experienced when a loss cannot be openly recognised as a loss, because it is not socially acknowledged (Doka, 2002; Hooyman & Kramer, 2006). The expectations for medical specialists to not express any overt emotional reactions, because it is not part of their professional persona, downplays the emotional nature of their encounters with dying patients and the impact these deaths may have on their lives, despite the fact that beyond professional and societal expectations, medical practitioners are people with the same feelings and responses as anyone else.

4.2 Contribution to medical training

Findings derived from this study indicate that medical specialists develop their own mechanisms to deal with death and dying, frequently by trial and error. Many aspects of their practice, such as breaking bad news, and the process of decision-making, progressively changed as they had more professional experience. Participants went through a transition from lack of experience, to gaining more practice and learning from experience. Furthermore, participants highlighted a perception from their training, as well as from their present practice, of a tendency to protect medical students from the death and dying of their patients.

Participants stated that training to deal with death and dying was almost non-existent in the curricula when they were training, at least in terms of practical aspects. Yet they also suggested that as young practitioners it was difficult to understand the extent of what dealing with death and dying entailed, and the likely exposure they

would potentially have in future practice. This may have perhaps lead participants to disregard any opportunities for training in these areas starting in their undergraduate years.

Uncertainty and lack of control are generally present in the treatment of patients with progressive life-limiting illnesses, with medical specialists' relationship style adding to these issues. Medical education could reduce the sources of stress that medical practitioners potentially face by offering discussions about the experience of grief as a normal reaction, both in preparation for the death of a patient, as well as after the death.

5 Methodological strengths and limitations

The decision to undertake a qualitative study was motivated by a lack of available literature exploring this area. The qualitative process provided an in-depth perspective into the experiences of participants, and the rigour and quality of the research and analytical process contributed to the trustworthiness and resonance of the findings.

5.1 Methodological strengths

The findings indicate that the methodology employed was appropriate to produce relevant insight into participants' experiences and coping mechanisms, providing resonant and novel findings that were instrumental in accomplishing the study aims and objectives. Participants' experiences were explored from their perspective, rather than from the researcher's ideas, and that constitutes a step forward in identifying medical specialists' experiences. The interest of the medical specialists to participate when they were invited made the sample size sufficient to reach saturation. Additionally, saturating participants' accounts allowed for the exploration of experiences that diverged from the mainstream 'storyline' (Morse, 1995), giving voice

to subtle narratives that could not have been explored from a quantitative approach. Furthermore, the triangulation process of codes and emerging themes between the PhD candidate and the supervisors, as well as the bracketing of the candidate's own responses when analysing the data, adds to the transparency of the findings. During the interviews, rapport was established with the majority of the participants quite quickly. Respect and differences of power and hierarchies between the interviewer and the participants did not seem to affect the interviews, allowing participants to self-analyse into deeper layers of their experience. The emphasis given to confidentiality and ethical considerations with participants may have allowed them to feel secure during the interview environment. Most participants appeared to forget about the recorder in the room, and spoke at length, uninterrupted.

5.2 *Methodological limitations*

As with any research process, there are limitations associated with the process and the design of the research. As highlighted in the papers, the research only focused on the experiences of medical specialists who are still in clinical practice, and who self-selected to participate in the research. Exploring the views of other medical specialists, who may have left the profession, could have enhanced the results by showing storylines that the participants may not have as part of their current and past experiences. The perspective of other health professionals, patients, and/or family members may have added more complexity to the descriptions provided by participants; the triangulation of medical practitioners' reports with those of other parties involved in their care, would have added more credibility and transferability to the results. Similarly, participant's checking of the interviews was not necessarily the best way to provide legitimacy of their interpretation and agreement with the results, since they only received a copy of their transcripts and were not asked to validate the

themes that arose from data analysis. Part of this process was done through the peer review process of the journal, where reviewers highlighted the resonance and potential transferability to other settings (See appendices 1, 2, and 3). Another added limitation may be related to the recruiting process, since participants were invited to participate by a known palliative medicine specialist (one of the supervisors of the research) they may have felt obliged to participate. However, specialists interested in participating were given the choice to reconfirm their desire to participate, once the PhD candidate established contact with them. An additional limitation is related to having inquired during the interviews about emotional responses rather than other instrumental expressions of participants' responses to their patients' deaths. Instrumental grief responses are those where people respond to loss cognitively or behaviourally, that is by thinking or doing, rather than feeling (Martin & Doka, 2000). Ultimately, instrumental responses were elucidated in terms of participants' coping mechanisms, however, it was an expectation during the interviews that there had to be an emotional response, rather than other forms of expression of their reactions, which were not equally explored. Grief literature has made an effort to include instrumental ways of grieving, particularly when it comes to gender differences of emotional expression (Martin & Doka, 2000). Despite this inconsistency in the research process, participants were able to locate and identify their emotional responses and discussed them at the same time that made reference to non-emotional components of their reactions.

Despite these limitations, the strengths of the research process, together with the constant effort to enhance rigour and quality of the research process (described in Chapter 1) provide a solid ground to the relevance and transferability of the research findings.

6 Suggestions for future research

The findings of this thesis provided a basis to understand the similarities and differences of how medical specialists, who are in frequent contact with patients dying of progressive life-limiting illnesses, experience and cope with the death of their patients.

These findings can be built upon to further the understanding of the effect of dealing with death and dying in other contexts, such as other specialties, health professions, places where cultural differences exist with the Australian context, and the experiences of retired medical practitioners, and practitioners who, through burn-out, leave their chosen profession. Some of the groups of medical specialists whose experiences may be of interest are those of geriatricians who care for the elderly with cognitive decline or with several comorbidities; haematologists, whose patients can easily recover or die suddenly; emergency medicine doctors who usually have no previous relationship with patients and face a decision making process where knowing prior facts about the patient may make a difference in their decisions. This study focused on patients with life-threatening illnesses, with a particular focus on cancer. Widening the scope to respiratory physicians, neurologists, or cardiologists who care for people over prolonged periods of time with ongoing degenerative or relapsing conditions with the possibility of death coming relatively precipitously, may broaden the perspective and offer more pathways that ultimately contribute to patient care and the wellbeing of medical specialists.

Religious and spiritual beliefs can be explored in similar groups of health care professionals so as to better understand how these dynamics may influence patient care, as well as health professionals' adjustment to dealing with death and dying.

The perspective of patients, relatives of patients, and of other health professionals, may also add to acquiring a more grounded perspective on medical specialists' experiences with the death and dying of their patients, as well as the impact of their beliefs and practices on patient care. Additionally, similar studies can explore other ways of grief expression, including instrumental forms of grieving patients.

Other approaches of inquiry such as ethnography, phenomenological approaches, grounded theory, and quantitative methods would be well suited avenues to further analyse medical practitioners' experiences and coping mechanisms when dealing with death and dying.

Appendices

1 Appendix 1. Reviewers' comments to Paper One (Chapter 2)

Comments to first submission:

Dear Miss Zambrano,

The editors have reviewed your manuscript and recommend that it is not high enough priority to be accepted for publication. Reviewer comments are appended below. The editors commented that this may be a more appropriate manuscript for a palliative care journal.

We appreciate the opportunity to consider your manuscript for publication, and wish you well. We hope that you continue your interest in XXXX, and we look forward to working with you in the future.

Sincerely,
Editor-in-Chief

Reviewers' comments:

Reviewer #1: The authors report on interviews with nine Australian surgeons analyzing their responses to the dying/deaths of their patients. Despite the small sample, and probably accounted by the authors' expertise and rigor, the manuscript rings true to this reviewer. It is well written, clear and lucidly presented. There are some minor punctuation errors that could be picked up in copyediting.

There are a couple of weaknesses vis-a-vis this report for this journal. First, it is an accounting of Australian surgeons, and the relevance to American surgeons (after all, this is the XXXX (Journal title)) and their attitudes and experiences is not established by the authors. Second, as the authors point out, the experience of death on a surgical unit is shared amongst patients, families, nurses and surgeons. It cannot be discerned from the study whether the surgeons' experiences had meaningful impact on others' experiences. Third, the sample size is so small that it is hard to determine whether this is representative of surgeons generally; of Australian surgeons, or of surgeons in Adelaide.

Reviewer #2: You are to be commended for your attention to this hitherto seldom studied aspect of surgical care. Just recently a paper was published (Schwarze et al. Ann Surg 2012;255:418-23) demonstrating that half of surgeons queried would refuse to operate on a patient with pre-existing restrictive directive (i.e. DNR order), thereby undermining the patient's autonomy and potentially depriving them of beneficial treatment, especially for the relief of pain. I believe this is to some extent related to surgeons' attitudes about death and their perceived role in the care of the dying patient. Your fellow Australian, surgeon Miles Little, described the quality of "proximity" to their patients surgeons possess that is so valuable in establishing a basis of trust necessary to allay the ultimate fear of all terminally ill patients - abandonment. Your paper has provided valuable evidence that should encourage surgeons not to shy from introspection as so well discussed by David Page whom you referenced.

Please consider further comment on:

- * The potential role of palliative care teams and specialists in providing the support that might benefit surgeons in responding to an impending patient death or afterwards.
- * Suggestions for surgical training
- * How could the future structure and purpose of the Mortality and

Morbidity rounds be influenced by your findings?

* I agree with your suggestion that the on-going relationship oncologic surgeons have with their patients during which they can witness a patients adaptation to his illness is the reason for their capacity to identify the positive aspects of dying and be less distant emotionally. Would you predict this would be true for pediatric and transplant surgeons given their long term

Reviewer #3:

This timely manuscript¹ is an example of quality translational research between the humanities and surgery. The authors use a hermeneutic approach looking at a purposeful sample probing for common themes with text analytic technology. The strength of the study is the in-depth review using rigorous methodology to determine all relevant themes and subthemes. Because it is a qualitative study it opens the eyes of the reader as to a mirror of reflection on surgical behaviors - notably dealing with bad news and end of life. The study albeit small in subject numbers is robust in methodology.

The strength that may be perceived as a weakness by the casual reader is the in-depth meta analysis of the literature in the introductory section with very little elaboration vs. the robust discussion of the theme analysis in the results section. It is recommended that the authors (for the purpose of communication) use real life examples in addition to the references.

In the future of this very important work, we might suggest enlarging the sample to include a symmetrical cohort of biological sexes as well as comparing and contrasting surgical subspecialties as suggested by the authors.

In summary, a robust well designed study that should be considered a welcome addition to the surgical literature.

1.Yurkiewicz, I- When a patient is ready to talk about death, but a medical student is not Scientific American (Blogs) March 14, 2012, Retrieved March 16 at <http://blogs.scientificamerican.com/unofficial-prognosis/2012/03/14/when-a-patient-is-rea>.

Reviewer #4: This is an interesting report of how surgeons cope with the death of one of their patients. It articulates behavior patterns I have observed in surgeons in my own practice. It is a small sample and 9 of 12 surgeons were willing to respond.

Is it possible to determine why 3 surgeons did not participate and their years of practice and sex?

The level of detachment in treating these patients can be problematic since objectivity must be a priority yet empathy is essential.

Are there any similar studies involving other physician groups such as medical oncologists?

Any data on how patients and family view surgeons who treat this group of patients?

Are the observed behavior patterns acceptable to patients and family?

Reviewers' comments from second journal where the decision has been appealed and is pending revision.

Reviewer(s)' Comments to Author:

Two of three experts felt the subject was of great interest, but the data set (9 surgeons) was insufficiently robust to meet the XXX threshold. I agree. Having said this, I would love to publish this paper if you could increase the number of interviews, to a dataset that would be credible with our editors. I cannot say exactly what number that should be, but I would suggest that you interview another 11 surgeons to develop a data set of 20 surgeons, preferably including surgeons from other locations in Australia or internationally, then send us a revised manuscript.

Reviewer: 1

Comments to the Author

Dear Authors

I enjoyed reading your interesting and very thought-provoking article. "How do Surgeons experience and Cope with the Death and Dying of their patients? A Qualitative Study in the context of Life-limiting Illnesses".

I applaud you for undertaking this bold study, as it covers a field that is not routinely researched, and many probably view as philosophical. Your study is deeply perceptive regarding the nature of surgeons and provides a glimpse into the innermost recesses of the surgeon's psyche. This permits surgeons to become more introspective and identify with their persona in a non-offensive manner. You also clearly articulated the explicit challenges that surgeons face regarding end-of-life issues in their patient population. This paper will strike a familiar chord with all types of surgeons.

I congratulate you on your foresight - this research is long overdue.

Reviewer: 2

Comments to the Author

This paper analyzes the attitude of surgeons against dying and death of their patients. Although the results are interesting, the work is based on analysis of deep surveys to only 9 surgeons. I think it lacks scientific strength.

Reviewer: 3

Comments to the Author

This study explores surgeons' experiences when caring for patients with life-limiting illnesses and surgeons' coping mechanisms in these difficult situations. Methodically the study is a qualitative analysis of in depth interviews from nine Australian surgeons (generalists/specialists). Thematic analysis was carried out with identification of themes and subthemes. The three major themes are: essence of surgical practice, experiences with death and dying, and coping mechanisms. Subthemes of these major three categories are also analyzed. Overall, surgeons' approach to their patients' death and dying was characterized by a high sense of personal responsibility for patient outcomes. Further patient deaths seem to have a lasting impact on surgeons.

Major criticisms:

- 1.) This study focuses on an underreported topic and is from this point of view very interesting.
- 2.) The qualitative design of this study gives no generalizable results.
- 3.) The number of interviews is very low (n=9) and consists of a very

heterogeneous group of participants (selection bias: male/female; generalists/specialists; very different age and experience of participants; range of interview time from 29 to 105min)

- 4.) Single center study representing local mechanism to handle these situations - probably not nationally and internationally generalizable
- 5.) No structured and reproducible interview method
- 6.) Results of these study are extrapolated to other studies and are just hypothetical

2 Appendix 2. Reviewers' comments to Paper Two (Chapter 3)

Editor's Comments: As you will see , the reviewer suggests considering minor revisions and clarifications. I imagine you can revise quite quickly. Do not feel you must respond to every comment. Focus on those that you feel may improve your paper. VERY IMPORTANT: PLEASE CORRECT THE HEADINGS OF YOUR ABSTRACT WHEN YOU REVISE AND RESUBMIT. THE CORRECT HEADINGS OF THE ABSTRACT ARE: OBJECTIVE, METHODS, RESULTS, SIGNIFICANCE OF RESULTS. PLEASE SUBMIT THE ABSTRACT SEPARATELY, AN ALSO INCLUDE IT IN THE FULL MANUSCRIPT.

Reviewer(s)' Comments to Author:

Reviewer: 1

Comments to the Author

Thank you for the opportunity to review this manuscript which I enjoyed reading very much. I will make my comments in the order that they come in the writing and then will give an overall summary.

The abstract is clear and concise and reflects the content of the paper. The introduction is very good, again it is clear and concise and well referenced on the whole. I would, perhaps, have liked to see a bit more detail in the methodology but recognise that word limitation may have impacted on this.

The results are most interesting and warrant some comment.

On p7 Line 7 I don't understand "in order to dignify the doctor-patient encounter"

Similarly, explain "care usually transitioned from less to more dedicated care (is this more care or more dedication for example?)

I was surprised by the finding about funeral attendance especially in light of the later comments about lack of time. Is this really typical of this group of professionals? (certainly atypical in my experience)

Again on p8 in the Breaking bad news section - how do you know that participants were the "first health professionals ...who clearly described diagnosis ...etc"? It seems unlikely again. Were there no academics in this group? Participants talk of administrative load but not of academic load which surprised me (but maybe it isn't a load?)

On p11 I don't understand the comment about "religious and spiritual interpretations were comforting..." does this mean that those with no religious belief found no comfort from their spiritual beliefs? I was alarmed that participants were unable to understand how atheist or agnostic specialists deal with the work - surely they will have worked with such people in their careers?

In the section on coping there seems to be no mention of the support of family or spouse - was it really completely absent?

In the discussion, which is helpful, there is no mention of professional supervision as a manner of coping. It is common in some areas but perhaps not in this one; why would that be? It would be worthy of comment. In the middle of p14 there is a comment that "not all physicians may be able to find rewards in their work with dying patients" does this mean general physicians or just this group. If this group, why are they doing it? Later in that paragraph I find it hard to agree with the statement about spirituality and religiosity. The discipline was founded by a strong religious woman and many services set up by similar people. Our modern understanding of spirituality has surely advanced from religiosity alone though.

Overall then, I found this to be a fascinating insight into a small sample of palliative care physicians which asks many questions only some of which

are answered. Some further clarification and illumination is needed in my view

3 Appendix 3. Reviewers' comments to Paper Three (Chapter 4)

Dear Miss Zambrano,

Manuscript ID bmjpscare-2012-000208 entitled "On the Emotional Connection of Medical Specialists Dealing with Death and Dying: A Qualitative Study of Oncologists, Surgeons, Intensive Care Specialists and Palliative Medicine Specialists" which you submitted to BMJ Supportive & Palliative Care, has been reviewed.

The paper is of general interest and well written. The reviewer has suggested some revisions to your manuscript. The comments are included at the bottom of this letter. We invite you to respond to the reviewer's comments and revise your manuscript accordingly. Please remember, that when writing revisions, the word limit still applies, so any additions will require other subtractions.

Reviewer(s)' Comments to Author:

Reviewer: 1

Comments to the Author

I greatly enjoyed reading this manuscript on emotional connection and found the contents fascinating and helpful. I will deal with the separate sections individually.

The abstract is clear and concise.

The introduction is brief and to the point.

The methodology is sound and as described is easy for readers to follow. I am not sure of the protocol but it may be helpful to add the appropriate reference number of the University Ethics Committee approval.

The results are well presented and clear. I was interested in the highlighting of the two-way nature of the caring relationship - such reciprocity is an aspect which has been highlighted in some of our own work and also that of others (for example Stephen Beutow). The section on longer term relationships may seem to be obvious but I agree it is important to add it here for completeness. In the section on seeking emotional distance it may be worth adding reference to the work of Frederick Hafferty (Into the Valley) who in turn, cites the work of medical sociologists in medical socialisation which includes emotional detachment. The section on finding a balance is well constructed.

In the discussion I was surprised that no mention was made of the role of professional supervision. Much has been written about this for nurses and of course for social workers, counsellors and psychologists. It is my understanding that this mode of 'reflection' is becoming more common for medical practitioners, especially in palliative care so it may well be worth acknowledging that here. Does spirituality have an impact on emotional connection and coping? Might be worth exploring that too? I am delighted to see the hidden curriculum mentioned as a force to be reckoned with.

The section on limitations is relevant and in my view accurate.

Thank you very much for doing this important work. I look forward to seeing more of it in the literature in due course.

4 Appendix 4. Paper Four

S.C. Zambrano, A. Chur-Hansen, G.B. Crawford (2012) On the emotional connection of medical specialists dealing with death and dying: a qualitative study of oncologists, surgeons, intensive care specialists and palliative medicine specialists.

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NOTE: This publication is included in the print copy of the thesis held in the University of Adelaide Library.

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